



# **A Critical Pedagogy for Understanding Diabetes- Related Stigma**

By

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*Thesis  
Submitted to Flinders University  
for the degree of*

**Doctor of Philosophy**

College of Medicine and Public Health

9 August 2021

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# **PUBLICATIONS AND PRESENTATIONS RESULTING FROM RESEARCH UNDERTAKEN FOR THIS THESIS**

## **Peer-review publications**

Pillen, H, McNaughton, D & Ward, PR 2019, 'A review of critical pedagogies in health and social care: findings from a 'best fit' framework synthesis', *Critical Public Health*, vol. 30, no. 4, pp. 468-486.

Pillen, H, McNaughton, D & Ward, PR 2020, 'Critical consciousness development: a systematic review of empirical studies', *Health Promotion International*, vol. 35, no. 6, pp. 1519–1530.

## **Industry publications**

Pillen, H 2020, 'Exploring Diabetes and Stigma', *MyLife*, June 2020, p.14.

## **Conference presentations**

Pillen, H 2020, 'Democratic spaces as sites for stigma-reduction work: deliberating on strategies for reducing diabetes-related stigma', paper presented to Australasian Diabetes Conference, 11-13 November 2020.

# SUMMARY

Patient advocacy groups and academics within the humanities and social sciences have a long history of challenging the way that chronically ill, disabled, and stigmatised groups are represented. These challenges largely relate to matters of identity, whereby dominant knowledges about chronically ill and/or disabled persons produce forms of identity thinking that function to reduce the status of chronically ill and/or disabled persons and legitimise practices that impinge on their lives. This phenomenon is particularly true for a proportion of persons living with type 2 diabetes (PWD), who experience feelings of shame or guilt for their diabetes diagnosis and/or its progression, an observation that researchers have attempted to explain by drawing upon the stigma concept. However, the largely individualised understandings of diabetes-related stigma found within this literature are largely out-of-step with the critical or structural turn in stigma research, which focuses attention on the way that stigmatisation relates to broader social relations of power and control. Although stigma researchers and those involved in stigma-reduction work are exhorted to think about health-related stigma in more socially critical ways, there is limited indication of how this shift in understanding might be practically achieved. This doctoral research has addressed this limitation by taking an educational program informed by critical pedagogy and using a case study methodology to identify: what social and pedagogical processes facilitate or constrain the critique of stigmatised identities; what constitutes a critical understanding of diabetes-related stigma; and where critical forms of education might be located within existing public health policy and practice. Critical pedagogy is useful here because of its role in developing literacies that might be used to disrupt reified thinking about members of stigmatised groups, thus allowing for alternative discourses and representations of stigmatised groups to emerge.

This research involved two main research activities. The larger first component involved conducting a five-week education program with two groups of PWD ( $n = 8$ ) who experienced a perceived or self-stigma in relation to their diabetes. Using a qualitative case study methodology, longitudinal interviews with research participants were analysed to identify changes in representations of persons with diabetes and stigmatising events. These interviews provided insight into how discursive regimes were used by participants to construct, legitimise, resist, or transform stigmatised social identities, and provided insight into the way that participants implicated certain processes or structures in the production of diabetes-related stigma. By way of case comparison, it was then possible to identify processes of learning that contributed to these discursive changes. The smaller second component of this doctoral research involved a facilitated deliberation on earlier research findings with staff and board members ( $n = 25$ ) from a state-wide Australian diabetes organisation. The purpose of this research was to locate critical pedagogy within a current landscape of public health, patient advocacy, and stigma-reduction work, with the intention of providing guidance on how to bring this pedagogical approach from the margins into the mainstream of stigma-reduction education.

In performing this research, this doctoral thesis has advanced knowledge about diabetes-related stigma and the role of critical pedagogy within stigma-reduction work in several important ways. Firstly, this research has established an understanding of what processes of learning are involved in supporting an epistemic challenge to stigmatising representations of identity. Put simply, the research findings suggest that learners must engage with questions of: who exactly is stigmatised; whether the application of stigmatising concepts is fair; what dominant knowledges are used to construct stigmatised groups and how these knowledges are applied; and what alternative concepts might be used for representing PWD? Secondly, this research has resulted in the development of a critical theory of diabetes-related stigma that draws attention to the way that the government of risky bodies establishes conditions conducive to a process of othering, whereby moral concepts are used to constitute the stigmatised identities of tragic-disabled, irresponsible, and obese PWD. It is within this context of risk that medicalised understandings of PWD and ideological assumptions about (responsible) bio-citizenship are drawn upon as resources for constructing and legitimising stigmatised identities as participants sought to manage temporal uncertainty and overcome the nature of their vulnerable bodies. In doing so, this doctoral research has been able to relate the individual, ideological, and structural dimensions of diabetes-related stigma, extending the largely individual-level analysis that has dominated existing understandings of diabetes-related stigma. Thirdly, this research has found that democratic fora relevant to diabetes prevention and care, contained within activities of person/patient-centred care, service co-design, and media advocacy, offer sites where those with diabetes can re-define the concepts used to construct identity. Specifically, representing PWD as socially-embedded agents offers a defence against reified thinking that seeks to give moral meaning to physical attributes of disability-disfiguration and obesity. Representing PWD as such may offer a standpoint from which to critique normative aspects of diabetes prevention and care. However, as this research has shown, critical forms of education should complement these democratic fora or otherwise risk PWD further contributing to the othering of certain sub-groups of PWD, potentially re-distributing feelings of shame and guilt away from 'normal' PWD and towards the 'more deserving' disabled, irresponsible, and obese sub-groups of PWD.

These findings have important implications for how public health practitioners and stigma researchers might go about their work. In relation to diabetes-related stigma, practitioners and researchers should focus their attention on the way that discourses of medicalisation and bio-citizenship are deployed within surveillance and educational activities, and how these discourses function to form implicit categories from which to construct stigmatised identities. In relation to health-related stigma more broadly, practitioners can use the pedagogical approach described in this research as a more democratic and considered way of identifying dominant knowledges used to represent stigmatised groups in certain ways. However, further research is required to test this pedagogical approach in a more refined form and within naturalistic public health settings.

# DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

A handwritten signature in black ink, appearing to be 'A. M. S.', written over a set of diagonal lines.

Signed

Date 16 February 2021



## ACKNOWLEDGEMENTS

Within this doctoral thesis, my voice as author is the product of the support, ideas, and opportunities provided by funders, supervisors, research staff, and study participants. Formally, I would like to acknowledge the financial support provided through the Australian Government Research Training Program Scholarship, which made conduct of this research possible. I would also like to acknowledge the funding and in-kind support provided by Diabetes South Australia through their 2018/19 Research Grants Program. In particular, I would like to thank Angelique Pasalidis (Chief Executive Officer), Fiona Benton (Executive Manager Health & Research), members of the governing board, and Diabetes SA staff for their work in supporting participant recruitment and the dissemination of research findings.

I would like to thank my primary supervisor, Professor Paul Ward, for his insightful critiques and reminders about the technical, normative, strategic, and practical dimensions of public health research. I am also grateful for the support of Associate Professor Ben Wadham, who stepped into the role of associate supervisor towards the end of my candidature. In particular, I have valued his assistance in deepening my understanding of socially critical forms of education and critical theories of identity. As an associate supervisor in the early stages of my candidature, I would like to thank Associate Professor Darlene McNaughton for her assistance in helping me explore the relationship between concepts of stigma, blame, and shame as they relate to diabetes and obesity. In support roles, I would also like to thank Dr Toby Freeman, Associate Professor Anna Ziersch (Southgate Institute for Health, Society and Equity) and Dr Simon Behenna (College of Medicine and Public Health) for their assistance in the recruitment of research participants, and librarians Nikki May and Jessica Tyndall for their assistance in developing the search strategies used in the literature reviews featured within this thesis.

Importantly, I would like to acknowledge the contributions that research participants have made to the research. This doctoral research demanded a considerable investment of time and cognitive-emotional resources, and each participant contributed these resources generously. These participants have greatly shaped my thinking about diabetes-related stigma and critical pedagogy, and I hope that this thesis has done justice in interpreting their complex narratives about what it means to live with type 2 diabetes.

Finally, I would like to thank Tanieka and Hugh Pillen for their resilience, support, and understanding during my candidature.

# 1. INTRODUCTION: WHY A CRITICAL PEDAGOGY FOR UNDERSTANDING DIABETES-RELATED STIGMA?

I would just like to share a story where a friend of mine was in a rehabilitation hospital recovering from a very major stroke which nearly killed her, and she had to learn to walk and talk and write and dress herself and do everyday functions all over again, and she's got to the point now where she's nearly probably 90% back to what she was, but she'll never get fully back. But all that was through sheer determination and hard work; she would never have achieved what she has without sheer determination and hard work. She was in hospital at that time with a lady that had had a foot amputated because of diabetes and this lady basically had chocolates delivered to her and was up all night; you could hear them rattling, eating all the chocolates and then saying to the nurse in the morning, "Oh, I don't know why my sugar level would be so high," when she was tested. Wouldn't get up and do anything except lay in bed and whinge. So people can only do so much to assist; at the end of the day it is up to you to do it, so I'm in a bit of two minds about this one. Yeah, none of their business – well the government spends millions and probably billions of dollars on diabetes to assist people and to help themselves manage, so that's a bit of a selfish attitude I think. (Staff member from an Australian state diabetes organisation)

This vignette, taken from a participant in this doctoral research, offers insight into the type of phenomena examined within this thesis. The narrative within the vignette reveals how persons living with type 2 diabetes mellitus (PWD) exist within a cultural, social, and political milieu that threatens to re-shape their identity along the lines of the (disgusting) diseased and/or immoral Other. In an attempt to conceptualise this experience of living with diabetes, researchers have increasingly drawn upon the stigma concept to explain why certain persons conceal their diabetes status, internalise negative beliefs about themselves as a PWD, and avoid healthcare services for fear of encountering discrimination (Abdoli et al. 2018; Earnshaw & Quinn 2012; Kato, Yamauchi & Kadowaki 2020). The stigma concept is particularly useful for guiding public health practice given how it can be used to re-focus attention on the cultural, social, and political processes that give rise to spoiled identities (Goffman 1963). However, one of the challenges for stigma-reduction work is that these social processes tend to be difficult to discern because of the reification<sup>1</sup> or naturalisation of stigmatised identities, with the health-related stigma literature yet to articulate a method for making these processes more visible among non-academic audiences. Fortunately, there is an expansive literature exploring how learners might be supported to engage in a social critique of marginalisation and inequality, specifically seeking to unearth how individual subjectivities are shaped by ideologically informed logics and practices. Such a *critical pedagogy* can be found in diverse disciplinary fields that include education, sociology, psychology, social work, and community development. Cognisant of similarities in purpose between forms of critical pedagogy and critically informed stigma-reduction work, this doctoral research is broadly concerned with how critical pedagogy might function when repurposed for understanding diabetes-related stigma in a more critical manner.

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<sup>1</sup> Reification here refers to cases where categories are inappropriately transferred onto objects as the 'intrinsic, natural properties of objects' (Benzer 2011, p. 18)

In using the term 'critical' in relation to learning, I take this to mean the way that learners engage in a self-reflective critique of historical-hegemonic ways of knowing, identify the material conditions that position certain subjectivities (in relation to identity and selfhood) as dominant and others as marginal, and act in ways that might support the accommodation of alternative subjectivities. This notion of 'criticality' incorporates elements of structural theory, implicating political, economic, and material conditions in the production of diabetes-related stigma, with a post-structural norm critique that examines forms of knowledge used to structure relations of deviance (Reimers 2020). The blending of such perspectives responds to the idea that together, social deviance and social oppression paradigms for understanding disability and chronic illness may offer more useful insights and support more productive forms of social and political action than either alone (Charmaz 2020; Thomas 2007, 2012). Such a blending of perspectives is encapsulated within Charmaz's (2020, p. 40) call to action following her reflection on narratives of chronic illness that she encountered over her research career:

Qualitative researchers must attend to people's various social positions, situations, bodies, and interactions that shape their experience of illness, disability, and identity. In turn, we must specify the conditions under which this experience leads to stigma and inequity. That means we must be attune to neoliberal perspectives, policies, and practices and when and how they affect the people we study. It means we must attend to the structural conditions of their lives and to their understandings of their situations. It also means our studies of stigma and an exclusion must go beyond Goffman's analysis.

This chapter is concerned with establishing a case for why this research is needed and how it might advance knowledge about stigma-reduction work in public health contexts. Firstly, this chapter briefly establishes how the field of public health has problematised type 2 diabetes (T2DM), providing important context for a later discussion of research findings. Secondly, this chapter presents evidence that establishes T2DM as a stigmatised condition and presents an argument for why the field of public health should concern itself with reducing diabetes-related stigma. This leads to discussion establishing why a new approach to stigma-reduction is needed, in the form of critical pedagogy, and how this new approach responds to issues raised in a broader literature examining stigma-reduction education. Finally, this chapter provides an outline of the aims and objectives of this doctoral research and provides a brief overview of the structure of this thesis document. To assist with readability, T2DM is referred to simply as 'diabetes' unless there is a need to clearly distinguish it from other forms of diabetes or where use of medical terminology is contextually appropriate. Similarly, persons (living) with diabetes will be referred to as PWD.

## **Locating type 2 diabetes within the field of public health**

Prior to the advent of insulin in 1922, to have diabetes meant having a terminal or life-limiting illness. For those with type 1 diabetes (T1DM), death was relatively swift owing to a fatal acute ketoacidosis. But for those with T2DM, death was preceded by a more protracted period of living with comorbidities of neuropathy, vascular disease, and chronic infection (Ahmed 2002; Feudtner 2003). However, the

advent and clinical use of insulin from 1922 and the later introduction of oral hypoglycaemic agents meant that diabetes was rapidly transformed into a manageable and thus chronic condition, with PWD indebted themselves to medical and dietary intervention (Feudtner 2003). From this point up until the 1980s, diabetes was regarded more as a clinical disease suitable for medical management and less as a concern for the field of public health (Vinicor 1994). The emergence of diabetes as a public health problem followed findings from large-scale epidemiological studies conducted in the United States in the 1980s and 90s (Burke et al. 1999; Harris et al. 1998) that highlighted an increasing incidence of T2DM, accounting for approximately 90-95% of cases of diabetes (American Diabetes Association 2014). Type 2 diabetes here is distinguished from other forms of diabetes according to its causal physiological mechanisms (Franks & Merino 2018; Muoio & Newgard 2008) and the prominent aetiological role of modifiable risk factors, including obesity, diet, and inactivity (Bellou et al. 2018). Global data has shown how the age-standardised prevalence of T2DM has increased across all low, middle, and high-income countries, with global prevalence increasing from 4.7% in 1980 to 8.5% in 2014 (WHO 2016). Like other non-communicable diseases (NCDs), the rapid rise in global prevalence and the potential for disease prevention has brought T2DM squarely within the scope of public health practice (Herrick 2020).

However, a key omission here is the role of diabetes-related complications. Because the increase in blood glucose concentration that occurs with T2DM often takes place gradually over time, threshold values for diagnosis have been established based on estimates of risk for diabetes-related complications (American Diabetes Association 2014). As this diagnostic criteria suggests, the overriding public health concern with diabetes lies in its comorbid effects, reflected in policy statements such as the 2016 *Global Report on Diabetes* (WHO 2016) and the *Australian National Diabetes Strategy 2016-2020* (Commonwealth of Australia 2015). These comorbid effects, which are commonly referred to as diabetes-related complications, typically include the microvascular and macrovascular effects of chronically elevated blood glucose concentrations, including retinopathy, renal failure, neuropathies, cardiovascular events, peripheral vascular disease, and amputation (Adler et al. 2000). These complications contribute to projections suggesting that the global economic burden of diabetes (all types) will increase from \$1.3 trillion (USD) in 2015 to \$2.5 trillion in 2030, assuming continuation of past trends (Bommer et al. 2018). For diabetes-related complications, direct medical costs have been shown to increase by 10-30% for simple escalations in medical care (including use of oral medications and management of early-stage complications) through to a 60-90% increase in costs following the initiation of insulin therapy and management of cardiovascular events and renal failure (Brandle et al. 2003). The indirect costs of diabetes are also substantial, including costs related to labour-force drop out, mortality, absenteeism, and presenteeism, contributing to 34.7% of the economic burden of diabetes (Bommer et al. 2017).

Given this, it is not surprising that governments and health systems have responded with strategies to prevent or delay the onset of T2DM and diabetes-related complications, drawing from a range of

interventions for the primary, secondary, and tertiary prevention of disease<sup>2</sup> (Bowman et al. 2003). Two important guiding policies in Australian and international contexts include the *Australian National Diabetes Strategy 2016-2020* (Commonwealth of Australia 2015) and the *Global Diabetes Plan 2011-2020* (International Diabetes Federation 2011a). In these policy documents, primary prevention efforts have focussed on persuading individuals to ‘increase levels of physical activity, reduce sedentary behaviour and improve healthy eating’ (Commonwealth of Australia 2015, pp. 10-1), particularly amongst those identified as being at high risk of developing T2DM. Mass education approaches (or social marketing) have played a prominent role in such persuasion, attempting to raise awareness about the seriousness of diabetes and the importance of taking preventative action via risk assessment and lifestyle change. In an Australian context, diabetes-specific social marketing has run parallel to social marketing campaigns aiming to prevent population weight-gain and obesity, which themselves have attempted to motivate individuals to change their lifestyles in order to avoid the negative consequences of chronic disease (Dunbar et al. 2011).

For those already living with diabetes, achieving ‘tight’ glycaemic control forms the overarching goal for medical- and self-management activities, drawing inspiration from prospective cohort studies demonstrating significant reductions in diabetes-related complications with such ‘tight’ control (Selvin et al. 2004; Stratton et al. 2000). In the context of the current self-management paradigm, emphasis has been placed on improving glycaemic control through participation in interventions designed to support and promote healthy lifestyles, particularly through participation in structured self-management education programmes (Commonwealth of Australia 2015; Diabetes UK 2016; International Diabetes Federation 2011a). Emphasis is also placed on the early detection and treatment of diabetes-related complications, particularly through participation in regular eye examination, measurement of urine protein, foot assessments, and assessment of cardiovascular health (International Diabetes Federation 2011a). More recently, greater attention has been given to management of the psychological effects of living with diabetes. In particular, reducing what is termed ‘diabetes distress’ has emerged as a major policy issue, owing to its high prevalence amongst persons with T2DM (with 36% of persons with T2DM likely to demonstrate evidence of distress (Perrin et al. 2017)), its persistence over time (Fisher et al. 2008), and its adverse effects on glycated haemoglobin, blood pressure and lipids, risk of cardiovascular disease, mortality, and quality of life (Robinson et al. 2018). The emergence of the stigma concept within the diabetes literature appears to have followed this broader concern about the adverse psychological effects of living with diabetes (Kato, Yamauchi & Kadowaki 2020; Speight et al. 2020). At this point, it is helpful to clarify what is meant by ‘stigma’ and why the concept is relevant to the experiences of PWD.

## **Identifying type 2 diabetes as a stigmatised condition**

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<sup>2</sup> Here, primary prevention refers the prevention of diabetes, secondary prevention refers to the early detection and management of diabetes so to prevent the onset of diabetes-related complications, and tertiary prevention refers to the management of these complications so to prevent or limit disability (Bowman et al. 2003).

The flawed *self* or *identity* is a central idea within the stigma concept. Goffman (1963, p. 3), who first articulated the concept through his ethnographic studies of persons with severe mental illness, claimed that stigmatisation draws on ‘deeply discrediting’ attributes that are used by others to transform the stigmatised person ‘from a whole and usual person to a tainted, discounted one’. This work suggested that one’s identity or sense of self is not a given, but rather is formed through a process of social interaction (McVittie & McKinlay 2017). What exactly is implied by the term *social interaction* depends on the disciplinary and theoretical perspectives used to examine the stigma concept, something explored in more detail within Chapter 2. In relation to the stigma concept however, it is important to recognise that such social interaction emerges as a reaction to *difference*. Stigmatisation heuristically draws upon certain forms of difference, made salient by evolutionary (Phelan, Link & Dovidio 2008) and socio-cultural (Hubert 2000) processes, in order to differentiate between ‘us’ and ‘them’, or the self and other (Phelan, Link & Dovidio 2008; Toyoki & Brown 2014). The question therefore is what evidence is there that PWD are subjected to social interactions that seek to position them as ‘not us’ on the basis of their inferior and flawed identity?

There are three forms of evidence that can be drawn upon to argue that PWD are subject to stigmatisation. The first involves research that has attempted to quantify the stigma experience of PWD. Drawing on results from an internet survey of 3,850 persons with T2DM within the United States, Liu et al. (2017) found that 52% of persons agreed with the statement that diabetes is ‘associated with stigma’, with 81% of this number agreeing that this stigma was related to beliefs about personal character flaws or the failure of personal responsibility. Within this survey, the experience of stigmatisation was found to disproportionately affect those with greater body-mass-index, higher HbA1c, and poorer self-reported blood glucose control. Results from the second international Diabetes Attitudes, Wishes and Needs study (DAWN2™), suggested that between 11% and 28% of persons with diabetes (both T2DM and T1DM) have experienced discrimination, with considerable inter-country variation (Benedetti 2014). Admittedly, these two sources of evidence are fairly weak given the former’s reliance on lay interpretations of ‘stigma’ and the latter’s focus on discrimination, which fails to engage with the self/internalised, felt, or symbolic dimensions of stigma that are more frequently observed within the diabetes-specific stigma literature (Browne et al. 2013; de-Graft Aikins 2006; Kato et al. 2016a; Kato et al. 2016b). A validated psychometric instrument specific to diabetes-related stigma (DSAS-2) has been developed by Browne and colleagues (2016), and although this instrument is yet to be deployed amongst a representative sample of PWD (A Ventura 2017, pers. comm., 13 November), validation studies suggested that 19.3% of the sample demonstrated a ‘potentially problematic perceived and experienced diabetes stigma’ (Browne et al. 2016, p. 2145).

The second form of evidence comes from a growing body of diabetes-specific literature that has attempted to explain the illness experience of those with diabetes by drawing upon existing knowledge about mechanisms of stigmatisation. This literature falls into two broad groups. The first

group of literature presupposes the existence of certain negative stereotypes and prejudice towards PWD, which affects PWD to different extents and prompts different adaptive responses. This literature has focused on identifying and describing the content of these stereotypes, involving beliefs about sickness, fatness, and irresponsibility (Abdoli et al. 2018; Broom & Whittaker 2004; Browne et al. 2013; Schabert et al. 2013) and describing the productive and maladaptive ways that PWD manage a perceived stigma (Basinger, Farris & Delaney 2020; Della et al. 2020; Earnshaw & Quinn 2012; Hallgren, McElfish & Rubon-Chutaro 2015; Hopper 1981; Jones & Crowe 2017; Kato et al. 2016b; Kato et al. 2020b). This literature, which reflects a social psychology, problematises cultural beliefs (in the form of stereotypes) and the way in which PWD respond to these beliefs. In contrast, a second group of sociological literature has problematised the way that neoliberal economic and political ideas have embedded themselves within discourses that shape how PWD might view their selves, bodies, and obligations for self-care (Brookes & Harvey 2015; Kendall et al. 2011; Lupton 2014; Seligman et al. 2015). Although the stigma concept is less prominent within this literature, such literature has helped explain why certain stereotypes of the sick, obese, and irresponsible 'diabetic' are maintained.

The third form of evidence that diabetes exists as a stigmatised condition comes, practically speaking, from the attention given to concepts of stigma and discrimination by diabetes organisations purported to represent the interests of persons with diabetes. For example, the International Diabetes Federation (IDF) is a peak organisational body representing the interests of PWD via engagement with over 230 national diabetes associations (International Diabetes Federation 2017). Within the IDF, attention has been placed on advocacy to 'stop discrimination against people with diabetes', representing one of three objectives in their *Global Diabetes Plan 2011-2021* (International Diabetes Federation 2011a). Another example is the recent Diabetes UK position statement on *transforming the mental well-being for people with diabetes*, which made 11 research recommendations, one of which being to understand the 'multifactorial impact of social stigma' (Wylie et al. 2019, p. 1533). Although clearly a matter of concern for diabetes organisations and psychological research (Speight et al. 2020), an argument needs to be made for why the field of public health should concern itself with understanding and addressing diabetes-related stigma.

## **Diabetes-related stigma as an issue of public health concern**

Although different disciplinary areas within public health possess slightly different ideas about what constitutes a public health issue or problem (Baum 2016; Beaglehole & Bonita 2000; Blyth, Van Der Windt & Croft 2015; Hughes & Margetts 2011; WHO 1986), certain criteria cut across these disciplinary areas, including:

- that the health-related issue/problem results in an unacceptable social, personal, and economic burden, particularly when this burden is distributed in an inequitable way;
- the causes of this issue/problem can be conceptualised at a population or group level; and,
- these causal mechanisms can to some extent be addressed through the usual range of public health interventions related to education, advocacy, community development, policy, legislative and regulatory interventions, settings-based approaches, and the structuring of healthcare.

With regards to the first point, articulation of the burden of diabetes-related stigma has focused on the negative effects of self/internalised or felt/perceived/anticipated stigma. In terms of psychological outcomes, cross-sectional studies have demonstrated that the perception of stigma is significantly associated with greater psychological distress and depressive symptoms (Gredig & Bartelsen-Raemy 2017; Holmes-Truscott et al. 2020; Kato et al. 2017), poorer social support, and quality of life (Gredig & Bartelsen-Raemy 2017; Kato et al. 2017), and that the internalisation of stigma is directly related to poorer quality of life (Earnshaw & Quinn 2012). The internalisation of stigmatising beliefs has also been demonstrated to lead to qualitative patterns of social avoidance/withdrawal and social conflict (characterised as a struggle between maintaining a patient role and other social roles) (Kato et al. 2016b), however there is disagreement from quantitative research as to whether this internalisation of stigmatising beliefs does in fact adversely affect medical and behavioural outcomes (Holmes-Truscott et al. 2020; Kato et al. 2020a; Kato et al. 2016b). Stigmatisation also contributes to the avoidance of healthcare services because of the fear of enacted stigma (Earnshaw & Quinn 2012; Winkley et al. 2015). When these findings are interpreted together, there is a case to be made for how the experience of stigmatisation detracts from the ability of PWD to engage in desired self-care behaviours and the monitoring of diabetes-related complications, thus limiting realisation of preventative health goals.

A public health issue or problem can also be claimed when the drivers of this issue/problem can be conceptualised at a population level. Writing from a public health standpoint, Hatzenbuehler, Phelan, and Link (2013) articulate a model of stigmatisation where stigmatising processes can be conceptualised at individual, interpersonal, and structural levels. It is at the structural level that public health is most interested, forming the 'societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized' (Hatzenbuehler & Link 2014, p. 2). Although much research examining diabetes-related stigma has tended to focus on the way in which *individuals* experience adverse effects in response to a perceived public stigma, there is a smaller social science literature that has attempted to describe these 'societal-level conditions' from which diabetes-related stigma emerges and is maintained. For example, Whittle and colleagues (2017) have examined how state welfare arrangements have contributed to moral discourses that function to blame PWD for their illness, whereas other studies have focused on the way in which stigmatising discourses are produced through (public) health pedagogies (Brookes &



Harvey 2015; Kendall et al. 2011; Leahy 2013; Lupton 2014). These latter studies provide glimpses of the socio-structural processes that maintain diabetes-related stigma, opening the stigma concept up to further public health analysis and action.

The field of public health is also well placed to address diabetes-related stigma. Although a review of diabetes-related stigma literature was unable to 'identify any literature regarding strategies to reduce, or assist people to cope with, diabetes-related stigma' (Schabert et al. 2013, p. 7), the strategies employed within stigma reduction work (involving combinations of education, contact, and education (Gronholm et al. 2017; Heijnders & Van Der Meij 2006; Thornicroft et al. 2016)) are broadly consistent with the types of strategies typically used within public health practice (Golden & Earp 2012).. This doctoral research is particularly interested in the role of education within stigma-reduction work. In the past, educational strategies have tended to presuppose that inaccurate stereotypes are responsible for the perpetuation of stigmatising beliefs, and that by replacing these (inaccurate) stereotypes with more accurate beliefs (via education) stigmatisation can be interrupted. In their review of stigma intervention strategies, Heijnders and Van Der Meij (2006), identify that educational interventions have tended to focus on correcting misunderstandings of the causes of disease, its transmission, and treatment, making use of educational methods such as presentations, discussions, simulations, audiotapes, and films.

However, educational approaches targeting the public have tended to produce mixed and inconsistent results, in some instances producing changes in attitudes towards stigmatised groups but having little impact on knowledge or behaviour (Thornicroft et al. 2016). There are a number of possible explanations for this observation<sup>3</sup>; however, this doctoral research engages with the idea that stereotypes are particularly resistant to change because the content of these stereotypes are ideologically and materially structured and reinforced, resulting in what Van Dijk (2006) refers to as taken-for-granted or naturalised knowledge. After all, such knowledge about members of stigmatised groups tend to be 'learned from an early age, anchored in strong affect and longstanding beliefs, and repeatedly reinforced by society over the course of development' (Herek 2007, p. 913). Overt stigmatisation in the form of discriminatory acts tends to be rare due to the effect of social norms and anti-discrimination laws. Rather, stigmatisation is more likely to occur as stigmatising beliefs and attitudes become universalised or taken-for-granted. This taken-for-grantedness allows processes of stigmatisation to be misrecognised at a structural-level, within interpersonal interactions, and within the stigmatised individual's own conscious and unconscious thought processes (Link & Phelan 2014). Therefore, what is needed is an approach to education that might destabilise taken-for-

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<sup>3</sup> The tendency for education-based approaches to produce inconsistent results has been explained in relation to: the psychological mechanisms that maintain stereotypical beliefs (Corrigan & Penn 1999; Herek 2007; Parker & Aggleton 2003); the variable capacity of individuals to confront difficult thoughts and emotions in relation to stigmatisation (Masuda et al. 2007); possible unexamined or latent effects of stigma-reduction interventions (Pescosolido & Martin 2015); and difficulties in identifying the precise effects of education given how educational interventions tend to be used alongside other stigma-reduction interventions and may moderate or mediate the effects of these other interventions (Heijnders & Van Der Meij 2006).

granted beliefs about diabetes in order to support a more conscious and considered analysis about how their experience of stigmatisation might relate to social, cultural, and political processes that act to devalue PWD or sub-groups PWD. It is in relation to this learning outcome that critical pedagogy emerges as a promising educational approach.

## **Critical pedagogy as an alternative educational approach within stigma-reduction work**

This doctoral research is built on the premise that critical pedagogy offers a useful way of facilitating stigma-reduction work, addressing some of the limitations of existing educational approaches. The use of critical pedagogy in supporting stigma-reduction work follows the call-to-action from Parker and Aggleton (2003), which reflects a similar logic for thinking differently about stigma and stigma-reduction education:

To move beyond the limitations of current thinking in this area, we need to reframe our understandings of stigmatization and discrimination to conceptualize them as social processes that can only be understood in relation to broader notions of power and domination. In our view, stigma plays a key role in producing and reproducing relations of power and control. It causes some groups to be devalued and others to feel that they are superior in some way. Ultimately, therefore, stigma is linked to the workings of social inequality and to properly understand issues of stigmatization and discrimination, whether in relation to HIV and AIDS or any other issue, requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings. (Parker & Aggleton 2003, p. 16)

Critical pedagogy is an educational approach that is ideally positioned to examine the 'intersection between culture, power and difference' (Parker & Aggleton 2003, p. 17) that is recognised to occur with stigmatisation (Deacon 2006; Hannem 2012; Hatzenbuehler & Link 2014; Link & Phelan 2001; Scambler 2006b). As an educative approach informed by structuralist and post-structuralist ideas within Critical Theory, critical pedagogy broadly seeks to support learners to better understand and challenge social relations of domination (Kincheloe 2004). As a constructivist approach to learning, it attempts to achieve this outcome by drawing on the past experiences of learners, with this experiential content then used to facilitate a process where learners question taken-for-granted assumptions that underlie these experiences. In doing so, learners can create new knowledge about the world in a way that informs an alternative interpretation of events. This alternative epistemology then provides the basis for different ways of acting (Ledwith 2016). Integrating these things, a critical pedagogy layers an ontological concern with legitimated systems of domination onto conventional pedagogical concerns regarding the process by which knowledge is constructed and the 'transformation of consciousness' that occurs through interactions between knowledge, the learner, and the educator (Lusted 1986, p. 3). Although critical pedagogy has been conceptualised in various ways, these different approaches share common features that include (Kincheloe 2004):

- analysing competing power interests within society;
- assisting individuals and groups to achieve greater control over forces that constrain agency;

- recognising intersections of oppression (and similar terms of domination, inequality, marginalisation); focusing on humanistic goals rather than on technical rationality;
- resisting seeing individuals as rational beings separate from their sociopolitical context;
- assuming a future orientation towards a socially just world;
- a focus on hermeneutics; and,
- the conceptualisation of power in hegemonic, ideological, and discursive forms.

Despite a dominant public health focus on the stigmatisation of persons with HIV-AIDS, mental illness, disability, and obesity, diabetes-related stigma contains several features that makes it stand out as a candidate for the study of critical pedagogy in stigma-reduction education. First and foremost is the way that stigmatising representations of PWD are justified within public health pedagogies given the (perceived) ability of these representations to motivate desirable self-care behaviours (Brookes & Harvey 2015; Kendall et al. 2011; Lupton 2014). As Seligman and colleagues (2015) suggest, the sense that PWD are flawed must be understood within a biomedical context in which good glycaemic control (and the emergence of diabetes-related complications) is directly attributed to diabetes self-care. This context establishes a rich site from which to examine the exercise of power in hegemonic, ideological, and discursive forms. Secondly, unlike for other stigmatised statuses of HIV (Gillett 2003), obesity (Cooper 2016), mental illness (Holland 2018), and disability (Beckett & Campbell 2015), there is limited evidence that PWD have engaged in an organised process of contesting forms of knowledge used to construct a flawed sense of self. Therefore, focusing on diabetes-related stigma offers a relatively uncluttered space from which to examine attempts to critique and contest the social production of stigmatisation.

At the time of writing this thesis, no dissertation or published research had examined use of a critical pedagogy as a stigma-reduction strategy for persons with T2DM. In a systematic review of health and social care interventions employing critical pedagogies (see Chapter 4), no study was identified that applied such methods to persons with diabetes, or to stigmatisation more generally. Although one dissertation (Schoen 2016) claimed to use a critical pedagogical approach in developing an educational curriculum for persons with diabetes, it did not feature an analysis of power or employ the dialogical methods that characterise a critical pedagogy (Kincheloe 2004). Furthermore, no comparable studies, past or present, were found to be registered on the NHMRC's National Register of Public Health Research, the Australian Research Council's Grants Search, or the US National Library of Medicine's Clinical Trials Registry (initially accessed 18 October 2017 and reviewed 10 February 2021). This means that this doctoral research is positioned to contribute new knowledge regarding the application of critical pedagogy to stigma-reduction work.

## **Aims and objectives of the doctoral research**

Specifically, this research primarily sought to *identify what understandings of diabetes-related stigma are produced through participation in an educational intervention informed by a critical pedagogy*

*and what pedagogical and non-pedagogical processes contribute to these understandings. As a secondary aim, this research also sought to identify a suitable location for the practice of critical pedagogy within the field of public health, as this practice relates to stigma-reduction work.* Addressing these aims are valuable to those within the diabetes community, where there is currently limited understanding of what constitutes diabetes-related stigma and what interventions might facilitate stigma-reduction work. Evidence for this claim comes from the Diabetes UK position statement on *transforming the mental well-being for people with diabetes*, which suggests that further research needs to be done to ‘explore issues relating to stigma in more detail through qualitative research, recognising both the similarities and differences in how stigma affects people with different types of diabetes’ and to ‘identify interventions designed to reduce stigma, learning from existing successful stigma reduction interventions for other stigmatised conditions’ (Wylie et al. 2019, pp. 1533-4). This doctoral research brings these two points together through the use of critical pedagogy, which is concerned with both developing an understanding of the ideological production of marginalised identities and using this understanding to construct alternative discourses (Giroux 2004). Addressing these research aims is also valuable to public health-oriented stigma-reduction work more broadly. Although not the case for diabetes-specific literature, health-related stigma researchers have frequently appealed to their audiences to adopt a more critical approach to their analysis of stigmatisation. Notable examples include articles by Parker and Aggleton (2003), Tyler and Slater (2018), Monaghan (2017), Scambler (2018a), and Link and Phelan (2001; 2014). However, this literature has not yet articulated a specific educational approach or method for achieving this, a gap that this doctoral research sought to fill. Breaking these research aims down further, specific objectives of the research involved:

- constructing a model of diabetes group education based upon a critical pedagogy and performing this education program with two self-selected groups of PWD (T2DM) who have experienced a felt, perceived, or internalised stigma;
- drawing inferences about the processes involved in the stigmatisation of persons with type 2 diabetes;
- identifying changes in representations of persons with diabetes and stigmatising events following participation in the education program;
- explaining how processes of learning and education inform different representations of diabetes-related stigma;
- explaining how non-pedagogical processes inform different representations of diabetes-related stigma;
- identifying and explaining the emergence of personal projects of stigma-reduction following participation in the research; and,

- locating critical pedagogy within a landscape of stigma-reduction work and public health practice.

One of the challenges in performing this research is its inter-disciplinary nature, crossing disciplinary boundaries of education, social psychology, sociology, and public health. This means that the research's contribution to knowledge focuses specifically on how critical pedagogy might function and produce useful learning outcomes in the context of stigma-reduction work, rather than directly engaging with more discipline-specific questions that confront the stigma concept or critical pedagogy. However, in examining the translation of critical pedagogy into a public health context, this research also responds to common critiques regarding the application of critical pedagogy, especially that related to the development of methods for making practical the dense and abstract concepts contained within critical scholarship, identifying micro-politics of knowledge construction and intersections of power, identifying limits to individual reflexivity and agency with education, and assessing learning within critical pedagogy (Evans 2008; Keesing-Styles 2003; Lather 1998; Mayo 1994; Vaughan 2016).

## **Outline of the doctoral thesis**

This doctoral thesis is divided into four sections. The first section contains three short chapters, in the form of literature reviews, that expand on the ideas introduced in this first chapter and lay the theoretical foundation for later sections. In this section, Chapter 2 provides a review of key theories, models, and frameworks for understanding stigmatisation, which was done to locate diabetes-specific literature within broader theorising about stigmatisation and to identify approaches that share similar ontological assumptions to that contained within critical pedagogy. Chapters 3 and 4 then review how learning in response to critical pedagogy might be assessed and what type of learning has been produced from existing attempts to implement a critical pedagogy within public health contexts, drawing content from articles previously published by the doctoral candidate (Pillen, McNaughton & Ward 2019; Pillen, McNaughton & Ward 2020). The second section then provides an overview of the research project, including an overview of the development of the educational intervention (Chapter 5) and an overview of the research methodology (Chapter 6). The third section presents the findings of this research, including chapters that; provide an overview of the learners and their engagement with the research (Chapter 7), explain observed changes in representations of PWD (Chapter 8) and stigmatising events (Chapter 9), identify and explain the emergence of personal projects of stigma-reduction (Chapter 10), construct a critical theory of diabetes-related stigma (Chapter 11), and seek to position critical pedagogy within existing stigma-reduction work performed by a state-wide diabetes organisation (Chapter 12). Section four then brings these findings together to answer the research question, re-iterate how this doctoral research has advanced knowledge regarding diabetes-related stigma and the use of critical pedagogy for stigma-reduction work, and describe the implications of this knowledge for future stigma-reduction work (Chapter 13).



## Section One: Theorising Stigma and Critical Pedagogy

The purpose of this section is to lay down a theoretical foundation for development of the research methodology and interpretation of findings. Specifically, there are three important theoretical considerations that this section will address. The first consideration, covered in Chapter 2, relates to how this doctoral research might approach the stigma concept. Because different approaches to critical pedagogy contain their own ontological assumptions about the nature of social reality, it is necessary to be purposeful about the choice of theoretical perspective from which to view stigmatisation. This chapter provides a review of important critical theoretical orientations from which to view the stigma concept and locates existing diabetes-stigma literature within this landscape. The findings within this review were also later used to establish an analytical frame for the interpretation of research findings.

The second consideration relates to how learning might be assessed within critical pedagogy. Consideration of assessment is important within the doctoral thesis because, in contrast to conventional public health pedagogies that seek to communicate health-related knowledge to relevant population groups, critical pedagogy adopts a process-oriented approach to education that seeks to produce new forms of knowledge through an interrogation of existing taken-for-granted knowledges. Therefore, the challenge lies in being able to assess the process of learning and to relate learning to the production of novel discourses and practices. Chapter 3 develops a foundation for assessment through a review of empirical literature involved in developing models and frameworks of critical consciousness and related constructs. These review findings were used to develop a synthesised framework of critical consciousness development, which was later used as a framework to analyse learning within this doctoral research.

The third consideration relates to the learning outcomes produced when critical pedagogy is applied in contexts relevant to public health practice. Because understandings of the theory and practice of critical pedagogy is taken from its use within the discipline of education, it is relevant to identify the patterns of learning that occur when critical pedagogy is applied within settings outside of the classroom. Chapter 4 examines this novel application through a review of empirical educational research performed in health and social care settings. This review also provides verifiable evidence, based on a comprehensive and systematic literature search, that this doctoral research is novel in its use of critical pedagogy to support stigma-reduction work within a public health context. Note that this work draws on but is distinct from critical approaches to health and physical education within school settings (Fitzpatrick 2014) given the way that public health research operates within different intersecting fields of practice (in the Bourdieuan sense) to that observed within educational organisations (Fitzpatrick & Burrows 2017).

Within this section, chapters 3 (Pillen, McNaughton & Ward 2020, see Appendix 1) and 4 (Pillen, McNaughton & Ward 2019, see Appendix 2) were each adapted from published articles. Footnotes are used within these chapters to make clear what parts are original and what parts are drawn from the published manuscripts. For each article, the doctoral candidate was responsible for the conception and design of the research, the analysis and interpretation of the research data, and production of the manuscript. The specific contributions of co-authors are described within the methodology sections within each chapter.



## 2. CONCEPTUALISING STIGMA

Following the seminal work by Goffman (1963), the stigma concept has been widely used to conceptualise human responses to difference. As Toyoki and Brown (2014, p. 716) concisely put it, 'stigma, fundamentally, is an all-too-common human observation that seeks to communicate and justify negative responses to perceived difference'. The fundamental concern with the social production and maintenance of human difference brings under itself a vast and diverse body of theory from various disciplinary fields and theoretical perspectives (Pescosolido & Martin 2015). This conceptual complexity creates a situation where the stigma literature 'is creaking under the burden of explaining a series of disparate, complex and unrelated processes to such an extent that use of the [stigma] term is in danger of obscuring as much as it enlightens' (Prior et al. 2003, p. 2192). In light of this complexity, this chapter goes about establishing the theoretical scope of this doctoral research in relation to the stigma concept. Therefore, this chapter functions as a formative component of this doctoral research, used to inform development of a critical education program and support an analysis of learning. Although this chapter provides a conceptual starting point for this doctoral research, the findings presented in Section Three of this thesis help expand upon theoretical understandings of the stigma concept discussed here.

One of the initial issues that faced this doctoral research was that diabetes-related stigma has been conceptualised in a limited way. Here, understandings of stigmatisation have been influenced by a relatively small body of psychological literature that has focused on the emotional and behavioural responses of individuals to the internalisation or perception of stigmatising beliefs and attitudes (Abdoli et al. 2018; Basinger, Farris & Delaney 2020; Hernandez et al. 2020; Kato et al. 2020a; Kato et al. 2016a, 2017; Kato et al. 2016b; Kato et al. 2020b; Sadeghzadeh et al. 2019; Schabert et al. 2013). In contrast, analyses of issues of power and the socially structured nature of stigmatising beliefs and practices exist towards the margins of diabetes-stigma research (Brookes & Harvey 2015; Seligman et al. 2015; Whittle et al. 2017). Because critical pedagogy seeks to engage with issues of power and structured forms of oppression/domination (Kincheloe 2004), it is important for this doctoral research to take a broader view of stigmatisation than that offered within the extant diabetes-specific stigma literature. This approach follows Deacon's (2006, p. 419) logic that:

One of the problems with the size of this body of literature is that most studies cannot review the broader stigma literature outside of HIV/AIDS, or reflect on the broader debates (notable exceptions being the work of Link & Phelan, 2006; Parker & Aggleton, 2003). In our own literature reviews, we therefore specifically sought insights from other areas of work, and different disciplinary approaches to the problem.

In following this lead, this chapter provides an overview of the different theoretical approaches used to understand and explain stigmatisation, *where these frameworks draw attention to power and/or the socio-political basis of stigmatisation*. By focusing on these aspects of stigmatisation, this narrative literature review omits a large and dominant body of theorising about stigma, including that

along the lines of dramaturgical and symbolic interactionist, (social) psychological, and trans-theoretical (for example, Pescosolido et al. 2008; Pryor & Reeder 2011) perspectives. This omission is acceptable for the purpose of this doctoral research, which is less interested in processes of stereotyping, prejudice, and discrimination that occur within interpersonal stigmatising interactions and more interested with developing an understanding of the ideologies and knowledges used to construct stereotypes and enable prejudice/discrimination. This chapter firstly provides an overview of the current status of theorising about stigmatisation within the diabetes-specific literature. It then examines four approaches to theorising about power that might be drawn upon to examine diabetes-related stigma in a more critical way<sup>4</sup>, making reference to relevant diabetes-stigma literature. These approaches include critical political-economic theories of stigmatisation, stigmatisation and governmentality, and symbolic stigma and social inequality.

## **How diabetes-specific literature has conceptualised stigmatisation**

The earliest explicit example of diabetes-specific stigma research can be observed in the work of Hopper (1981). In this research, Hopper drew upon Goffman's (1963) interactionist-dramaturgical perspective to identify how PWD manage their illness as either a 'discreditable' and 'discredited' condition, with the latter becoming relevant following the onset of physical impairment such as blindness or limb amputation. For the low-income respondents within Hopper's study, diabetes symbolised the potential for disabling complications and premature death, which were seen to be brought about by personal failures of self-care. Diabetes-specific stigma literature has continued to follow this groove since this time, bringing to attention beliefs about the sick or diseased body and the immoral conduct and characters of PWD. In their recent review of stigmatising features of diabetes amongst persons with T1DM and T2DM, Abdoli et al. (2018) identify how persons with T2DM are represented as being 'sick' or diseased in a manner that evokes images of death and disability (and contagion in certain cultural contexts) and are regarded as morally culpable for their diabetes diagnosis because of transgressions of diet and exercise or because of divine punishment for other moral/spiritual transgressions. This separation between matters of 'sickness' and morality follows de-Graft Aikens (2006) distinction between symbolic stigma and disease stigma in relation to diabetes. For de-Graft Aikens, symbolic stigma reflects a 'value-based ideology that imposes moral judgements on others to affirm the in-group's safe and moral identity', whereas disease stigma focuses on stereotypical beliefs and negative attitudes associated with the disease itself that are 'not justified by the medical effects of disease on the human body' (de-Graft Aikens 2006, p. 428).

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<sup>4</sup> A general feature of critical analyses of power is the belief that power, or the capacity for certain agents to achieve desired outcomes, is 'a property of the relationship between agents or groups', meaning that 'all social relationships are power relationships' (Crossley 2004, pp. 214-15). However, there exists numerous different perspectives for understanding how power operates within these relationships (Allen 2008; Crossley 2004). In relation to this doctoral research, power is recognised as being intimately related to the construction of identity, both in relation to the shaping of human subjectivity and in relation to enabling critically reflexive acts of identity transformation (Allen 2008, pp. 2-3).

Although there has been some examination of the way that beliefs about the sick, ill, or disgusting body contributes to stigmatisation (Lupton 2014; Schabert et al. 2013), the vast majority of the diabetes-stigma literature has focused on the moral basis of stigmatisation. The moralisation of diabetes is reflected in two inter-related themes found within the diabetes-stigma literature, that related to individual responsibility for disease prevention and management, and that related to the moralisation of obesity and fatness<sup>5</sup> and its conflation with diabetes. In relation to the former, there is a thematic idea that there exists a proportion of PWD who perceive that ‘society’ blames them for bringing about their own condition and for failures in self-management (Basinger, Farris & Delaney 2020; Broom & Whittaker 2004; Jones & Crowe 2017; Montenegro & Dori-Hacohen 2020; Schabert et al. 2013), a perception that accurately reflects broad public opinion about PWD (Anderson-Lister & Treharne 2014; Gollust, Lantz & Ubel 2010). This blame is observed to operate through moral discourses produced by both healthcare professionals and PWD themselves (Broom & Whittaker 2004; Montenegro & Dori-Hacohen 2020), functioning to construct individuals as naughty (or good) children corresponding to their ability to maintain adequate blood glucose control and practice appropriate dietary and medical care self-care behaviours. In this way, suboptimal diabetes management is taken to be informative of poor personal character (Broom & Whittaker 2004; Kato et al. 2016b; Seligman et al. 2015). The effect of this is that a certain proportion of PWD to express feelings of culpability and negative self-image as they blame themselves for suboptimal treatment outcomes and disease progression (Beverly et al. 2012; Della, Ashlock & Basta 2016).

Fatness and obesity have also been recognised as contributing to the stigma experienced by persons with diabetes given the way that fatness and diabetes have been culturally conflated by way of the ‘diabesity’ discourse employed by healthcare/public health and news organisations (Foley, McNaughton & Ward 2020; McNaughton 2013). In this way, the experience of weight-stigma and diabetes-related stigma becomes intertwined, a taken-for-granted idea within the diabetes-stigma literature that is increasingly being subject to empirical study (Himmelstein & Puhl 2020a; Olesen, Cleal & Willaing 2020; Piatt 2019; Potter et al. 2015; Tsenkova et al. 2010). Although the precise relationship between weight stigma and diabetes-related stigma remains unclear, this literature has quantitatively demonstrated how fatness and obesity play a prominent role in the experience of stigmatisation. Clarifying this relationship is important given how the perception of weight stigma amongst PWD is significantly associated with a range of adverse outcomes including higher HbA1c

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<sup>5</sup> Within this doctoral thesis, fatness is taken to refer to the cultural meaning surrounding ‘large’ bodies (where fat can be framed in negative or productive ways), whereas obesity is the product of the medicalisation of fatness, which frames fatness in pathological ways (Warin & Zivkovic 2019). Throughout this thesis, use of the terms ‘fatness’, ‘(excess) weight’, and ‘obesity’ also reflect the context from which these terms are taken. For this chapter, this reflects the terminology used within the cited studies. However, in the presentation of participant accounts, use of the term ‘obese’ reflects the language used by participants to describe persons regarded by participants to be ‘very overweight’ or ‘fat’ (see p.118). This relates to an argument established later in this thesis that the medicalisation of fatness (i.e., obesity) follows the groove created by the medicalisation of the self following a diabetes diagnosis.

levels (Potter et al. 2015; Tsenkova et al. 2010), higher levels of diabetes-related distress, and poorer self-care behaviours (Potter et al. 2015).

What is apparent from this body of research is that it assumes a distinctively social psychological and interactionist perspective on stigmatisation. This perspective draws attention to the way in which reflective appraisals by members of stigmatised groups influence the development of identity and how individuals actively manage a stigmatised identity in interaction with others (Kaufman & Johnson 2004, p. 811). Dominance of this interactionist perspective likely explains the attention given to studies of self-stigma and stigma management strategies amongst PWD (Basinger, Farris & Delaney 2020; Costabile, Boland & Persky 2020; Della et al. 2020; Earnshaw & Quinn 2012; Kato et al. 2020a; Kato et al. 2016a; Montenegro & Dori-Hacohen 2020). This perspective on diabetes-related stigma reflects a wider (social) psychological interest in processes of self-stigma and the internalisation of stigmatising beliefs (Corrigan, Watson & Barr 2006; Corrigan & Calabrese 2005; Rusch et al. 2006), which is used to explain how certain members of stigmatised groups come to recognise, accept, and apply stigmatising beliefs and attitudes to themselves. The focus on self-stigma is likely a reflection of the disciplinary orientations of leaders in the field of diabetes-stigma research, including Kato and colleagues (Kato et al. 2020a; Kato et al. 2016a, 2017; Kato et al. 2016b; Kato, Yamauchi & Kadowaki 2020; Kato et al. 2020b) and psychological researchers from the Australian Centre for Behavioural Research in Diabetes (Browne et al. 2013; Browne et al. 2016; Holmes-Truscott et al. 2020; Schabert et al. 2013; Speight et al. 2012; Speight et al. 2020).

Outside of this mainstream literature, there are also studies which have attempted to engage with understandings of the ideological and socio-political production of diabetes-related stigma (Brookes & Harvey 2015; Seligman et al. 2015; Whittle et al. 2017). These studies are examined in more detail under the following headings, which explores how stigma literature has engaged theoretically with ideas about the socio-political structuring of health-related stigma. Although a discussion of this literature is broadly organised according to structuralist, social constructionist, and symbolic perspectives on power, it is recognised that several authors drawn from multiple theoretical perspectives in understanding the processes contributing to stigmatisation.

## **A political economy perspective on health-related stigma**

A critical political economy perspective on stigmatisation draws attention to the way that financial capitalism contributes to the stigmatisation of certain groups by way of economic class structures and capitalist ideologies (Lupton 2012a; Scambler 2018b). Such a perspective can be observed, for example, in work by Scambler (2004), Monaghan (2017), and Tyler and Slater (2018). This literature identifies how stigmatisation is used as an indirect method by which powerful economically organised groups may achieve their own goals, with stigmatised individuals accepting (or internalising) the logic of their own inferior status. This literature generally avoids treating stigmatisation as purely a consequence of the interactions occurring between stigmatising and stigmatised persons, instead

focusing on how stigmatisation is covertly reproduced via economic and political ideologies and institutions. Along these lines, Tyler and Slater (2018) discuss how social anxieties and hostility are generated towards those considered to drain from scarce social and economic resources, including groups such as welfare recipients, the sick, the elderly, and the disabled. This hostility can be observed via discourses of personal responsibility that emerge in response to economic austerity measures operating under the logic of financial capital accumulation. For Tyler (2013), this arrangement means that stigmatisation often operates without any perceivable stigmatiser, but forms part of the pervasive day-to-day experiences of members of the stigmatised group. The following quote illustrates this shift in analysis away from the motivations of the stigmatisers and towards the logic contained within political and economic systems that make stigmatisation possible.

However, while research on stigma has started to critically engage with questions of power, it is still often hampered by a limited understanding of 'power': where power is still imagined primarily as a force exercised by individuals – 'the aims of stigmatizers' (Link & Phelan, 2014, p. 24) – rather than conceptualised vis-a-vis the motives of institutions and states within a broader political economy of neoliberal capitalist accumulation. (Tyler & Slater 2018, p. 732)

A similar logic is observed in the work of Scambler (2006a) in his examination of the relationship between stigma (as an ontological deficit) and deviance (as a moral deficit). Building on his own reflections on the stigma concept in relation to 'cultural norms of identity' and 'system imperatives of the economy and state' (Scambler 2004, p. 37), Scambler (2006a) relates configurations of stigma and deviance to the logic of capital accumulation and economic class relations. According to Scambler, this logic has led to the introduction of a culture-ideology of consumerism that emphasises personal responsibility that places emphasis on culpability as individuals are expected to address their ontological deficits. Under this arrangement, power is exercised through individual self-policing or governance, drawing from theory relating to governmentality (discussed later in this chapter).

Similar ideas have been expressed in relation to PWD. For example, Whittle and colleagues (2017) have examined how state welfare arrangements may contribute to moral discourses that act to stigmatise those with diabetes. In the context of a retraction of state-funded welfare support within the United States, the authors suggest that a chronic illness diagnosis has become a gateway for accessing welfare support, resulting in public perceptions of those with chronic illnesses as being 'disability fraudsters' (Whittle et al. 2017, p. 182). On the back of appraisals of deservingness, Whittle et al. (2017) highlight how certain persons living with diabetes and receiving disability welfare payments experienced a triple stigma related to their illness, poverty, and their reliance on state welfare, which comes with its attributions of laziness or immorality. In this way, stigmatisation is experienced via interactions with members of the public as well as the penalising and obstructing way in which welfare support is administered. This experience was interpreted by the authors as being a consequence of political-economic changes within the United States that have transformed protective social welfare into a form of 'disciplinary workfare' combined with a movement of

responsibility from the state to the individual as a form of neoliberal governance (Whittle et al. 2017, p. 187).

What is apparent from this literature is that political economy perspectives on stigma tend to be used alongside social constructionist perspectives, reflecting attempts to relate the material conditions that structure stigmatisation with the discursive processes that function to construct a stigmatised identity. For example, an economic perspective would implicate medical professions and health authorities in the maintenance of stigmatisation given their ability to represent problems as medical issues and claim authority in managing these problems, itself afforded by their class status and state-sanctioned control over knowledge regarding the production of health and prevention of illness (Lupton 2012b). Therefore, medicalisation functions in one way to obscure how financial capitalism contributes to social inequalities in health, whilst also functioning to give rise to expert knowledges which are used to understand the chronically ill self. This function of expert knowledges is examined further with reference to theories of governmentality.

## **Stigmatisation and governmentality**

Drawing from Foucault, a governmentality perspective on stigmatisation examines the ways in which neoliberal societies manage risk through discourses and practices that discipline and regulate members of society, with the exercise of power operating through expert knowledges, the self-regulation of individuals following the internalisation of social goals, and the moralising of personal responsibility for risk reduction (Lupton 2003). Within this perspective, healthy lifestyles have been framed as an appropriate solution to mitigating and managing disease risk. Thus, the ability of an individual to shape their own lifestyle becomes a signifier of responsible citizenship, and their failure to do so invites the attribution of blame, irresponsibility, and justification for negative outcomes, creating the stigmatised other (Crawford 2006). Through their ability to shape and define legitimate knowledge, dominant social groups exercise their power in order to manage the risk associated with the onset and progression of diabetes, subjecting affected individuals to a series of interventions, examinations, regulations, and surveillance in their own 'best interests' (Hannem 2012).

In relation to diabetes, Seligman et al. (2015) and Mendenhall et al. (2016) have identified how medical knowledge and other forms of knowledge compete in shaping one's sense of self and experience of stigmatisation. For Seligman et al. (2015), the moral discourse observed amongst PWD can be related to cultural contexts in which clinical/biomedical frameworks are used to frame diabetes prevention and management. In their research, Seligman and colleagues identify how Mexican migrants residing within the United States manage competing ideologies of selfhood drawing from Mexican and clinical/biomedical socio-moral worldviews. Here, research participants described selfhood and diabetes management with reference to their role within a broader family unit, conflicting with clinical discourses of self-care and with modernist ideas of individual responsibility and self-discipline. There is also variability in the experience of diabetes-related stigma

within countries where alternative frameworks for understanding health exist. For example, in India there is both a *Ministry of Health* (in a biomedical or allopathic sense) and a *Ministry of Ayurveda, Yoga and Naturopathy, Unani, Siddha, and Homoeopathy* (in a non-allopathic sense). From the perspective of the latter, the causes of diabetes tend to be held external to the individual, which removes the basis for personal guilt or shame regarding a diabetes diagnosis. Thus, it was concluded that a non-allopathic understanding of health acted as a shield against 'biomedical frames of shame and stress in association with diabetes' (Mendenhall et al. 2016, p. 305).

Although not directly or primarily engaging with the stigma concept, a governmentality perspective has been emphasised by several researchers in their study of diabetes and other chronic illnesses. Drawing on findings from an ethnographic study of health education classes within three secondary schools in Victoria, Australia, Leahy (2013) found that the pedagogical strategies employed by teachers acted to reproduce health-related risk discourses and individualise responsibility for health, but also to reproduce negative attitudes towards persons living with chronic disease through affective tactics of attaching disgust and shame to undesirable health-related behaviours and outcomes. Kendall and colleagues (2011) describe how chronic disease self-management models have been adopted by healthcare professionals and policy makers in response to desires for improved patient compliance and reduced government spending. These models may also reproduce disciplinary power by reinforcing the notion of the responsible individual exercising free choice, associating poor health with poor self-management and irresponsible behaviours, and reinforcing healthcare professionals as legitimate owners of knowledge. In her analysis of mass education campaigns employing tactics of disgust and fear for purposes of disease prevention, Lupton (2014) demonstrates how these tactics are used to reinforce distinctions between the healthy self and diseased other, stigmatising those that smoke, are obese, or have diabetes.

In this way, stigmatisation is employed by neo-liberal states to legitimise mistreatment of stigmatised individuals on the basis of their assumed personal failings. Drawing on billboards and flyers used within the joint Diabetes UK-Tesco diabetes awareness campaign, Brookes and Harvey (2015) demonstrated how campaign material acted to amplify the danger of diabetes and the grief associated with it in an unjustified manner, whilst also personalising notions of risks and personal responsibility for health. This strategic deployment of fear and anxiety-inducing messages was considered less likely to raise awareness of diabetes risk and more likely to force viewers to draw from pre-existing and possibly stigmatising beliefs about who gets diabetes.

## **Symbolic stigma and social inequality**

Implied in the discussion so far is that stigmatisation and social inequality are somehow related, a point that is well recognised within a public health stigma literature (Deacon 2006; Hatzenbuehler

2016). Here, stigmatisation is observed to 'follow the fault-lines of existing social marginalisation or social exclusion' (Deacon 2006, p. 422), reflecting implicit cultural biases where disease becomes associated with existing understandings of the poor and/or racialised 'other'. In relation to diabetes, this type of thinking is observed in Bock's (2012) ethnographic study of African American men and women with diabetes in Ohio. In this study, Bock describes how stereotypes related to race and class are discursively used to reinforce disease-specific stereotypes related to poor lifestyles and the lack of self-control, which has the effect of creating powerful forms of stigmatisation directed towards already stigmatised or marginalised social groups.

Furthermore, stigmatisation is theorised to maintain existing forms of social inequality through further reductions in social status and the associated loss of social resources such as educational attainment, stable housing, and employment, which is compounded by social isolation, stress, and the depletion of coping resources (Hatzenbuehler, Phelan & Link 2013). For Hatzenbuehler and colleagues (Hatzenbuehler & Link 2014; Hatzenbuehler, Phelan & Link 2013; Hatzenbuehler 2016), these effects are produced when cultural biases become embedded within institutional policies and legislation that systematically disadvantage members of stigmatised groups, often in misrecognised ways (Hatzenbuehler 2016). This idea reflects a form of thinking consistent with the concept of structural discrimination, which is used to describe the ways that seemingly neutral institutional policies, under the control of dominant racial, ethnic, and gender groups, comes to exert harmful effects on minority social groups (Corrigan, Markowitz & Watson 2004; Pincus 1996). In relation to diabetes, structural discrimination is reflected in the way that healthcare policies and institutionalised practices have been found to disadvantage low-income (Page-Reeves et al. 2013), migrant (Page-Reeves et al. 2013), African American (Ryan, Gee & Griffith 2008), and Indigenous (Jacklin et al. 2017) populations. Therefore, the layering of stigma onto existing forms of social inequality deserves greater attention within the diabetes-stigma literature given the way that such inequalities 'create a material and discursive environment' where 'stigma can flourish and gain new layers of meaning' and 'become socially acceptable' (Deacon 2006, p. 423).

## **The stigma concept and its implications for this doctoral research**

What this discussion has demonstrated is that the diabetes-stigma literature has largely drawn upon social psychological and interactionist understandings of the stigma concept, generating knowledge about the content of beliefs and attitudes towards PWD and the psychological response of PWD towards these beliefs and attitudes. With some exceptions, what this literature lacks is an engagement with theories of stigmatisation that centre their analysis the relationship between knowledge, values, social relations, and power, something that is fundamental within critical pedagogy (Giroux 2004; Kincheloe 2004). What is apparent within critically-oriented health-related stigma literature is the way that analytical focus has coalesced around issues of *power*. This focus is particularly evident within seminal literature by Link and Phelan (2001), Parker and Aggleton



(2003), and Scambler (2004), which sought to critique and address the limitations of social psychological and interactionist accounts of health-related stigma. From this chapter, it appears that this critique can be applied to theorising about diabetes-related stigma too.

Although this chapter examined this literature in relation to its emphasis on the exercise of different forms of power, in terms of the political economy, expert discourses, and structural discrimination, understandings of stigmatisation expressed within this literature tended to blur these theoretical boundaries. This crossing of boundaries is particularly evident in the work by Scambler (2006a), who suggests that economic class relations and a logic of capital accumulation have led to the introduction of a culture-ideology of consumerism that gives rise to individual self-policing. In this way, he integrates understandings of social inequality, the political economy, and governmentality to help explain why individuals might feel stigmatised in the absence of an apparent perpetrator. This logic has special relevance to diabetes-related stigma, which as the chapter has demonstrated has largely focused on a perceived, felt, or self-stigma. Because these feelings emerge from a context shaped by the self-management paradigm of diabetes care (Kendall et al. 2011) and economic imperatives for the prevention of diabetes-related complications (see Chapter 1), a critical theory of diabetes-related stigma has the potential to relate these seemingly personal experiences of shame and/or blame to certain knowledges and discourses, which themselves are underwritten by powerful economic and political logics. Therefore, it appears that diabetes-related stigma may offer a fertile site for analysing how discourse, ideology, and the politics of health impinge upon the illness experience of PWD.

Although stigma researchers and public health practitioners are frequently exhorted to engage in thinking about the structural basis of stigmatisation (Hatzenbuehler & Link 2014; Parker & Aggleton 2003; Tyler & Slater 2018), in this doctoral thesis I assert that members of stigmatised groups also have an important role to play in this process. As Link and Phelan (2001, p. 365) suggest, the main challenge to the stigma concept lies in the observation that frameworks of stigmatisation have largely been developed separate from and remain detached from the lived experience of those who belong to stigmatised groups, which has resulted in the 'perpetuation of unsubstantiated assumptions' about what it is to be stigmatised. Furthermore, much of the discussion on the effects of stigma has positioned the stigmatised person as responding to stigmatisation in a rather passive and helpless manner, ascribing them with a victim status and neglecting issues of human agency (Link & Phelan 2001). In relation to diabetes, where resistance to stigmatisation does occur, this resistance has been framed in terms of maladaptive behaviours of illness concealment and social avoidance (Kato et al. 2016a). However, this perspective fails to acknowledge that all individuals do not necessarily internalise the logic of stigmatisation. Scambler and Paoli (2008, p. 1851) suggest that certain individuals might actively resist or defy this logic via 'project stigma', which they define as the 'strategies and tactics devised to avoid or combat enacted stigma without falling prey to felt stigma'. According to Scambler and Paoli, these projects ultimately require a commitment to radical political

and social change in order to modify systems that make stigmatisation possible. For Scambler (2013a, pp. 307-8), this critical project is likely to be entertained by a group of dedicated meta-reflexives, who are those that 'stick their necks out and contest growing inequality' as a consequence of being 'value' and 'other' oriented. In the following chapters, I examine how such a critical project of stigma-reduction might look in practice. In Chapter 3, I specifically look at the learning processes involved in thinking about social inequality in a more socially critical way. Then in Chapter 4, I examine how critical pedagogy has been used in public health contexts to facilitate such learning.

### 3. UNDERSTANDING LEARNING WITHIN CRITICAL PEDAGOGY

As the previous chapter has demonstrated, critical perspectives on stigmatisation tend to assume that stigmatisation is produced via the operation of social processes that transcend interpersonal stigmatised-stigmatiser relations and that these processes are tied to particular configurations of ideological, economic, and political power. Therefore, a critical pedagogy used to understand stigmatisation fundamentally seeks to provide learners with an alternative interpretative framework that can be used to re-interpret their experiences of stigmatisation along ideological and socio-political lines. In other words, the central concern with critical pedagogy is ‘with understanding the sociopolitical construction of the self in order to conceptualize and enact new ways of being human’ (Kincheloe 2004, cited in Horn 2011, pp. 81-2). There are a group of theories and models of learning that have been used to describe how individuals might develop this critical interpretative framework. This includes models of sociopolitical development (Watts et al., 2003) and critical consciousness development (Diemer et al., 2016), which attempt to explain how individuals might become aware of the sociostructural basis of marginalisation, and transformative learning theory (Taylor, 2007), which attempts to explain how individuals modify their frames of reference following a critical self-examination of personal assumptions and beliefs.

Because these theories and models of learning are constructivist and humanistic in their approach, valuing the process of learning over pre-defined learning outcomes (Narayan et al. 2013), the question for this doctoral research is what constitutes meaningful evidence of effective (or useful) learning? This is an important question to address if this doctoral research is to relate changes in representations of PWD and stigmatising events to relevant processes of learning. By drawing on existing literature to develop a synthesised framework of critical learning, this doctoral research is able to engage more closely with broader theorising about learning in the context of critical pedagogy. Within this chapter, the ideal process of learning is referred to as *critical consciousness development*, defined as the ‘intentional cultivation of self-awareness in context that attends to the dynamics of power in relationships and the structural environment invoking action toward social justice’ (O’Neill 2015, p. 626). This definition is helpful as it refers to the key constructs underpinning critical forms of learning, including an awareness that is derived from reflection on oneself within one’s social context, examination of the exercise of power as the focus of this self-reflection, recognition that some are advantaged and disadvantaged because of this power relationship, and a future orientation towards reducing social inequality (Kincheloe 2004). In this chapter, I firstly describe the methodology used to develop a synthesised framework of critical consciousness development, involving a systematic review and qualitative synthesis of relevant literature. I then present the findings of this synthesis, describing a series of learning processes that appear to function to support a critical analysis of social inequality. In addition to facilitating an assessment of

learning within this doctoral research, these findings will be useful for researchers or critical pedagogues seeking a framework for assessing learning within their own educational work.

## **Review methodology<sup>6</sup>**

The aim of this review was to systematically locate literature describing the processes involved in critical consciousness development and to qualitatively synthesise these findings in order to identify key stages involved in this learning process. Although there exists a vast literature that theorises how this process might occur, for the purpose of this review we are only concerned with studies that have developed theories or models of critical consciousness development from empirical data. Given questions regarding the ability of certain approaches to critical education to achieve their educative goals (Sicilia-Camacho & Fernandez-Balboa 2009; Tinning 2002), it was considered more appropriate to focus on observed versus theorised learning processes and outcomes.

The 'BeHEMoTh' strategy (Behaviour/Phenomenon of Interest, Health context, Exclusions, and Models or Theories) proposed by Carroll and colleagues (2013, p. 2) was used to construct the eligibility criteria used to identify relevant models and theories of critical consciousness development. Studies eligible for inclusion in this review must have contributed to the development or refinement of frameworks, models, or theories of critical consciousness development or related constructs using empirical methods. For the purpose of this review, related constructs included socio-political development (Watts, Williams & Jagers 2003), transformative learning theory (Taylor 2007), and theories/models of learning developed within the context of critical pedagogy (Kincheloe 2004), as identified through an earlier scoping review. Eligible studies must have examined the process through which individuals come to understand and act upon social relations of domination and power and given that the process of critical consciousness development is considered to consist of elements of critical reflection and action within a critical praxis (Diemer et al. 2016; Ledwith 2016), eligible studies must also consider processes related to both reflection and action. Eligible study populations included those experiencing marginalisation (or related terms of discrimination, powerlessness, prejudice, vulnerability, and disadvantage) on account of their social identity, persons working in a professional capacity with those experiencing marginalisation, and members of relatively advantaged social groups. These populations reflect those that are typically targeted for participation within critical education programs in public health contexts (Pillen, McNaughton & Ward 2019).

Searches were conducted within academic databases of PsycINFO, SCOPUS, and ProQuest using keywords of 'critical pedagog\*', 'critical consciousness', 'sociopolitical development', and 'transformative learning', which were then combined with keywords of 'framework\*', 'model\*', 'theor\*',

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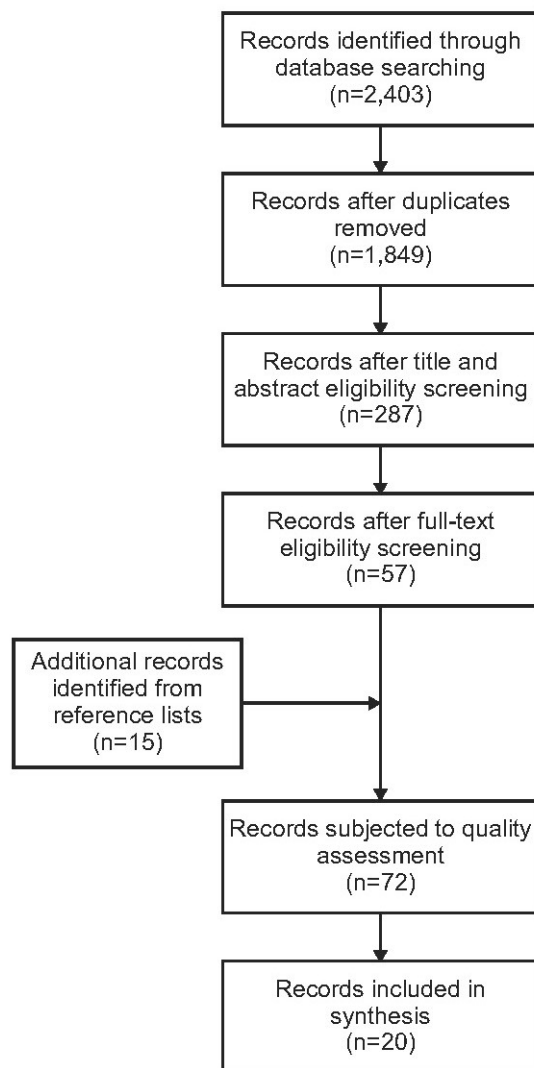
<sup>6</sup> This section, up until page 35, is taken from an article published by the doctoral candidate (Pillen, McNaughton & Ward 2020, Appendix 1).

and 'concept\*'. Searches were limited to English-language articles produced between January 1970 and May 2017, including both published and unpublished literature. Following the removal of duplicate articles, the title and abstract of each article was examined against the review's eligibility criteria in a first round of screening and followed by a more thorough full-text assessment of potentially eligible articles. All stages of searching and study selection were performed by a single reviewer (doctoral candidate). The reference lists of all eligible articles were scanned to identify additional articles not identified through the original search. Two reviewers (doctoral candidate and primary supervisor) then independently assessed the quality of included articles using the Joanna Briggs Institute's critical appraisal tool for qualitative studies (Joanna Briggs Institute 2017) and an additional tool for the critical appraisal of psychometric instruments (Jerosch-Herold 2005). Following independent appraisal, the reviewers compared and discussed ratings until consensus agreement was obtained. Studies deemed to be of poor methodological quality were excluded from the synthesis.

An inductive qualitative thematic analysis was used to synthesis findings from the reviewed literature. While thematic analysis provides a structured method for generating insights from qualitative data with few imposed theoretical constraints (Braun & Clarke 2006; Nowell et al. 2017), for this reason it can be prone to producing untrustworthy findings due to a lack of theoretical coherence within and between constructed themes (Nowell et al. 2017). To address this limitation, we conceptualised critical consciousness development within a rational constructivist framework of adult development (Moshman 2003). Therefore, the task of this analysis was to qualitatively identify and describe the key stages involved in understanding and challenging social relations of domination and to identify how these stages might be ordered in a progressive or developmental configuration. In order to arrive at such a developmental configuration, the research used Attride-Stirling's (2001) thematic networks approach as an analytical tool for identifying relevant themes (representing qualitative developmental stages) and interpreting patterns within our data (representing the developmental relationships between these themes). Using this approach, the authors (doctoral candidate and associate supervisor) constructed a coding framework following analysis of five articles, which was then used to code text from the remaining articles using an iterative process of constant comparison. Following this process, themes were constructed and refined by reviewing coded text, and then assembling text into basic, organising, and global themes. A visual network relating these themes was then constructed and used as a tool for further examining the text and generating analytical insights. All data were organised using the NVivo qualitative data analysis software (QSR International Pty Ltd. Version 11).

## **Findings: learning processes within a synthesised framework of critical consciousness development**

From the 1,849 articles identified via the initial search, 20 were included in the synthesis of frameworks, models, and theories of critical consciousness development. The process of study selection is described in the PRISMA flowchart presented in Figure 1, with study characteristics provided in Table 1. Thematic analysis of these findings produced a framework of critical consciousness development consisting of six qualitative processes and the relationships between them. Although several studies used language suggestive of epochal developmental changes, such as ‘a-ha’ moments (Landreman et al. 2007), or born-again metaphors (Wallin-Ruschman 2014), texts overwhelmingly acknowledged the incremental and cyclical nature of development.



**Figure 1. Process for selecting literature examining frameworks, models, and theories of critical consciousness development**

**Table 1. Characteristics of included studies – frameworks, models, and theories of critical consciousness development**

Study	Methodology	Setting for study	Population
Addleman et al. (2014)	Phenomenological interviews	Cultural immersion field trip within Austria and Ecuador	Students attending a Master of Arts in Teaching program at a private university within the USA (n =24)
Baker and Brookins (2014)	Mixed-methods	Rural village and high schools within El Salvador	Adolescents from a rural village (n = 11) and students attending high school (n = 682) within El Salvador
Barlas (2000)	Qualitative case study	Private not-for-profit university within the USA	Students who identified themselves as being transformed through their participation in a doctoral program (n = 20)
Carlson, Engebretson and Chamberlain (2006)	Photovoice	A poor neighbourhood located within a large urban centre within the USA	Self-selected community members residing within the study area (n=45)
Diemer and Rapa (2016)	Cross-sectional survey	Sample drawn from amongst the 150 schools who participated in the 1999 US Civic Education Study (CIVED)	Ninth graders sampled from populations of poor or working class African American and Latino/Latina adolescents (n = 2811)
Diemer et al. (2017)	Cross-sectional survey	Sample drawn from across five urban high schools plus one African American high school student association within the USA	High school students, with the majority self-identifying as African American (63% of sample) or as multiracial (24.6% of sample) (n = 326)
Frank (2005)	Qualitative interviews	Care providers working in disability support organisations within the USA	Disability support workers who were identified as experiencing perspective transformation (n = 3)
Furumoto (2001)	Qualitative case study	Two elementary schools in southern California	Working class Mexican women volunteering as school-based parent leaders (n =8)
Goerdts (2011)	Qualitative case study	Social work students from the United States and Germany who participated in an intercultural exchange via video/teleconference	13 German and 4 US social work students (n = 17)
Kairson (2009)	Qualitative case study	Women enrolled in a collaborative leadership development program offered by a labour union within a large private university within the USA	14 women, drawn from a population of 228 women who were enrolled in the leadership development program between 2000 and 2007
Landreman et al. (2007)	Phenomenological interviews	Two large US universities with histories of institutional commitment to multiculturalism	University educators varying by ethnicity, gender, and sexual orientation (n = 20)

Study	Methodology	Setting for study	Population
McWhirter and McWhirter (2016)	Cross-sectional survey	Sample drawn from a 2012 Latina/Latino youth leadership conference within the USA, attended by approximately 1,100 high school students	Samples of 476 Latina/Latino students from across 65 high schools (study I) and 870 Latina/Latino students from across 74 high schools (study II)
Mustakova-Possardt (1996)	Qualitative case studies	Sample drawn from participants of the Midlife Development in the United States (MIDUS) survey (Boston area). The Bulgarian sample was drawn from across a large capital city and a small rural town.	20 US and 8 Bulgarian adults, aged between 35 and 60 years (n = 28)
Osajima (2007)	Narrative interviews	Sample drawn from a population of Asian American college students involved in Asian American Studies at a large university within the USA	Asian American college students who described themselves as having a strong pan-Asian American identity (n = 12) and Asian American activists identified through snowball sampling (n = 18)
Peet (2006)	Qualitative case study	Sample drawn from a cohort of graduate-level social work students from a large university within the USA	Social work students that had participated in curriculum oriented towards developing a social justice orientation (n = 111)
Saheli (2003)	Participatory inquiry	Members of a 'churches of Christ' community within the San Francisco Bay Area (USA)	African American men and women aged 55 years or older (n = 6)
Scott (1991)	Grounded Theory	Sample drawn from members of the Lincoln Alliance, a multi-issue organisation that existed in Nebraska (USA) from 1974 -1982	Five past presidents, two past vice presidents, and three organisers from the Lincoln Alliance (n = 10)
Shin et al. (2016)	Cross-sectional survey	Paid online survey	In the first study, the average age of the sample was 33.9 years and consisted of predominantly female (64.8%), Caucasian/European American (68.1%), heterosexual (83.3%), and middle-class (41.9%) respondents (n = 210). In the second study, the average age of the sample was 33.7 years and consisted of predominantly female (53.8%), Caucasian/European American (71.2%), heterosexual (85.0%), and middle-class (49.8%) respondents (n = 406)
Thomas et al. (2014)	Cross-sectional survey	First year students from across two universities within the USA	The mean age of participants was 18.98 years, with a majority of female (67.5%) and African America (40.0%) and White (32.2%) students comprising the sample (n = 206)
Wallin-Ruschman (2014)	Qualitative case study	Students participating in the Girl Power Senior Capstone, which is taught at an urban public university within the USA	Mostly female college students of varying ethnic backgrounds and sexual orientation (n=17)



## **Priming of critical reflection**

The organising theme of 'priming' was developed to help explain why discrete forms of experience (relating to the following theme) might function to trigger reflective processes for one individual but not another. The concept of 'priming' was chosen to illustrate the way in which earlier events, incidents, or cognitive frameworks might influence a person's response to subsequent events, increasing the likelihood that subsequent exposure might provoke a deeper or more perseverant consideration of the event. Amongst the reviewed studies there were three identified phenomena that served a priming function, including the historical exposure to oppressive events or incidents, the adoption of belief systems cognisant of unjust social relations, and having unmet needs in relation to self-actualisation. The following excerpts provide some illustration of how these factors functioned in a priming capacity:

For minority learners, an alternative type of dilemma, one based on racist or sexist experiences and the accumulated effects of a lifetime of discriminatory actions may also trigger the start of the transformative process. (Kairson 2009, p. 138)

All three participants shared an interest in social justice and helping people that began during their formative years...this commitment was significant in fostering their openness to the transformational experience in later life. (Frank 2005, p. 56)

The catalyst for the transformative process in the minority women was the search for something they felt was missing in their life. (Kairson 2009, p. 137)

## **Information creating disequilibrium**

This theme represents the way in which information (broadly defined to include both cognitive and affective experiences) received through discrete events might generate uncomfortable thoughts, feelings, or emotions. Implicitly, it makes reference to Mezirow's concept of a disorienting dilemma (relevant to perspective transformation in adults) (Taylor 1997), which is concerned with how individuals can integrate information incompatible with existing schemata/frames of reference via the process of perspective transformation.

Within reviewed studies, there existed four sources of information that were noted to create a sense of disequilibrium, disorientation, or discomfort. All were alike in that they presented an alternative version of social reality that conflicted with previously accepted or unquestioned models. One source of information involved the witnessing of oppressive acts, either through personal acts (Landreman et al. 2007; Saheli 2003), media representation (Osajima 2007), or through the embodiment of social inequality in objects of separation and segregation (Saheli 2003). Secondly, exposure to non-dominant perspectives provided a way in which individuals might question the validity of dominant understandings of social reality, such as was the case in the following study:

He questioned why he hadn't learned any of this before? Why was his experience absent from U.S. history courses? This process had led him to think more critically about the racism embedded in his educational experiences. (Osajima 2007, p. 67)

Thirdly, the experience of disequilibrium was created through the identification of deviant cases contradicting group stereotypes, leading to questions regarding the validity of these stereotypes (Saheli 2003). And lastly, a deep or immersive exposure to cultural difference provided sustained and contextualised sources of information that might contribute to a state of disequilibrium (Landreman et al. 2007).

### **Introspection**

Introspection is taken to refer to the individual's self-examination of thoughts and emotions in response to a state of disequilibrium. Within the reviewed studies, the objects of self-examination included personal beliefs, motivations, and identity, which were used to make sense of the disorienting incident. For example, a disorienting incident may bring into focus the individual's belief system, and so it becomes possible to evaluate whether personal actions are congruent with these beliefs. The following excerpt illustrates how introspection occurs recursively throughout the process of critical consciousness development, with social action contributing to the receipt of new information that in turn facilitates further self-examination:

While traditional adult education classes focus on dialogue and discussion to create disequilibrium, social action is a blatant, obvious way to facilitate disorientation and disequilibrium. The action of working on an issue was significant enough to create disequilibrium in the assumptions, beliefs or self-interests of a person. (Scott 1991, p. 217)

### **Revising frames of reference**

The focus within this stage was on the cognitive models involved with analysing and explaining social relationships (i.e., frames of reference) and how these might change following a critical analysis of the assumptions underlying these relationships. Amongst reviewed studies, existing frames of reference were shown to be modified through interrelated processes involving the questioning of assumptions informing existing frames of reference and the reconstruction of beliefs used to explain social reality. Amongst texts examined in this review, there appeared to be three assumptions about social reality that needed to be unsettled in order for a revision of frames of reference to occur. First was the assumption that the existing state of social relations represented a fair or just arrangement. Second was the assumption that powerful groups (defined politically and economically) were responsive to the needs of marginalised groups. By questioning these assumptions, individuals come to learn that aspects of social organisation are unfair, and that they cannot trust those with the power to address such injustice to act accordingly:

Participants also demonstrated an understanding of how those in positions of power (e.g., those with wealth and in political leadership) do not often provide help or support to people from lower socioeconomic groups or those who are seen as having less influence such as young people. (Baker & Brookins 2014, p. 1023)

For an unsettling of assumptions to occur, there had to be a questioning of the status or validity of knowledge. Amongst reviewed texts, critical consciousness development required a recognition that assumptions about social reality did not represent natural, universal, or fixed social facts, but rather

were constructed in a way that represented the interests of dominant social groups (Goerdt 2011). Following the unsettling of assumptions, individuals were observed to develop a frame of reference informed by sociostructural understandings, with individual experiences related to social structures that, to some extent, acted to pattern group experiences and behaviour:

The chance to talk to other Asians about their lives and experiences with discrimination had helped respondents to see that their individual experiences were not unique. As they had seen similarities and patterns, it was easier for them to see how broader forces, like racism, shaped their individual lives. (Osajima 2007, p. 67)

In some cases, the revised frame of reference was structured around dualisms of the oppressed and oppressors (or the powerless and powerful). More common however, was the recognition that marginalised groups may also participate in the reproduction of oppressive social relationships. Intersectionality was one strategy used to understand and locate oneself within unequal social relationships, drawing upon experiences related to a co-existing marginalised social identity as a framework for interpreting other unequal social relationships. For example, one study described how for some participants 'understanding their gay/lesbian identities served as a gateway to think about other oppression around them' (Landreman et al. 2007, p. 287). Here, the ability to locate oneself within a system of social relations required clarification of one's social identity or group membership. Within reviewed studies, the revision of social identity involved: a) a realisation that individual identities have a social as well as personal basis, b) that an individual possesses multiple social identities, and c) that aspects of one's identity is amenable to change. Take for example the following excerpt from a study examining critical consciousness development in higher education:

The findings presented here illustrate the intersectional and intersubjective nature of identity development, that who and what we "are" in any given moment is shaped by our interactions within ever changing institutional, cultural, and group experiences that influence how we create meaning from words, the structures of institutions, and our own individual agency. (Peet 2006, p. 385)

### **Perceptions of personal agency**

Agency is regarded here as the ability of a person to successfully perform actions in response to insights generated through a revised frame of reference. Despite the existence of an extensive body of literature theorising human agency (Hitlin & Elder 2007), literature examined within this study provided little indication about what frameworks were used or assumed in explaining the operation of personal and collective agency. Our interpretation of the reviewed literature is presented with this limitation in mind.

Findings from this review are broadly consistent with McWhirter and McWhirter's conceptualisation of 'critical agency' as consisting of both a commitment to change and perceived self-efficacy (McWhirter & McWhirter 2016). However, the analysis reframed 'commitment to change' as 'assuming responsibility for change', which reflected the way in which individuals drew motivation for change from their own implication in the reproduction of oppressive social relationships. Within this

review, self-efficacy appeared to relate to the individual's ability to direct learning, communicate and refine ideas within a group environment, and validate new knowledge within the group, which led to the perception that future actions would be sufficient for achieving change. Reflecting a critical praxis, personal agency was also found to be dependent on processes of action and reflection occurring within and outside of formal learning environments. Within this process, changed behaviour produces new experiences that may trigger further introspection and revision of existing frames of references. This cyclical process has the effect of clarifying the nature of social relationships and ways in which personal influence might operate within these relationships. Through action, skills may also be developed which in turn may lead to more effective forms of action into the future.

### **Resisting or challenging social inequality**

Given the importance assigned to social action within this literature, it was surprising to see that social action was under-theorised and under-reported in texts featured within this review. It was possible to identify actions occurring at either an individual level, in which individuals had control over the terms and execution of the action, or at a group level, which required actions beyond the capacity of individuals to fully plan and execute. The focus of attention for individual action was the reproduction of oppressive social relationships through interpersonal encounters, where discursive strategies might be used to 'interrupt' oppressive discourses:

...learning about interruptions gave them [study respondents] a sense of efficacy—a feeling that they could do something to intervene in injustice. Many participants viewed this practice as a powerful force for personal and political change (Wallin-Ruschman 2014, p. 206)

Less clear was how this action related to the content of reflection. Examining the study from which the above excerpt was taken, there appeared to be some disjuncture between the sociopolitical framework used to conceptualise oppressive group relations and the mode of social action chosen (i.e., 'interruptions'). It was also unclear in this example and others (Landreman et al. 2007) which discursive strategies were being used to interrupt oppressive discourses and in which contexts they were being used. For group-level actions, the focus was on the process of group organisation and how organisation occurred in a way that might afford the group greater influence in addressing oppressive social relationships. However, what these features of group organisation were and how group organisation might be used to gain influence was not explored in any of the reviewed texts.

### **Implications of these findings for this doctoral research**

In developing this synthesised framework of critical consciousness development, this chapter responds to Keesing-Styles' (2003) claim that identifying evidence of critical consciousness development forms an important consideration for assessment within critical pedagogy. At the outset, learning process contained within this synthesised framework appear to engage closely with strategies of stigma-resistance found in extant literature. One of the most prominent examples of a critique and challenge to an oppressive frame of reference has come from the social disability

movement, which has sought to challenge medicalised notions of disability/impairment through use of a social model of disability. This social model of disability (as a novel frame of reference) has provided a way of 'destabilising the present' and bringing 'the future into view' (Beckett & Campbell 2015, p. 272), thus contributing to a 'collective disability consciousness' (Oliver 2013, p. 1024). In this way, the social disability movement provides a good example of the way in which disorienting information (in terms of the medicalisation of bodily impairment), the revision of frames of reference (along the lines of the social model of disability), and challenges to disabling policies and practices function as a form of critical praxis.

Although this chapter has provided a useful framework for supporting the analysis of critical forms of learning, it also raises a series of questions about the precise nature of this learning. These questions include: what is the relationship between these different process of learning (i.e. how are they connected); how might a critical praxis develop; and what role do emotions (vs cognition) play within critical reflection? One of the glaring issues, both within this review and within broader literature, is whether the process of critical consciousness development represents a progressive movement towards a 'higher' state of critical understanding (reflected in the development of scales purported to measure critical consciousness by McWhirter and McWhirter (2016) and Diemer et al. (2017)), or whether it represents a cyclical process with no identifiable end point. Emphasis within reviewed literature was placed on the progressive movement of individuals towards a state of moral maturity, similar to that observed in stage models of moral development (Kohlberg & Hersh 1977). This moralisation of learning was evident in the use of rebirth metaphors, both in reference to personal revelations and radical social change (for example, see Wallin-Ruschman, 2014). The metaphorical use of rebirth is not surprising given historical attachment of consciousness raising efforts to liberation theology, expressed through the works of educators Freire and Horton (Roberts 2000; Thayer-Bacon 2004), and also given more recent attention provided to the role of spirituality within critical consciousness development (Dirkx 2001; Roberts 2009; Watts, Griffith & Abdul-Adil 1999). This observation is important given critiques that critical approaches to education can act to position particular worldviews as being superior to others, with these worldviews being employed as dogmatic moral codes of practice (Sicilia-Camacho & Fernandez-Balboa 2009) and reducing the capacity for critical reflection (Wallin-Ruschman 2014).

An alternative perspective suggests that different levels of (critical) consciousness do not necessarily represent lower or higher orders of thinking, but rather represents 'different ways of making sense of the world, some of which were [more or] less likely than others to disrupt the status quo' (Roberts 2000, p. 145). Within this interpretation, critical consciousness is evaluated according to its usefulness in generating practical action, which connects to the notion of a cyclical and continuously evolving critical praxis that involves a synthesis of critical reflection and action. In this way, a critical praxis is the desired outcome of educational intervention, which itself is never ending because a) there is always the potential to revise and re-construct former understandings, and b) because it is

not possible to be critically conscious about all aspects of one's current frames of reference at any given time. Unfortunately, the reviewed literature featured little theorising of the processes relating changes in frames of reference to personal agency and social action, which leaves uncertainty regarding the process by which a critical praxis develops and sustains itself. However, reviewed studies did appear to represent agency and structure as two analytically distinct phenomena, similar to Archer's (2003) morphogenetic sequences, in which antecedent structures constrain or enable the action of agents, who in turn reproduce or modify these structures. This process, according to Archer, is enabled by human reflexivity that involves an inner-dialogue about the relationship between personal concerns and social circumstances. Further engagement with theories of human reflexivity and agency may therefore help extend current understandings of critical consciousness development. In light of this critique, a key task for this doctoral research is to scrutinise the data for evidence of a critical praxis.

It is also apparent that the synthesised framework of critical consciousness contains somewhat of a cognitive-rational bias. Although the synthesised framework does incorporate both cognitive-rational and extra-rational (Cranton 2010; Dirkx, Espinoza & Schlegel 2018) modes of knowledge production, its closer alignment with transformative theory does mean that the former is privileged over the latter (Taylor & Cranton 2012). Although this bias might expose the synthesised framework to criticism given the way that dominant cognitive-rational approaches to learning may contain Eurocentric and androcentric biases (Cross-Townsend 2011; Ledwith 2016), transformative learning theory has been adapted for use in critical Indigenous education programs (Jackson et al. 2013), which suggests that it is flexible enough to accommodate alternative epistemologies. However, it does mean that within this doctoral research attention needs to be given to the role of emotions in facilitating learning about diabetes-related stigma.

In summary then, this chapter has described a framework containing a series of learning processes that appear to play an important role in helping learners understand, critique, and challenge the sociopolitical construction of social inequality. Although these processes of learning appear to be relevant for a critical analysis of stigmatisation, further investigation is required to identify the type of learning outcomes that might be produced when educational methods, informed by critical pedagogy, are used to facilitate learning within public health settings. This translational issue is addressed in the following chapter, which specifically examines the learning outcomes produced following the use of critical pedagogies in contexts of health and social care.

## **4. SURVEYING CRITICAL PEDAGOGIES IN HEALTH AND SOCIAL CARE**

Although critical pedagogy has a history of use and development within formal education (Evans 2008; Kincheloe & McLaren 2011), this doctoral thesis is interested in how this approach to education

might function in contexts similar to that encountered within stigma-reduction work. For critical pedagogues in education, educational institutions and practices are seen to be complicit in transmitting the (capitalist) values of the state and in reinforcing social hierarchies related to class, race, and gender (Kaufmann 2010; Tarlau 2014). In reaction to these processes, critical pedagogy proposes its alternative model of education, using educational tools to help students critique the way in which certain values are reproduced through school cultures and systems of knowledge production (Steinberg & Kincheloe 2010; Tarlau 2014). Re-interpreting and applying this educational project to diabetes-related stigma, it might be assumed that health education and health-related practices are also complicit in transmitting certain concepts and values that contribute to the stigmatisation of certain PWD. A critical pedagogy in this context would seek to help PWD to critique the way in which these values are reproduced through taken-for-granted knowledge about PWD.

Within contexts of formal education, the overarching outcome of critical pedagogy is the democratisation of societies. More specifically, Steinberg and Kincheloe (2010) suggest that an appropriate outcome is for marginalised voices to be articulated and included within democratic processes, recognising that dominant cultures tend to dominate decision-making processes. At the coalface of student education, they suggest that an immediate outcome is for students to actively question the truths and obligations handed to them, which 'provides them the ability to act in empowering ways that were previously impossible' (Steinberg & Kincheloe 2010, p. 145). Within a framework of a moral critical pedagogy, they also suggest that an appropriate outcome is for individuals (as members of one or more dominant social groups) to better understand the perspectives of, and advocate for the rights of 'oppressed' groups. This outcome is consistent with Tinning's (2002) 'modest pedagogy', for which a meaningful educational outcome would include a rational critique of taken-for-granted beliefs and practices and an emotional commitment for change. In the context of his fierce anti-neoliberal stance, Giroux (2004, p. 34) also claims that democratisation is also an important goal, although he rejects a purely modernist interpretation of democratisation, but rather describes democratisation as an ongoing process in which 'power is not transcended, but reworked, replayed, and restaged in productive ways'. In this way, an outcome of critical pedagogy for Giroux is for learners to understand the relationship between knowledge, values, social relations and power and to make visible alternative forms of democracy, which is then used to support the development of learners as political agents. In other words, learners must first make problematic their representation of certain issues through a process of deconstruction, which is then used to create alternative discourses.

Turning to a more concrete examination of critical pedagogy in public health practice, this chapter establishes what learning outcomes are evident when critical approaches to education have been applied within public health contexts. Despite calls for greater use of critical methods in health education (Martos 2016; Nutbeam 2000), a comprehensive review and synthesis of the effects of interventions informed by such methods is notably absent within academic literature. To bridge this

gap, I conducted a literature review, based on a systematic search of published and unpublished literature, to identify learning outcomes resulting from participation in educational interventions informed by critical pedagogies and delivered within contexts of health and social care. Rather than focusing more narrowly on stigma-reduction interventions, which would have produced limited findings, the scope of the review was expanded to include educational interventions within settings of health and social care that employed critical pedagogies to examine and address issues relating to any form of social or health inequality. In this chapter, I firstly provide an overview of the literature review methodology, followed by a synthesis of findings from this review. These findings are then discussed in relation to the doctoral research, with the purpose of identifying how this research can address the theoretical and methodological shortcomings of existing critical educational research in public health contexts.

## **Review methodology<sup>7</sup>**

The protocol for this review was published prospectively on the PROSPERO database of systematic reviews and meta-analyses (<https://www.crd.york.ac.uk/PROSPERO/>) under registration number CRD42017067777. This review follows the refined “best fit” framework synthesis’ approach described by Carroll and colleagues (2013). This approach uses a systematic literature search and thematic analysis of relevant theories, models, and frameworks to construct a conceptual framework for the phenomenon of interest, with this ‘best fit’ framework then used to analyse the findings of primary research studies identified via a second systematic literature search. Given that the previous chapter performed the task of the first literature search and synthesis, this chapter will focus only on the procedure involved with the second literature review.

In this literature search, there were several eligibility criteria. Eligible educational interventions could relate to any health or social issue, accommodating the breadth of issues examined within socioecological approaches to health education (Fitzpatrick 2014); however, the education intervention must include an analysis of underlying issues of social power relations or social inequalities. The theoretical framework used within each study must have been explicitly stated and there should be evidence that this framework had informed intervention development and assessment/evaluation. Interventions delivered as part of the primary or secondary schooling curriculum or within school settings were excluded from this review. Eligible study populations included those experiencing marginalisation (or related terms of discrimination, powerlessness, prejudice, vulnerability, and disadvantage) or persons working in a professional capacity with marginalised groups. Learning outcomes were assessed against a framework of critical consciousness development, as described in Chapter 3.

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<sup>7</sup> This section, up until page 45, is taken from an article published by the doctoral candidate (Pillen, McNaughton & Ward 2019, Appendix 2)



Searches were conducted within academic and grey literature databases of PsycINFO, MEDLINE, SCOPUS, ProQuest, Web of Science, Trials Register of Promoting Health Interventions, Database of promoting health effectiveness reviews (DoPHER), Campbell Collaboration, CDC Database of Interventions, EPPI-Centre Database of Education Research, NHS Evidence in Health and Social Care, UNESDOC: UNESCO Documents and Publications, Google Advanced, and WorldCat. Searches were limited to English-language articles published between January 1970 and May 2017, regardless of publication status. The search string was developed in PsycINFO (Appendix 3) and translated into the syntax required for the other databases.

Following the removal of duplicate articles, the title and abstract of each article was examined against the review's eligibility criteria in a first round of screening and followed by a more thorough full-text assessment of potentially eligible articles. All stages of searching and study selection were performed by a single reviewer (doctoral candidate). The reference lists of all eligible articles were scanned to identify additional articles not identified through the original search. Following the retrieval of articles, two reviewers (doctoral candidate and primary supervisor) independently assessed the quality of included articles using the Joanna Briggs Institute's critical appraisal tool for qualitative studies, which uses a 10-item checklist used to assess methodological rigour, analytical transparency, and ethical conduct within qualitative research (Lockwood, Munn & Porritt 2015). Following independent appraisal, the reviewers compared and discussed ratings until consensus agreement was obtained. Studies deemed to be of poor methodological quality were excluded from the synthesis.

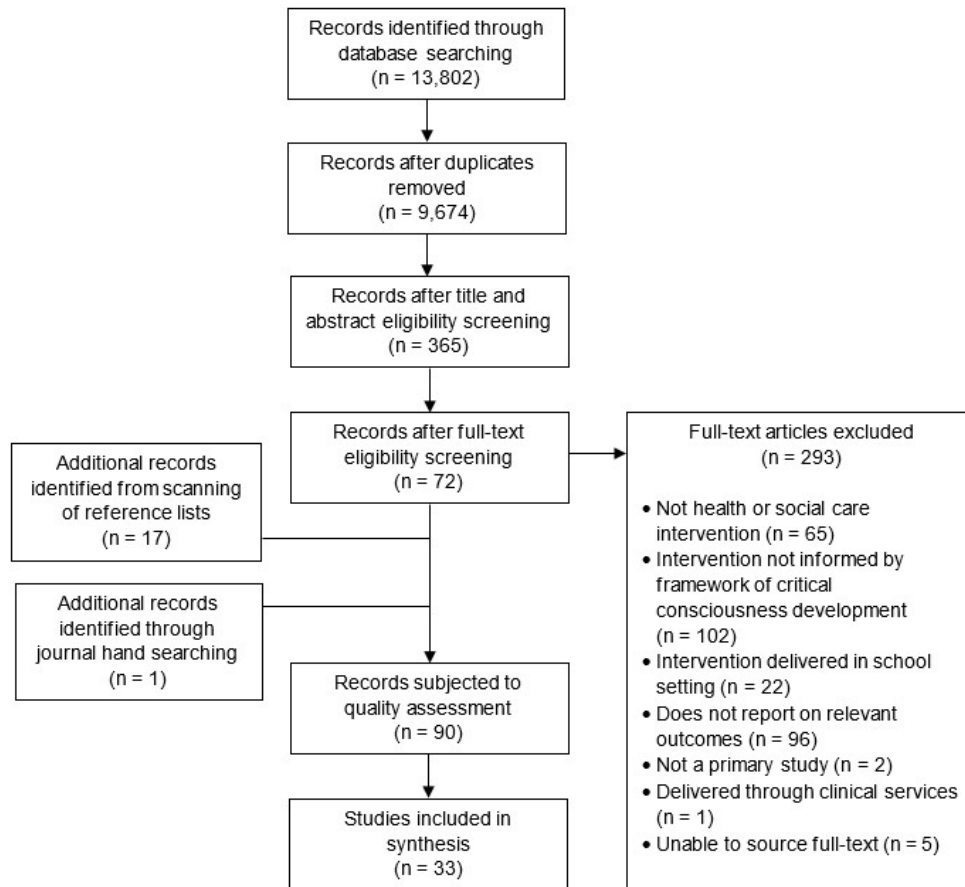
Data were extracted

by a single reviewer (doctoral candidate) using a template that collected information regarding: the study design; population characteristics; intervention purpose, context, and characteristics; intervention fidelity; research methodology; outcomes assessed; and research findings. Using the synthesised framework of critical consciousness development, the findings of primary interventional studies were coded deductively by a single analyst (doctoral candidate) with cross-checking and discussion with a second reviewer (associate supervisor). A thematic analysis of findings not captured by the *a priori* framework was then conducted by a single reviewer (doctoral candidate). NVivo qualitative data analysis software (QSR International Pty Ltd. Version 11) was used to support organisation and analysis of the extracted data.

## Findings

Of the 9,674 articles identified from this search, 33 were found to satisfy the inclusion criteria and were of sufficient quality to be considered within this review (Figure 2). Characteristics of the 33 included studies are provided in Appendix 4. Findings from the analysis are presented according to those stages contained within the synthesised framework of critical consciousness development

(Chapter 3). An additional theme of 'adverse effects' was created to capture adverse outcomes resulting from educational intervention.



**Figure 2. Process for selecting literature examining critical education interventions within health and social care settings**

### Revision of frames of reference

Of interest within this section are the cognitive frameworks (frames of reference) that individuals use to interpret their observations of events and the assumptions that these frameworks rest upon. Within the reviewed literature, emphasis was placed on describing the content of revised beliefs about social reality, with less detailed reporting on the processes by which learners questioned assumptions and constructed knowledge within the educational setting. This emphasis is problematic, as it acted to obscure the process through which these revised beliefs and assumptions were formed, and whether these changes reflect a constructivist approach to learning or the adoption of a preformed account of social reality. Moving beyond the level of description and examining changes in an individual's frames of reference at a more abstract level, a consistent theme within reviewed studies was the development of a socio-structural understanding of oppression/social inequality. This revised frame of reference could be characterised by a) a recognition of a systematic organisation of social relationships, b) the placement of individuals within this system according to certain personal characteristics such as gender, race, ethnicity, age, wealth, education, and disability

status, c) the ability to attribute personal experiences to the effects of social organisation, and d) the positioning of oneself within unequal social structures. In reviewed studies, the process of revising frames of reference involved the individual naming their own social identity, and in some cases, acknowledgement of the co-existence or intersection of identities of relative advantage or disadvantage. Take the following excerpt for example:

For the predominantly white, female, and heterosexual group of educators, blind spots emerged as they developed an awareness of white privilege, male privilege, and straight privilege. Several white educators discussed how they had never considered the concept of white privilege prior to the course and how it opened their eyes to advantages they never realized they had. By virtue of being white, male, or straight, some educators grappled with the recognition that they benefited from a system that oppressed others. (Bondy et al. 2015, p. 239)

An important question here is what role did the questioning of taken-for-granted assumptions or knowledges play in changes to the individual's frame of reference? Examining such self-reflective or introspective processes of learning is important because it may assist with understanding how learners interpret reality and form personal projects in light of this reality (Archer 2003). However, the questioning of taken-for-granted assumptions or knowledges used to understand reality was poorly reported within the reviewed studies. Of the studies that did report on such introspective processes, two features of learning were frequently referenced. The first was a recognition that personally held assumptions used to explain a given event do not represent an objective and universally valid truth, but rather are produced via social and cultural processes. The second outcome related to a questioning of assumptions about the fairness of existing social arrangements.

### **Perceptions of personal agency**

Agency is regarded here as the ability of a person to perform desired actions in response to insights generated through a revised frame of reference. In the absence of longitudinal observation, perceived self-efficacy or intention to change were used as proxies for action following conclusion of educational interventions. In several studies, reference was made to learners 'willingness' to enact some form of change in working towards socially just goals. The term 'willingness' was frequently used yet poorly defined or conceptualised within the reviewed literature. Related to a willingness to change were learners accounts of their perceived ability to enact change. However, these statements of self-efficacy did not refer to particular targets for action, thus it was not possible to identify particular activities or contexts within which self-efficacy relates. The following excerpts provide examples of how studies framed this 'willingness' or sense of personal agency in exceedingly broad and non-specific terms:

Analysis of the data revealed an increase in their willingness to engage in and facilitate critical, constructive inquiry regarding issues of social justice and equity. (Brown 2004, p. 31)

[Participants] discovered strengths and capacities within themselves that had, until that time, gone unnoticed. In particular, participants described how they became confident in their ability to communicate and take control of their own lives. (Foster-Fishman et al. 2005, p. 281)

Another prominent learning outcome reported within certain studies was the way in which the group functioned to refine and validate newly constructed ideas. The concept of 'voice' used in some studies is helpful here (Brown 2006; Jeanetta 2006). Although not explicitly described within these studies, voice implied the ability of learners to give structure or form to experiences related to oppression/social inequality, to refine the content and expression of ideas, and validate the worth of these ideas amongst their peers:

The women in the Circles of Hope develop voice by having education programs that introduce new information; the women have opportunities to speak and that helps them to find clarity and organize their thoughts, and they practice speaking with peers in the Circle. (Jeanetta 2006, p. 282)

### **Resisting or challenging social inequality**

Individual-level action represented a dominant action-oriented outcome within this review. Individual-level action could be further separated into actions that attempted to improve one's own circumstances through individual betterment, and those actions through which oppressive discourses and practices were resisted in interactions with others. In the former case, although the causes of an individual's disadvantage might have been regarded as consequence of an unjust social structure, the appropriate response for learners was to manage its effects through an individual cognitive-behavioural response:

All four of the women in the study who acknowledged perspective transformation also changed how they acted on the world. Debbie changed how she approached her public policy work. Elizabeth's new self-image made it possible for her to go to school. Gene's new perspective on community made government more accessible to her. Danielle's experience made her more tolerant of people who had been in jail. (Jeanetta 2006, p. 280)

Actions at an interpersonal level focused on transforming oppressive social relationships by purposefully altering the usual course of interactions with others. Such actions included strategies of confronting or interrupting language containing oppressive ideologies (Atkinson 2012; Bondy et al. 2015; Wallin-Ruschman 2014), resisting the tendency to assume subordinate roles within interactions (Bhukhanwala & Allexaht-Snyder 2012; Bhukhanwala, Dean & Troyer 2017), or exerting control over the terms of social interactions (Bowers & Buzzanell 2002; Kosutic et al. 2009; Paxton 2003; Zion, Allen & Jean 2015). A more complete analysis of these interpersonal interactions is not possible because these interactions were self-reported by individual learners (via interview or writing) in broad terms. Consequently, it was not possible to identify what discursive strategies were being used and under what conditions these strategies might be more or less effective. It is also unclear what effect reported actions might have had on others participating in the interactional exchange.

Group-based actions were less commonly reported and occurred exclusively within the context of educational interventions delivered as a component within larger community development projects (George 2007; Hess et al. 2014; Jeanetta 2006; Travers 1997; Wiggins et al. 2009). This made it difficult to identify whether community organisation was a spontaneous outcome of critical reflection

or whether it was the consequence of other concurrently used community development frameworks. The excerpt below, taken from one such community development project, demonstrates how social action might occur in the absence of a socio-structural analysis of social disadvantage. In this case, the focus of analysis was on the abandoned building and its symbolic meaning, rather than on those social processes that expose poorer populations to such conditions:

During her reflection that week, she shared her negative feelings about the [derelict] building and discussed its effect on her neighborhood. Four weeks later, the same participant brought in another photo of the same building that was now cleaned up as part of a neighbourhood beautification project she had organized. (Foster-Fishman et al. 2005, p. 284)

This last point raises important questions about the relationship between reflective outcomes (related to changes in an individual's frame of reference and their perception of possibilities for change), social action, and the transformation of social inequalities. If the espoused theory of critical pedagogy is true, then we would expect to observe some evidence of development of a critical praxis, that is, a cyclical process of self-reflection, social action, and social change (Shapiro 1999). However, only a limited number of studies examined the relationship between self-reflection and social action (Bondy et al. 2015; Bowers & Buzzanell 2002; Foster-Fishman et al. 2005; Kosutic et al. 2009; Paxton 2003; Travers 1997; Wallin-Ruschman 2014). Within these studies, individuals began to interpret the actions of others in quite different ways following a revision of their frames of reference, with observation of these actions providing information that prompted further reflection and revision of these frames of reference. For example, one study reported on an organised visit of a low-income parent centre by a government minister for social services, in which the attending media worked to reproduce the stereotype of a low-income mother. This observation of media tactics was used by group members to further reflect on the way in which stereotypes were reproduced within society (Travers 1997). However, no study offered a discussion about the implications that changes in frames of reference might have on future social action and how such action might contribute to social change.

### **Adverse effects**

Several studies acknowledged the potential harms that might emerge from participating in these educational interventions (Brown 2004; Carlson, Engebretson & Chamberlain 2006; Kraehe & Brown 2011; Rondini 2015; Wallin-Ruschman 2014). Although some studies observed moderate levels of discomfort associated with engaging in personal reflections (for example, Brown (2004)), one study reported high levels of emotional distress experienced by some individuals as formerly valued relationships were re-interpreted as having an oppressive quality (Wallin-Ruschman 2014). In another study, a sense of frustration and hopelessness was evident amongst some individuals, who perceived the task of social change to be overwhelming and unattainable (Rondini 2015). Although

these individuals maintained a desire for social change, rooted in justice-oriented beliefs, they felt that a socio-structural understanding of marginalisation excluded the possibility of human agency, such as evident in the following excerpt:

Student reflections also revealed ambivalence about the extent to which they felt that their individual-level efforts could meaningfully impact social change, despite their ideological investments in such processes. Several students indicated feeling overwhelmed by the structural understandings of health-related inequities that the course was designed to highlight. In this interview excerpt, and other similar examples, students' articulations of frustration and anger in response to deeper understandings of structural inequities complicated, rather than precluded, their ideological commitments to social justice and social change. (Rondini 2015, p. 143)

In one study (Wallin-Ruschman 2014), some participants showed evidence of an uncritical acceptance of frameworks used to conceptualise marginalisation (as an infallible 'truth'), contributing to pseudo-religious conversion experiences and precluding further critical analysis of the issues involved. Similar outcomes of indoctrination were not reported in interventions involving members of disadvantaged groups, which may be attributed to the more experiential educational methods used within these interventions and their tendency to be learner rather than educator-driven. Within this group however, there appeared to be some difficulty in disrupting naturalised individual-level explanations for disadvantage or oppression, acting to conceal the socio-structural basis of marginalisation and contributing to victim-blaming. Such an outcome is evident in the below excerpt:

Comments from the participants during the first workshop, and many of the photographs and stories, clarify how the rhetorical moral message "We have to do something" is undermined by the cultural norms of distrust and blame that are pervasive and destructive to all attempts at individual and collective action. The photographs and stories categorized at this level of critical consciousness were narratives of despair and anger. Emotions were salient in these narratives and the cognitive-emotional interpretation is one of helplessness. (Carlson, Engebretson & Chamberlain 2006, p. 843).

## **Implications of these findings for this doctoral research**

The purpose of this review was to identify relevant learning outcomes when members of marginalised social groups (and those working with members of these groups) participate in critically-informed educational interventions, and to determine how these learning outcomes might contribute to a critical praxis. In truth, the findings from this review are underwhelming, and raised more questions than offer answers. This was largely due to the limited provision of details regarding methods of assessment and analytical strategy, the opaque narratives used in the presentation of case study findings, and the frequent use of universalising and modernist discourses of change and enlightenment. These are critiques that have been long directed at the reporting of critical forms of educational research and the reporting of case study research more broadly (Bassey 1999; Keesing-Styles 2003; Lather 1998; Rogers et al. 2005). The following excerpts provide good examples of the opacity that characterised the reporting of outcomes within these studies.

Participants broke a culture of silence by sharing experiences among themselves and came to recognise the common and political roots of their oppression, which assisted them to shed their self-blame. (Travers 1997, p. 349)

...the CritG [Critical Genogram] exercise allowed for reflection on the nature and origins of worldviews and provided an opportunity to create new narratives about lives and experiences. Many of these narratives changed the perception of participants' place in society. (Kosutic et al. 2009, p. 168)

Vitaly, no single study offered a comprehensive and transparent account of how a critical praxis might develop. Despite the absence of a comprehensive account of learning, studies did succeed in contributing an understanding of the *content* of learning, describing qualitative changes in beliefs about social reality, how learners position themselves within their social world, and how learners envisage actions to address issues of marginalisation. However, in the absence of a comprehensive examination of reflective/reflexive processes involved in this learning, it becomes difficult to determine to what extent this is a learning outcome based on the interpretation and critique of personal experience (constructivism) or an interpretation of reality through the lens of an adopted sociological framework. Most notably within this review, the asymmetric use of personal experience as the content of learning (at the expense of theory) tended to minimise the influence of social structure, with agency perceived to trump structure. Therefore, future research needs to better identify how personal experience and social theory integrate with one another as part of reflexive processes and what implications this integration has for how learners engage conceptually with matters of structure and agency.

Although there is little empirical evidence within reviewed studies to suggest that educational interventions are resulting in specific projects that might contribute improvements in the status of socially marginalised groups, this finding should be interpreted in the context of the methodological and reporting limitations of reviewed studies. Limitations include the dominance of cross-sectional study designs, with data collected either during or shortly after participation, and poor reporting of the specifics of action where longitudinal data did exist. A consequence of these methodological and reporting limitations is that it is difficult to identify evidence of a critical praxis. Methodologically speaking, this observation suggests that this doctoral research would benefit from the use of longitudinal methods of data collection to better evaluate the relationship between reflection and action and to examine how a critical praxis may develop over time. In the absence of this longitudinal assessment of change, it becomes difficult to engage with conceptualisations of learning and human agency that involve a temporal dimension, such as with Archer's (2015) morphogenetic approach. The use of case comparison may also assist in overcoming the universalising and generalising tendencies of existing research, bringing to the fore the characteristics of learners and features of learning that might explain variations in learning outcomes.

Importantly for this review, no study was identified that explicitly used critical methods of education to examine the production of health-related stigma. This finding highlights a need for further research

involving members of stigmatised groups and with the process of stigmatisation as its analytical focus. Such research will help determine whether educational interventions informed by a critical pedagogy might represent a viable component within broader stigma-reduction work. The following section provides a strategy for addressing this existing gap in knowledge whilst seeking to overcome the theoretical, methodological, and reporting issues raised within this chapter.



## Section Two: Research and Educational Methodology

Up to this point, this doctoral thesis has laid a theoretical foundation for the research. Specifically, it has identified how the stigma concept might be interpreted to ensure that assumptions about stigmatisation are theoretically coherent with assumptions contained within critical pedagogy, how learning might be assessed given the aims of critical pedagogy, and what learning outcomes might be expected when critical pedagogy is used in contexts comparable to that encountered within stigma-reduction work. Within this section, I have drawn upon this work to develop an educational intervention and a research methodology for addressing the questions posed by this doctoral research.

In Chapter 5, I provide an overview of the educational program used within this research and describe how it was adapted for use in examining diabetes-related stigma. This chapter deliberately seeks to integrate theoretical considerations regarding the content, form, and intended outcomes of education (Tarlau 2014) with practical considerations regarding lesson planning and classroom strategy. In Chapter 6, I then provide an overview of the case study methodology used to examine learning in response to the educational intervention (part one) and the deliberative democratic methodology used to locate critical pedagogy within an existing landscape of stigma-reduction work (part two).

## 5. DEVELOPMENT OF THE EDUCATIONAL PROGRAM

Although certain principles cut across different approaches within critical pedagogy, including the role of dialogue in the construction of knowledge, the use of personal experience as a resource for learning, and the analysis of power (Kaufmann 2010; Roberts 2000; Steinberg & Kincheloe 2010), critical pedagogy itself is light-on details when it comes to technical educational practices of lesson planning and classroom strategy. Often this limited guidance is justified by the necessity of taking a more situated approach given that educational programs will vary in purpose, contain varying theoretical assumptions about social reality and the exercise of power, and work with learners of differing ability (Keesing-Styles 2003). However, inattention to articulating what specific educational practices might be expected within a critical pedagogy can act 'to restrict its audience to those readers who have the time, energy, or inclination to struggle with it', limiting its audience and therefore its potential for social change (Keesing-Styles 2003, p. 6). In her critique of critical pedagogy, Gore (1993) suggests that the (over) use of abstract concepts, particularly around the notion of empowerment, acts to impose unrealistic requirements on educators without any real practical guidance for achieving desired educational outcomes. Likewise, Keesing-Styles (2003, p. 6) suggests that while 'there is clearly a responsibility on the teacher to create, adapt or determine the appropriate strategies for the particular context', more could be done to acknowledge the realities of educational work.

The chapter responds to this critique by providing an outline of the development of a brief educational program, informed by a critical pedagogy, which is designed to facilitate a process where PWD might engage in a self-reflective critique of historical-hegemonic ways of knowing about PWD, identify the material conditions that position certain subjectivities (in relation to identity and selfhood) as dominant and others as marginal, and act in ways that might support the accommodation of alternative subjectivities. The aim of this chapter is to make transparent the educational method used to support this critique, whilst illustrating the logic involved in selecting and adapting an educational program that is consistent with key tenets of a critical pedagogy. Read alongside Chapter 7, which provides an overview of the learners and their engagement with the education program, this chapter will help maintain transparency in relation to how this doctoral research was planned and the practical realities of performing such educational work.

### **Selecting the education program**

Following on from the earlier review of critical pedagogies in public health contexts (Chapter 4), it was apparent that there already existed a range of educational approaches that could potentially be adapted for the purpose of examining health-related stigma. Fortunately, the evidence-informed practice paradigm within public health provides several criteria that might be used to select the most appropriate educational model, taking into account evidence of effectiveness, the needs of the target

population, available resources, environmental and organisation enablers and constraints, and ethical considerations (Brownson, Fielding & Maylahn 2009; Kass 2001). An overview of the criteria used in selecting an appropriate educational model is provided in Table 2.

In selecting the educational program, a short-list of educational approaches were drawn from literature identified through an earlier systematic search of critical educational interventions delivered within settings of health and social care, prior to the exclusion of non-empirical literature. This shortlist included 365 articles, of which 55 were identified as providing a suitable fit for purpose and were theoretically coherent, that is, they offered a process-oriented approach for helping persons with diabetes critique the way in which certain taken-for-granted assumptions and knowledges regarding diabetes are reproduced. Fook and Gardner's *Model of Critical Reflection for Professional Practice* (2007) was then chosen as the most suitable program for this research following assessment and ranking of this literature. Theoretically speaking, this model of education was particularly relevant to the aims of this research given its focus on the reflexive critique of taken-for-granted assumptions, its focus on the dialectical relationship between theory and practice (i.e., praxis), and its use of critical theory incorporating a post-structuralist critique. Furthermore, this educational model offered a relatively brief and structured form of education, for which method was extensively described.

Fook and Gardner's (2007) Model of Critical Reflection for Professional Practice was originally designed to support social work and human services practitioners to develop an awareness of the implicit and explicit theory and assumptions involved in their practice with the intention of closing the gap between their espoused practice and the realities of everyday practice. Building on theoretical frameworks of the reflective approach to theory and practice, reflexivity, post-structural deconstruction, and critical social theory, the premise of their educational method is that individuals tend to internalise and personalise their social world and that critical reflection, through the unsettling of assumptions, may contribute to an unearthing of the hidden social aspects of their lives and in turn generate options for challenging the status quo. The overall aim of this educational method is to recognise personal influence within specific contexts in developing a sense of agency, or as the authors describe it:

A critical perspective on critical reflection simply involves the idea that when dominant social understandings or assumptions are exposed (through a reflective process) for the political (or ideological) functions that they perform (i.e. that they exist for political reasons in supporting the status quo, apart from whatever inherent truth they might have), the individual who holds those assumptions is given a choice. Once these hidden ideas are exposed people who hold them are given the power to change them and the guidance to change them in ways that may overturn previous inequitable arrangements. (Fook & Gardner 2007, p. 38)

**Table 2. Criteria used in the selection of a suitable educational program**

Criteria	Rationale	Important considerations for selection of an appropriate educational model
<i>Fit for purpose</i>	<p>Because there currently exists limited evidence of effectiveness of critical methods of education within public health contexts (Pillen, McNaughton &amp; Ward 2019), ‘evidence of effectiveness’ might be re-considered in terms of the interventions <i>fit for purpose</i> and <i>coherence</i> with the theoretical assumptions of this research. This is consistent with the earlier assertion that the design of critical methods of education should respond to localised interests and conditions (Keesing-Styles 2003, p. 4) whilst remaining grounded in critical social theory.</p>	<p>How well might the educational model be used to critique the way in which certain taken-for-granted assumptions and knowledges regarding persons with diabetes are reproduced?</p>
<i>Theoretical coherence</i>		<p>Does the educational program address the process of critical consciousness development in a comprehensive way, is it congruent with theories of experiential and adult learning, and is does it maintain a critical orientation?</p>
<i>Suitability for the learning needs of the target population</i>	<p>A useful intervention must be suitable for the (learning) needs of the target population (Brownson, Fielding &amp; Maylahn 2009; Kass 2001)</p>	<p>Research participants form a heterogeneous group of persons (by age, gender, educational attainment, and disease characteristics) with type 2 diabetes who have experienced stigmatisation, and who may have limited exposure to methods of education other than those delivered within the dominant paradigm of structured self-management education programs. Therefore, can the educational program accommodate sufficient scaffolding of learning and accommodation for learners of differing ability?</p>
<i>Feasibility</i>	<p>The adoption of critical methods of education within a public health context characterised by scarcity and competition over resources (Parkhurst 2017) raises the issue of the <i>feasibility</i> of any chosen intervention. In the earlier review of critical methods of education delivered within health and social care settings, it was observed that most interventions were conducted over relatively long periods of time and involved open-ended and highly flexible designs (Pillen, McNaughton &amp; Ward 2019). Whilst this longitudinal immersion and flexibility is desirable within critical pedagogy, it is likely to prove a poor fit for resource scarce organisations and for chronically ill persons (such as those with diabetes) that already experience additional work associated with the ongoing management of illness (Corbin &amp; Strauss 1988).</p>	<p>How efficiently does the program appear to function in relation to achieving its educational aims? Does the program appear to offer a valued return on the time invested by participants?</p>
<i>Adequate description of method</i>	<p>Because of the limited practical guidance available for the practical conduct of critical education, interventions that offer a detailed articulation of method were considered to be an advantage</p>	<p>Is the method of education adequately described in relation to educational/instructional strategies, learning activities, and learning outcomes?</p>

This approach follows the general task of critically-oriented education to disrupt hegemony by articulating different ways of making sense of the world (Razack 1999; Roberts 2000, p. 145; Steinberg & Kincheloe 2010), or what Hammond (2018, p. 6) refers to as 'dislocation', that is, to see reality in a different light in order to detach oneself from dominant social and political discourses. Fook and Gardner's approach then uses this dislocation (what they call the 'unsettling' of assumptions) to open up new opportunities to think and act, focusing on the opportunities afforded by engaging with the *process* of critical reflection rather than working towards pre-defined learning objectives. This approach is consistent with the point that 'criticality does not determine how we see the world nor does it provide a blueprint for particular actions. Critical theory helps us devise questions and strategies for exploring them' (Steinberg & Kincheloe 2010, p. 143). The chosen educational method facilitates this exploration by facilitating thinking about why stigmatisation exists as it does, and what knowledges and concepts might be used to understand PWD in less stigmatising ways.

The method is dialogical in the sense that group members assist one another to reflect on their own experiences, which they do by helping to connect personal reflections to collective thinking and offering alternative perspectives. For Fook and Gardner, dialogue takes on a character consistent with forms of communication described within Habermas's Theory of Communicative Action (1984), which assumes that any communicative activity establishes a normative understanding of society and that the act of dialogue should ideally proceed in a self-reflexive manner where individuals learn from each other by reflecting on their own premises and presuppositions. The role of the educator within this process is to maintain a group culture that promotes (as far as possible) equal participation in the dialogical process, whilst ensuring that the process runs smoothly. Doing so acts to de-emphasise the role of the educator in the construction of knowledge, and although this runs against the grain of a critical pedagogy defined by both educator and student assuming learning roles within the group (Tarlau 2014), it is an acceptable concession given the benefit that this arrangement is likely to have on improving the efficiency (therefore enhancing the feasibility) of the educational intervention. This approach also follows instructional strategies consistent with a constructivist approach to education, where cognitive modelling is used to demonstrate forms of reasoning that learners might use in approaching a particular problem and coaching is used to provide motivation for learning and the facilitation of increasingly critical reflective thinking (Jonassen 2009).

Examining the content of learning, Fook and Gardner place emphasis on the use of concrete experiences upon which to reflect, where suitable experiences are those that are significant to the learner, offer constructive ways of thinking critically about personal experiences, and are incidents that they want to learn from. These points sit well with ideals of the self-directed learner within theories of adult learning (Alford 2013), but also work well in directing attention towards the concrete interactional 'fabric' in which stigmas are made (Hebl & Dovidio 2005, p. 156). The focus on concrete interactions should resist the tendency to reduce the experience of stigmatisation to purely

psychological phenomena of felt or internalised stigma (contained within what Hebl and Dovidio refer to as ‘construal’ studies of stigma) and brings into focus the real-life interactions and forces that (re)produce stigmatisation. However, in order to facilitate a more critical analysis of oppressive (stigmatising) interactions, Fook and Gardner provide a series of questions that direct attention to the way that these interactions, and the assumptions/knowledges informing them, are ideologically and politically shaped. Such questions, adapted to the purpose of this research, are provided in Appendix 5.

## Adapting the education program

Certain modifications have been made to Fook and Gardner’s method to make it more appropriate to the learning needs of persons without formal training in social work or human/social services. In comparison to these professional audiences, it is assumed that PWD are less likely to possess easily communicated or shared frameworks (e.g. those related to the self-in-society, identity, and social justice) from which to form counter-hegemonic discourses and projects, and may have difficulty participating in language-intensive and self-reflective learning activities. Therefore, the education program requires additional attention to the scaffolding of learning, which involves the provision of temporary learning supports to assist with skill and knowledge development, with these learning supports gradually removed over time as learners become more independent and self-directed. As well as encouraging independent learning, which may be particularly challenging in the early stages of the group, scaffolding also functions to minimise the emotions of frustration and discouragement that result from performing a difficult task with insufficient support (Rojas-Drummond et al. 2013). In relation to the chosen education program, scaffolding was approached in two ways – in the setting of learning objectives for each session and in the choice of learning activities.

Although the establishment of specific learning objectives tend to be avoided by critical pedagogues on the basis that they reproduce unequal power relations in the educator-learner relationship, learning objectives provide helpful ways of directing the process of instruction and (formative) assessment in an explicit manner. It would be naïve to think that critical pedagogues do not have (implicit) objectives contained within their educational work and learning objectives do not necessarily have to focus on the attainment of ‘correct’ knowledge, but rather can focus on observable performances or behaviour and the use of specific tools that enable this behaviour to occur (Pagliaro 2012). Within the educational program, learning objectives (described in Table 3) were used to guide modification of learning activities both prior to implementation and to guide the assessment of learning during implementation.

**Table 3. Learning objectives for the adapted education program**

Cognitive*	Affective*	Psychomotor*
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The learner can describe the three-step process of critical reflection (remembering)	The learner listens to the narratives and perspectives offered by other group members (receiving)	The learner is able to explain their experience of diabetes-related stigma to others (communicating)
The learner can describe questions that may be used to facilitate critical reflection (remembering)		
The learner is able to demonstrate use of critical reflection as a tool for understanding diabetes-related stigma (applying)	The learner engages in discussion with others in response to their narratives and actions (responding)	The learner is able to explain their process of learning and reflection to others (communicating)
The learner independently applies a framework of critical reflection for addressing problems outside of the group setting (applying)	The learner relates stigma or related processes to their own experience of living with diabetes (valuing and organising)	
The learner is able to identify assumptions underpinning their experience of stigmatisation (analysing)		The learner participates in the creation of novel discourses and practices via role play (communicating and creation)
The learner evaluates and refines their understanding of stigma and the operation of power following reflection on interpersonal interactions (analysing and evaluating)	The learner influences others within the group to transform stigmatising discourses and practices (characterisation)	
The learner constructs a behavioural plan of action for challenging assumptions and knowledges that underwrite stigmatising practices (creating)		

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\* According to hierarchies described by Pagliardo (2012, pp. 106-15)

The scaffolding of learning was also supported by the incorporation of specific forms of instruction into learning activities, consistent with assumptions within a constructivist learning environment where the educator's role is to assist students to construct knowledge in order to solve pressing real life problems (Jonassen 2009). It is the 'problem' that features centrally within constructivist approaches and thus students learn or construct content in order to solve the problem. Drawing from Jonassen's (2009) overview of scaffolding strategies for creating constructivist learning environments, it is apparent that Fook and Gardner's method already accounts for a number of these strategies. For example, the requirement of learners to draw upon concrete experiences and offer contextualisation of these experiences creates what Jonassen (2009, p. 223) calls 'problem manipulation spaces'. Furthermore, the turn-taking format used to examine these experiences offers exposure to 'related cases' (i.e., cases that are representative of the current problem, but occur within different contexts), which exposes learners to multiple perspectives or interpretations of a particular problem. Additions to Fook and Gardner's method included the use of reflective journaling as a 'cognitive tool' (Jonassen 2009, p. 223), supporting an introspective process by which the learner examines, assesses, tests, and challenges their perceptions of the world, while also helping to connect inner thoughts with real-life processes in a way that bridges reflection and action (Hubbs & Brand 2010, p. 59). As conversation and collaborative tools (Jonassen 2009), participants were also provided with questioning guides (Appendix 5) that encouraged participants to ask questions

from multiple perspectives and in ways that might relate stigmatising events to the content and reproduction of specific knowledges about PWD.

In relation to the aims of this doctoral research, one of the limitations of Fook and Gardner's method is that it offers little opportunity for learners to 'manipulate the environment in order to construct and test their theories and models, and reflect on what they did, why it did or didn't work, and what they have learned from the activities' (Jonassen 2009, p. 230). Observation of such environmental manipulation is important for trying to establish how a critical praxis might unfold. To compensate for this limitation, participatory role plays were added to the education program, drawing from Augusto Boal's Forum Theatre methodology (1992). This methodology was developed by Boal as a practical education activity that might assist marginalised groups to develop strategies of resistance and the means by which to act on these strategies (Österlind 2008). Consistent with the centrality of the 'problem' within constructivist approaches to learning (Jonassen 2009), Forum Theatre presents participants with a problem that is first acted out in an unsolved form. Relevant 'problems' were taken from prior group discussion and used to construct a fictional script, which was developed and acted out by the educator and an assistant. On a second run-through of the script, participants (the so-called 'spec-actors') were then invited to act out solutions to this problem (Boal 1992).

To make the program less intensive and to encourage weekly reflection, the three-day format used by Fook and Gardner was broken down into five weekly group sessions, each being two hours in length and designed to accommodate six to eight participants. The chosen group size reflects a tension between creating an intimate group environment for learning and accounting for participant dropout, which has ranged from 7% to 33% in diabetes group education programmes of a similar length and intensity (Steinsbekk et al. 2012). An overview of the *a priori* content and structure of these sessions is described within a unit plan and a series of lesson plans in Appendix 6, which detail the learning objectives and activities for each session and the strategies used to scaffold learning. These plans function as a cognitive tool in helping the educator work through their method of instruction in an explicit way, which helps ensure that important tasks are not omitted from the session, supports reflection-in-action during the process of facilitation, and makes facilitation methods visible and therefore accessible for critique (Fautley & Savage 2013).

## **Addressing anticipated learning constraints**

Given that the education program is designed to support a critique of hegemonic, naturalised, or reified concepts in relation to PWD, it is unlikely that such learning will occur either spontaneously or easily. Therefore, it is important to identify and address likely constraints to learning. The first and most important consideration relates to assumptions about the relationship between human reflexivity, human agency, and social structure. Some important questions raised in relation to critical pedagogy is whether it is possible to assist individuals to become conscious of their own structured dispositions (Österlind 2008) and how human agency might be imagined in the face of a seemingly



monolithic social structure (Rondini 2015; Wynne 2019). Furthermore, binary distinctions between the powerful and powerless may generate resentment between those positioned at opposite poles, creating a 'politics of resentment' as the powerful are accused of sequestering power whilst the powerless are denied access to their own power (Healy 1999, p. 127).

These issues were largely addressed in this research through the type of questions used to deconstruct individual experiences of stigmatisation (Appendix 5), informed theoretically by a weak post-structuralist critical theory (Fook & Gardner 2007). This approach retains many of the assumptions of critical social theories, particularly a focus on the material basis of power and domination and a future-orientation towards a socially just end. Retaining a focus on the material conditions that structure diabetes-related stigma is important given the way that stigmatisation, social inequality, and structural discrimination are related (Hatzenbuehler, Phelan & Link 2013; Hatzenbuehler 2016). It is also important given the public health imperative to improve the conditions of living and the health status of stigmatised populations. However, a sole focus on the material conditions that structure stigmatisation overlooks the way in which stigmatised persons actively manage their identities via discursive strategies (Ranjbar, McKinlay & McVittie 2016; Toyoki & Brown 2014). In this way, discourse does not simply reflect identity, but also constitutes it (Benwell & Stokoe 2006). Within this doctoral research, the focus on the discursive construction of identity allows for a closer engagement with taken-for-granted knowledges (assumptions) that are drawn upon as resources to achieve stigmatisation. By articulating the form of such knowledges, learners are provided with a starting point from which to identify the material conditions and socio-political motivations that give rise to such knowledge. By taking this approach, this research offers learners an analytical logic where micro-interactional acts of managing a potentially stigmatising identity can be related to material conditions from which dominant knowledges emerge and others are marginalised. Relating these things provides the basis by which existing modes of resistance to stigmatisation can be destabilised and provide new opportunities for action (Healy 1999).

Another issue relates to the tendency of learners to reject critical pedagogies as being overly paternalistic, particularly in cases where critical pedagogues operate in ways that repress individual subjectivities and position particular worldviews as superior (Sicilia-Camacho & Fernandez-Balboa 2009). This observation highlights ethical issues with respect to how existing knowledge is problematised, the risks of doing so, and how the epistemic rights (i.e., individual claims to valid knowledge) of learners might be respected and maintained throughout their participation of the education program. Several strategies have been incorporated into the education program to avoid, as much as possible, this epistemological asymmetry. Consistent with the approach advocated for by Fook and Gardner (2007), rather than imposing certain truths or working towards content-based outcomes, the proposed educational method allows for the exploration of participant-generated content with no pre-defined end, meaning that participants are able to work with concepts 'within their sphere of influence' and to 'choose whether to legitimize, resist or transform the status quo'

(Sicilia-Camacho & Fernandez-Balboa 2009, p. 451). Because unequal power-relations also exist between individuals within the group (Kaufmann 2010; Lather 1998; Vaughan 2016) attention was also paid to developing a safe environment for dialogue, deconstructing dominant ideologies and discourses, and acknowledging and encouraging multiple subjectivities. Practically speaking, a safe environment was created through the development and frequent references to a formal set of group norms.

In relation to the feasibility of the educational program, there was uncertainty as to how well a critical approach to education might be received by persons with T2DM, who are likely to be more familiar with individual-oriented cognitive and behavioural approaches to diabetes education that are grounded within the self-management paradigm of care (Kendall et al. 2011). Although the described educational program does not compete with the self-management educational paradigm given that each has very different aims, Warin and Gunson (2013) point out the way that participants respond to research often reflects tacit understandings of themselves as problematic objects of research. For Warin and Gunson, who were recruiting to an ethnographic study of women, food, and bodies, this meant that the researchers were often approached by women asking if the research was going to help them to 'lose weight'. Thus, the terms of their engagement with the research was on the basis of their problematic 'obese' bodies, despite the researcher's avoidance of the term. In relation to this doctoral research, the problematisation of PWD may lead to participants asking, 'what's in it for me?' when held up against educational programs that claim tangible benefits in the form of improved glycaemic control. Furthermore, a critical pedagogy is likely to be very foreign when compared with the dominant self-management paradigm of diabetes education, with a critically-oriented approach drawing on personal experiences as the content of learning (cf. biological 'facts' about diabetes and PWD), being constructivist and dialogical in form (cf. expert driven) and seeking to ultimately produce outcomes that challenge forces that maintain a stigmatised identity (cf. improved glycaemic control).

Although there are some demonstrable individual-level benefits that might be accrued from participation in critical approaches to education, including cathartic release (Ares 2015; Jeanetta 2006; Kased 2013) and increased feelings of self-efficacy and self-worth (Teti et al. 2013), more desirable benefits (from the perspective of public health practice) include a more effective engagement with and challenge of stigmatising processes, which are likely to benefit PWD at a population level. Here, perceptions of benefit invokes the 'prevention paradox' in public health, where certain activities 'brings much benefit to the population [yet] offers little to each participating individual' ... and thus there is poor motivation for the subject [sic]' (Rose 1985, cited in Hunt & Emslie 2001, pp. 442-3). Drawing from lessons learned from past research involving recruitment from stigmatised and hard-to-reach populations (Hart-Johnson 2017), this issue was addressed by making the aims of the educational program as transparent as possible, involving an extended process of explanation during the provision of study information and in obtaining informed consent. Revolutionary change in the production of stigma is an unrealistic outcome for an educational

program of this size and scope, and the experience of stigma is also just one in many challenges of living with diabetes, and therefore participants should not see the educational programme as a panacea to all of these psychological and social difficulties.

In summary, this chapter has contributed knowledge regarding the design of an education program that might support stigmatised persons to critique the knowledges and material conditions that structure stigmatisation and facilitate a critical praxis that draws upon alternative knowledges about PWD. In expanding upon the design process, I have illustrated how the theory of critical pedagogy might engage with the practical realities of education work involving non-academic learners. Specifically, I have discussed how critical theory, educational theory, and instructional method might be integrated, coming together to inform the development of practical educational tools described within appendices 4 and 5. This chapter is useful in that it provides a *transparent* overview of exactly how the education program was developed, how it was adapted for purpose, and how it might facilitate a critical analysis of diabetes-related stigma. In the next chapter, a methodology is presented for examining the learning produced from participation in this education program.

## 6. RESEARCH METHODOLOGY

This chapter describes a strategy for answering the question: *what understandings of diabetes-related stigma are produced through participation in an educational intervention informed by a critical pedagogy and what pedagogical and non-pedagogical processes contribute to these understandings?* This chapter begins by clarifying the philosophical assumptions underpinning this research, drawing from the meta-theory of critical realism. Here, I argue that the ontological and epistemological assumptions within critical realism can be rightly assumed within this research given their congruence with the theoretical assumptions contained within critical pedagogy and with certain critically-oriented understandings of the stigma concept. I then describe the longitudinal and comparative case study design used within this research, identifying why this design is appropriate given these ontological and epistemological assumptions and how this design addresses some of the limitations of existing empirical research. I then provide an overview of the methods of data collection and following this provide an overview of the methods of participant recruitment, drawing attention to some of the considerations involved in the recruitment of persons from stigmatised or hard-to-reach groups. In responding to critiques regarding the lack of transparency and rigour in analysing the learning outcomes of critical approaches to education, I provide a detailed overview of the analytical strategy, which was used to relate changes in representations of PWD and stigmatising events to specific processes of learning (i.e., in relation to critical consciousness development). Although ethical and quality considerations are attended to throughout the chapter, I also make explicit these considerations as they relate to the conduct of case study research from a critical realist perspective.

At this point in the doctoral research, several findings emerged which prompted an expansion of the research project. Specifically, it was my pessimism around the feasibility of a critical education project, owing to the way that pervasive risk discourses were being used to legitimise stigmatisation and constrain a critical analysis of diabetes-related stigma (discussed in chapters 8 to 10), that raised the question of *how such risk discourses might be destabilised?* In addressing this question, the research turned to an Australian state-wide diabetes organisation, which like other diabetes organisations straddle responsibilities for the communication of ideas about risk and risk management and the articulation and communication of alternative representations of PWD. By taking the findings from earlier parts of the doctoral research, a second research activity was performed using a deliberative democratic methodology, where employed staff and board members within this diabetes organisation were supported to identify the implications of these findings for future stigma-reduction work. In this way, this additional research is a mark of quality within qualitative research given its responsiveness to the emergent conditions of social research (Popay, Rogers & Williams 1998). Furthermore, this research attends to calls for critical pedagogy to connect with organisations that might facilitate projects of social and political change (Tarlau 2014) whilst

also providing a form of research translation that seeks to locate a home for critical pedagogy within existing public health activities.

## Philosophical assumptions

This research adopts the meta-theoretical perspective of critical realism to inform the ontological and epistemological assumptions of this research. Specifically, this perspective seeks to explain social phenomena operating within open systems through the operation of mechanisms (the *real*), which when triggered produce events (the *actual*) that are experienced via the senses and meaning making of individuals (the *empirical*). In doing so, a critical realist perspective makes a clear distinction between ontology, assuming that these mechanisms exist and operate independent of our knowledge of them (a realist ontology), and epistemology, in which it is assumed that our knowledge of reality is only ever partial and fallible (a relativist epistemology), although some forms of knowledge are considered more or less fallible than others (Danermark, Ekstrom & Jakobsen 2002). There are several reasons why critical realism is considered a good theoretical fit for examining both critical forms of learning and the phenomena of diabetes-related stigma. These reasons are outlined below and elaborate on some relevant assumptions within critical realism that inform this research methodology.

A critical social science assumes that social structures exist, are shaped according to dominant social interests, and that they act to condition adherence to certain types of thought and behaviour in a manner that preserves the stability of these structures (Danermark, Ekstrom & Jakobsen 2002). Similarly, within stigma research the concept of structural stigma assumes the existence of 'societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatised', which in turn maintain the status quo of stigmatising social arrangements (Hatzenbuehler & Link 2014, p. 2). Within critical realism, the nature of structure is one of related objects that produce certain semi-permanent regularities. These structures enable the triggering of generative mechanisms, which give rise to effects given an appropriate trigger and permitting conditions. This means that 'people's actions are never determined by a certain structure; they are merely conditioned' (Danermark, Ekstrom & Jakobsen 2002, p. 56). By focusing on these structures and mechanisms, it is possible to *explain* how stigma might produce its effects. This type of thinking can be observed in the writing of Monaghan (2017) and Scambler (2018b), both of whom examine health-related stigma from a critical realist perspective in attempt to move beyond a Goffman-inspired focus on micro-interactional processes towards a focus on the structures and generative mechanisms that reproduce or transform stigmatising social relations.

Also connected to a critical analysis of social structure is the possibility of changing those structures that are labelled as unjust, unfair, or harmful to certain groups of people. The focus on human agency and social change gets to the core of this doctoral research, which is fundamentally interested in the relationship human agency and stigmatising social structures and the role that human reflexivity

plays in mediating this relationship. This type of thinking is influenced by the work of critical realist Margaret Archer, who approaches this issue by assuming a duality of agency and structure, where human agency and social structure exist as two analytically distinct phenomena (Archer 2010). This assumption about the relationship between human agency and social structure requires an analytical dualism that describes how 'structures constrain and enable the actions of agents, and the agents reproduce or transform structures' (Danermark, Ekstrom & Jakobsen 2002, p. 181). This process of reproduction/transformation is ordered temporally into what Archer (2015) refers to as morphogenetic sequences. Here, antecedent structures constrain/enable the action of agents to produce either intended or unintended actions, which in turn reproduces/modifies structures that then constrain/enable future action. This process, according to Archer (2003), is enabled by human reflexivity that involves an inner-dialogue about the relationship between personal concerns and social circumstances. This process is analogous to the concept of praxis described within critical pedagogy, a process that relates a self-in-society reflection with social action in a cyclical manner (Roberts 2000; Shapiro 1999). As Creaven (2007, p. 8) asserts, this dialect between human agency and social structure has important implications for how personal and social identities are reproduced and transformed.

...as humanity's species-being and attendant powers and capacities are transmitted 'upstream' into social interaction and socio-cultural relations (supplying the power which energizes the social system, constraining and enabling socio-cultural production and reproduction, and providing a certain impetus towards the universal articulation of particular kinds of cultural norms or principles), structural-cultural and agential conditioning are transmitted 'down-stream' to human persons (investing in them specific social interests and capacities, shaping unconsciously much of their psychological and spiritual makeup, and furnishing them with the cultural resources to construct personal and social identities for themselves.

As the following section demonstrates, these critical realist assumptions have important implications for the case study design (which seeks to produce theoretical generalisations based on data collected within complex *open systems*) and the analytical strategy (which seeks to identify *transfactual conditions* that enable and constrain learning and how learners reflexively engage with stigmatising processes).

## **Part one: examining learning in response to a critical pedagogy for understanding diabetes-related stigma**

### **Research design**

A qualitative case study design, incorporating longitudinal data collection and case comparison was used within this research to explain how changes in discursive representations of PWD and stigmatising events might emerge. The choice of a case study design is common within both educational research (Hamilton & Corbett-Whittier 2013; Johnson 2014) and within research examining the effects of critical pedagogy (see Chapter 4). The dominance of qualitative approaches within critical education research can partly be explained as a reaction to positivist methodologies,

which are seen to contribute to unequal power relations in the generation of knowledge given false claims to neutrality and objectivity (Hamilton & Corbett-Whittier 2013) and in failing to engage with ways by which power, shifting subject positions, and discourse influences the process and outcomes of research (Daley 2010). By attempting to gain a more comprehensive understanding of complex and contextually-bound educational phenomena, qualitative case studies also reject a narrow positivist 'what works' perspective that functions to de-contextualise the findings of educational research (Hamilton & Corbett-Whittier 2013). From a critical realist perspective, context is important because it helps understand how certain outcomes might be produced given the triggering of different generative mechanisms.

Although there exists multiple perspectives on what constitutes a case study, including its purpose and defining features (Bassey 1999), for the purpose of this research a case study is regarded as the qualitative investigation of a phenomenon within a real-life environment, in which there are blurred boundaries between the phenomenon of interest and contexts of group learning and interactions beyond the setting of the group (Yin 2014). This blurring of boundaries creates a situation where there is an abundance of variables of interest available within participant data and multiple sources of data are required to understand the phenomenon in a comprehensive way. This contextual understanding helps focus attention on group power dynamics introduced via imposed ideologies, the micro-politics of knowledge construction, and intersectionality, which are things that are claimed to have received insufficient attention in past studies of critical education (Chinyowa 2015; Esteva, Stuchul & Prakash 2005; Vaughan 2016). As Roberts (2000, p. 121, emphasis in original) suggests, 'knowledge, from a Freirean point of view, can only be acquired, or more correctly, authentically *constructed*, through practical experience; that is, through one's interaction with others and with the objective world'. Therefore, when examining critical understandings of diabetes-related stigma, the boundaries between individual processes of learning, group interactions, and learning activities are not only blurred, but also represent artificial divides given the interrelatedness of these activities.

Within this research, the purpose of the case study was explicitly explanatory, consistent with what Yin (2014) and Stake (1995) refer to as explanatory or extrinsic case studies, respectively. In this way, the research attempts to make generalisations beyond the case study itself, that is, what can be inferred generally about processes of learning that contribute to a critical consciousness of stigmatisation and what participants accounts infer about processes involved in the production of diabetes-related stigma. Likewise, Bassey (1999) suggests that the true value of education research lies in its potential to inform the real-life practice of educators, which requires the ability to generalise beyond the bounds of the case study. It is the scientific basis for this generalisation that forms the central issue confronting case study research (Bassey 1999). Bassey addresses this issue through the introduction of what he calls 'fuzzy generalisation', that is, turning a statement of 'in *this* case it *has been* found that...' to 'in *some* cases it *may be* found that...' (1999, p. 12, emphasis in original).

However, generalisation has special meaning given the meta-theoretical assumptions of critical realism. The aim of generalisation here is to make inferences from research data regarding underlying mechanisms and structures that are ontologically real, whilst accounting for a certain level of epistemological relativity or uncertainty.

In this study, the educational intervention was examined with individual participants as 'cases'. The purpose of this research was to identify changes in discourse, as it relates to representations of PWD and stigmatising events, and make inferences about how these changes might be explained in relation to learning process within a framework of critical consciousness development and in relation to stigmatising processes themselves. Therefore, analysis must begin by examining these processes from the standpoint of individuals. While it is acknowledged that education and learning is an interactional process (Rogers et al. 2005), changes in language and consciousness of social reality is itself a property of the individual. A focus on the individual also means that the analysis is less bound by modernist assumptions contained within some variants of critical pedagogy (particularly those assumptions related to authentic dialogue and the arrival at consensus of thought and action (Lather 1998)) and can better account for the function that language performs in (re)creating identity and shaping aspects of one's identity (Kaufmann 2010; Lather 1998).

The use of multiple cases will additionally allow the intervention to be scrutinised for its ability to produce similar results or to predict different results for theoretically predictable reasons (Yin 2014), and its longitudinal<sup>8</sup> design will enable examination of the qualitative changes in discourses and practices that occur with participation in the educational intervention. The latter point is important given that a critical praxis develops incrementally over time, rather than through epochal transformations in perspective (Landreman et al. 2007; Osajima 2007; Roberts 2000), and this temporal nature of change is less likely to be adequately captured within a cross-sectional design. This longitudinal evaluation of change is also important given earlier considerations about the temporal relationship between structure and agency, conceptualised using Archer's morphogenetic sequences. In introducing an educational intervention to this study, this case study takes the form of a 'social experiment', which attempts to manipulate a situation by questioning the natural order of things with the purpose of seeing how individuals handle this challenge (Danermark, Ekstrom & Jakobsen 2002, p. 101).

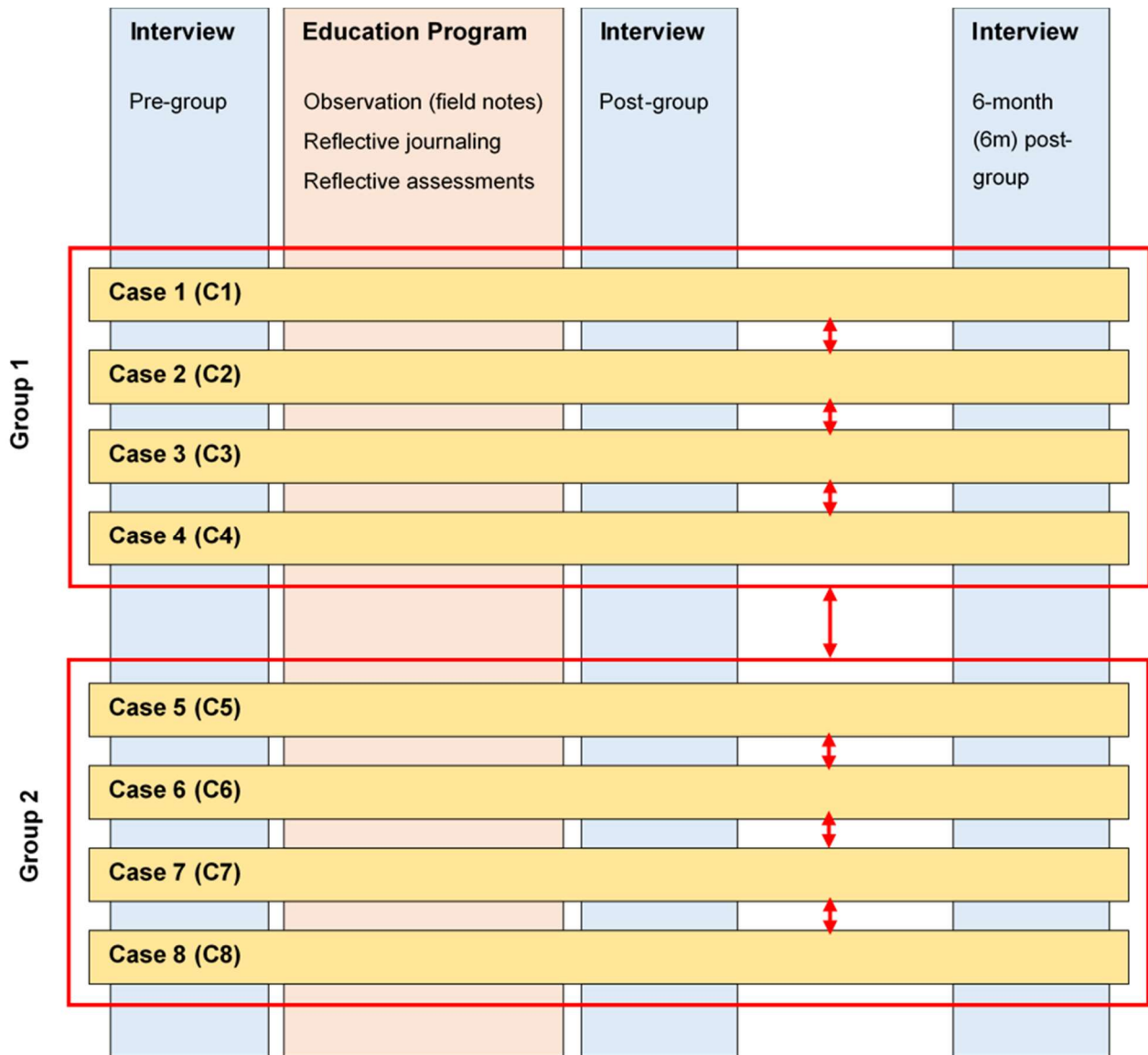
Figure 3 illustrates the case study design used within this research study. Semi-structured qualitative interviews form the backbone of data collection, which were used to support an empirical analysis of the way in which discourse, containing representations of diabetes and stigmatising events, might change following participation in the educational program. A six-month post-group interview was included in response to there being limited empirical evidence of longitudinal changes following the

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<sup>8</sup> Here, the term 'longitudinal' is simply taken to refer to repeated instances of data collection, as described by Saldana (2003), as opposed to ethnographic assumptions around long-term immersion that is sometimes assumed in use of the term within educational research (Hamilton & Corbett-Whittier 2013).



implementation of critical education programs (for example, see Zion, Allen & Jean 2015). Data collected during the educational program, including the participants' written self-reflections and researchers' observatory field notes and reflective session assessments, were used alongside interview data to make inferences about relevant processes of learning.



**Figure 3. Research case study design**

**Methods of data collection**

Within case study research, the choice of methods of data collection tends to be heavily influenced by the research question and the theoretical orientation of the researcher, which has resulted in eclectic approaches to data collection that involve the use of multiple methods and data sources (Bassegy 1999; Johnson 2014; Merriam 1998). However, it is still common for educational case studies to generate data through qualitative interviews, typically in combination with methods of observation and document analysis (Bassegy 1999; Merriam 1998). This interview-observation-document analysis configuration was commonly observed amongst studies included in the earlier

review of critical methods of education within public health contexts (Chapter 4). This doctoral research is no different. It has also used a combination of qualitative methods that include semi-structured interviews, observation, and document analysis, with selection of these methods also dictated by the research question and theoretical orientation of the research.

In relation to the research question, this case study is interested in identifying changes in understandings of diabetes-related stigma and how these understandings might have developed through interactions occurring between individual participants/learners, knowledge, and the group educator<sup>9</sup>. Therefore, interviews, observation, and reflective journaling offer insight into different interactional, discursive, and (meta)cognitive processes, with each data collection method functioning to address the limitations of other methods, thus supporting a comprehensive observation of learning processes within the earlier described framework of critical consciousness development. The post-structuralist leaning critical theory orientation of this research also dictates the choice of methods. Of particular interest here is how language, as a cultural tool, mediates unequal power relations in various ways (Rogers et al. 2005), or as Kaufmann (2010, p. 459) suggests:

It is only within the limitations of language that people are able to name their experience and thus construct their identities, subjectivities, and world. In this view, language is not a neutral site; it does not offer a pristine representation. It is embedded with political, ideological, geographical, and temporal referents. Through these hidden referents and the lack of vocabulary to name and interrogate its own discursive production, language operates as a discourse of oppression and domination...

Therefore, qualitative interviews provide a helpful method for eliciting discourse as it relates to the knowledges that function to legitimise or challenge the stigmatisation of persons with diabetes. The following sections provide further details about these methods of data collection.

### ***Interviews***

A semi-structured interview was performed with each participant within 1-2 weeks prior to group commencement (pre-group interviews), within 1-2 weeks following completion of the final group session (post-group interviews), and at six months following completion of the final group session (6m post-group interviews). Of interest within each of these interviews is the way in which the participants represent themselves and other PWD and how they represent incidents of stigmatisation. Representing the 'empirical' domain within critical realism (Danermark, Ekstrom & Jakobsen 2002), these accounts are not assumed to be faithful representations of individual PWD or experienced events (the 'actual'), but are (re)interpreted accounts of these interactions or events that are in turn re-contextualised for the purposes of the interview, which itself involves a discursive process of meaning-making. This follows the logic of what Tracey (2019, p. 141) refers to as the discursive interview, which 'pays attention to large structures of power that construct and

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<sup>9</sup> This triad of the learner, knowledge, and educator reflects Lusted's (1986) conceptualisation of pedagogy.

constrain knowledge and truth – and to how interviewees draw upon larger structural discourses in creating their answer’.

In terms of interview structure, a semi-structured approach was chosen because it allowed the creation of boundaries around the concept of stigma to ensure sufficient breadth and depth of discussion within these boundaries (focusing on representations of persons with diabetes and stigmatising events) whilst also accommodating the flexibility afforded by unstructured approaches that allow for emic understandings of complex accounts, including the relative importance of topics and access to unexpected perspectives (Tracy 2019). To support the establishment of conceptual boundaries around the concept of stigma and help relate abstract concepts to concrete life experiences, a hypothetical vignette was used to orient discussion at the start of each interview. The use of a vignette has the advantage of reducing the perceived threat that comes with responding to sensitive personal questions and may also function to prompt a more reflective response (Bryman 2012). When individuals respond to a vignette, they typically insert their own self (including their beliefs, motivations, and learned behaviours) into a fictional character or situation and in doing so allow some insight into the norms guiding their interpretation of the vignette (Jenkins et al. 2010). The vignette used in this research was adapted from qualitative studies that have examined the experience of diabetes-related stigma within an Australian population (Broom & Whittaker 2004; Browne et al. 2013) and constructed using principles for vignette development as described by Azman and Mahadhir (2017).

An interview guide was used in a flexible manner, asking questions related to the vignette within a SHOWED format (what is happening, how does the character feel about these things, what is causing these things, what can the character do about it, and how does this relate to your own life?) (Wallerstein & Bernstein 1988). This approach to questioning has been used in past critical educational interventions (Sharma 2006; Wang & Burris 1997) and may provide insight into processes relevant to the critical analysis of diabetes-related stigma. Following these questions, further questions were asked about the participant’s beliefs and attitudes towards their own diabetes, how others might perceive their diabetes, and how their diabetes has influenced interactions with others. These questions followed the categories of stigma described by Van Brakel (2006), incorporating internalised/self-stigma, felt stigma, and the experience of stigmatising and discriminatory practices.

The post-group interviews also followed the interview guide used in the pre-group interview, but included additional probing questions relating to relevant learning process (drawing on the framework of critical consciousness development described in Chapter 3) and provided participants with the opportunity to assess personal perceptions of difference and change that had occurred throughout the study period. Additional questions were added to the interview guides on a case-by-case basis to help interrogate preliminary assertions made in the analysis of earlier interviews and

to help fill in gaps or add detail where needed (Saldana 2003). In these interviews, hypothetical, devil's advocate, ideal position, and interpretative questions (Merriam 1998) were also introduced to add detail and depth to interviewee accounts - making reference to utterances and events observed within past interviews and the group education program. These questions were used to clarify particular representations of diabetes and to identify situations under which these representations might apply or how these representations are linguistically modalised by the participant.

All interviews were performed within a quiet and private space within the education venue or within a private space at the participants' home. All interviews were recorded using a digital audio recorder, with audio files professionally transcribed by an agency compliant with the university's conditions of confidentiality. All transcripts were uploaded and managed within the NVivo qualitative analysis software (QSR International Pty Ltd, Version 11).

### **Observation**

The purpose of observation within this research was to collect data on the interactions occurring between participants within the group education program, as these interactions relate to the development of a critical consciousness of stigmatisation. Observation is useful because it provides data that offers a faithful account of the behaviour of individuals within the group, something that is unlikely to be faithfully captured within either interviews or reflective journals. Data produced through observation was also used to triangulate findings from interviews and reflective journals in relating changes in critical consciousness to specific events and interactions occurring within the group setting. Observation was performed using a semi-structured observation guide that drew on literature discussing important considerations for observing features of the learner-educator-knowledge relationship within educational case study research (Fraenkel & Wallen 2003; Merriam 1998). Specifically, the observation guide was designed to examine interactions (both verbal and physical) occurring between participants and learning activities, between participants, between participants and the physical environment, and between participants and the group educator. Given how dialogue between learners is heavily influenced by imposed ideologies, the micro-politics of knowledge construction, and intersections of identity (Berger 1974; Chinyowa 2015; Esteva, Stuchul & Prakash 2005; Gottlieb & La Belle 1990; Mayo 1994; Vaughan 2016), this observation guide drew additional attention to processes involved in the dialogical examination and construction of knowledge, which included considerations such as who received the greatest share of attention, which perspectives dominated and how they were reinforced or resisted via verbal/non-verbal interactions, and how ideas were introduced and developed within the group. For participant-educator interactions, Stronge's (2007) checklist for effective teachers was used to raise visibility of features of these interactions that might impact on learning, taking into consideration characteristics and practices of the educator, the use and effect of group management strategies, and the use and effect of instructional strategies.

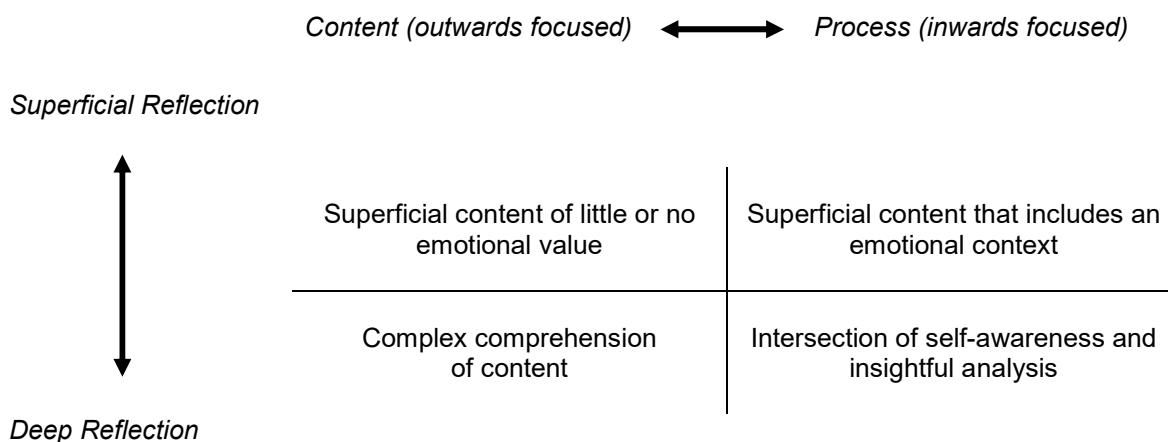
Within this research, the observer was a second doctoral researcher (in the discipline of psychology) who had experience in collecting qualitative data. In observing and recording group interactions, this observer assumed the role of what has been referred to as the 'researcher participant' (Gans (1982), in Merriam 1998, p. 102), that is, the observer participated minimally in the social setting of the group whilst retaining a primary researcher role. The adoption of this role meant that the observer was able to participate in discussion with research participants before and after the group, and during breaks, and also contribute to important insights in support of the group educator. However, at most times, the observer was minimally visible within the group, sitting outside of the field of vision of participants whilst completing field notes. This arrangement recognises that the observer is likely to have some influence over participant actions and interactions within the group simply by being present within the group, and that a certain level of participation in group proceedings may act to reduce distance between the observer role and the role of participants (Merriam 1998). The intention of this arrangement is to counter the feeling of being watched or observed amongst participants, whilst maximising the ability of the observer to immerse herself in the act of observation.

In recording relevant observations, the observer first familiarised herself with the content of the semi-structured observation guide, which was available for quick reference during the process of data collection. The observer then maintained a set of continuous field notes using pen and paper, with these notes time-stamped at 5-minute intervals. Although a full record of dialogue was not maintained, important ideas, terms, and phrases were recorded by the observer. Soon after completion of each session (within 24 hours), these field notes were transcribed into the format of the observation guide with additional elaboration on transcribed content. Time stamps were retained in order to retain a sense of the ordering of events within the session. These notes were then uploaded and organised within NVivo for further analysis.

### ***Document analysis***

Document analysis was performed using the content of each participant's reflective journals, which were completed after each of the five group education sessions. Unlike forms of document analysis that draw upon texts produced independent of the purposes of a given research project (Merriam 1998), the documents used in this research have been specifically designed to collect data that might facilitate an understanding of specific learning processes, informed by the framework of critical consciousness development described in Chapter 3. The use of reflective journals permits access to events, experiences, and thoughts occurring outside of the group setting, while also allowing insight into meta-cognitive process that focus on the process of learning itself, including how specific events within the group program might have contributed to changes in thinking about diabetes-related stigma. The reflective journal within this research used a structured format, drawing questions from Hubbs and Brand's (2010) framework for assessing critical reflection within reflective journals and adapting these questions to reflective processes contained within the synthesised framework of critical consciousness development. Hubbs and Brand's framework is useful for the purposes of this

research as it presents a range of questions that move from descriptive accounts of experience to more introspective accounts, incorporating movement from a focus on content to process on one axis, and movement from superficial to deep reflection on a second axis, as depicted in Figure 4.



**Figure 4. An overview of Hubbs and Brands' (2010, p. 65) framework for assessing critical reflection within reflective journals**

Each participant was requested to complete a reflective journal entry following each group session. During the first group session, participants were provided with a detailed overview of reflective journaling, explanation of the questions contained within the structured journal guide, and an example journal entry. Although there is a risk that participants might have concealed or avoided disclosing certain information in their journals in anticipation that their accounts might be identifiable to the group educator, there were limited options for mitigating this risk beyond attempts to establish respectful relationships with group participants and making clear how personal data would be used by the researcher and for what purpose. At the start of each group session, participants were asked questions about their journal entries (for those comfortable disclosing aspects of their entry to the group), with the intention of gauging the relative focus on content versus process and the depth of reflection. The educator then offered advice to the group as a whole about how they might re-orient their entries towards a *deeper* and more *process-oriented* reflection. Although participants were provided with a workbook containing space for written reflective journal entries, they were also encouraged to use audio-diaries as an alternative method of recording their thoughts. The journaling guide contained three main questions, which included a series of sub-questions that might be used to focus participant discussion. These questions, as presented to participants, included:

**1. Describe in detail what you learned**

What did I learn?

How do I feel about this learning?

**2. What might have contributed to this learning?**

Was there anything that triggered this learning?

How did interactions with other group members or the researcher contribute to this?

How have my own past experiences influenced this learning?

How have my own past beliefs influenced this learning?

### **3. What has changed as a result of this learning?**

How have my thoughts changed as a result of this learning (if at all)?

How have my actions changed as a result of this learning (if at all)?

Does this new knowledge change the way that I see or feel about myself?

How might this new knowledge change things for me in the future?

It is important to note that reflective journals serve a dual purpose. Not only do these journal entries provide data regarding the feelings, thoughts, and values of participants as they participate in the education program, but they actively promote introspective processes that form important forms of learning. In this way, reflective journaling has the potential to enable the learner to examine, assess, test, and possibly challenge perceptions of the world and to connect inner thoughts with real-life processes in a way that bridges reflection and action (Hubbs & Brand 2010, p. 59). Reflective journaling is also congruent with the experiential and constructivist learning theory drawn upon within the education program, which suggests that learning both draws upon personal experiences of the learner and involves the construction of knowledge through interaction with other learners (Alford 2013; Narayan et al. 2013). The latter task requires an appreciation that there exists different perspectives and other ways of knowing and involves a reflexive awareness of the learning process itself (Alford 2013; Hubbs & Brand 2005).

#### ***Researcher memos***

Written memos were maintained by the doctoral candidate from stages of recruitment through to the completion of analysis and the presentation of findings, providing a record of operational decisions, the development of analytical codes, and other analytical concerns (Birks, Chapman & Francis 2008). Operational memos were used to record research activities and maintain a record of decisions influencing the direction of the study, whereas coding and analytical memos were used to examine the process of organising data into units of meaning and how these meaning units are might relate to each other or theory in more abstract terms. Given that the formal process of analysis occurred concurrent to the group intervention, these memos helped provide momentum and responsiveness to emerging ideas and assisted with communicating analytical insights to the doctoral supervisors (Birks, Chapman & Francis 2008). These memos were also used to promote a reflexive engagement with the process of research, an analytical process described in further detail later within this chapter.

#### **Study population and sampling**

The study population within this research included adults ( $\geq 18$  years of age) with type 2 diabetes mellitus who have experienced a felt, perceived, or self-stigma in relation to their diabetes and who are willing to reflect upon their experience of stigmatisation. This criterion is justified by observations that critical methods of education tend to function best when participants are able to draw upon personal experiences of marginalisation (Kairson 2009; Landreman et al. 2007) and are self-

motivated to confront these experiences (Kairson 2009; Mustakova-Possardt 1996; Scott 1991). Therefore, purposive criterion sampling was used, with participants entering into the study via self-selection. Self-selection is justified for ethical reasons, as critical methods may contribute to changes in perspective that are difficult to reverse (Landreman et al. 2007) and may generate a certain level of emotional discomfort (Wallin-Ruschman 2014). Self-selection is also permissible theoretically given that generalisability within critical realism is concerned more with identifying transfactual conditions or generative mechanisms underpinning empirical observations and less with making inferences about a population based on data obtained from a population sample. In this way, sampling pathological cases (as is the case for those who experience stigmatisation) can assist the researcher to make inferences about underlying generative mechanisms, which are likely to present themselves in a purer or more clearly observed form within such pathological cases (Danermark, Ekstrom & Jakobsen 2002).

Diabetes status was identified via self-report, and excluded those with impaired glucose tolerance, impaired fasting glucose, T1DM, or gestational diabetes. The experience of stigma was assessed using the Type 2 Diabetes Stigma Assessment Scale (DSAS-2), which has been developed and tested in an Australian population of adults with T2DM and has demonstrated acceptable construct, convergent, and discriminant validity (Browne et al. 2016). Although no cut-off scores currently exist or intend to be developed in the near future (A Ventura 2017, pers. comm., 13 November), a score of one standard deviation above the mean for DSAS-2 total score or domain sub-scores ('blame and judgement', 'self-stigma', and 'treated differently') was taken to represent a 'potentially problematic perceived and experienced diabetes stigma' (Browne et al. 2016, p. 5). It is reasonable to regard sub-scores separately to total score given that this study is interested in different experiences of stigma, including felt/anticipated stigma (corresponding to 'blame and judgment'), the internalisation of stigmatising beliefs and attitudes (corresponding to 'self-stigma'), and enacted stigma (corresponding to 'treated differently').

To be eligible, participants must have lived with diabetes for a minimum of two years, which was considered to be a sufficient length of time following diagnosis to have had sufficient exposure to healthcare environments and discourses of self-management via participation in an annual cycle of care (Australian College of General Practitioners & Diabetes Australia 2016). As critical reflection is theorised to function best under conditions of difference and diversity (Barlas 2000), persons were included regardless of the presence of comorbidities related or unrelated to diabetes. However, individuals currently experiencing or receiving treatment for severe mental illness or depressive or anxiety disorders were ineligible to participate given the cognitive and emotional demands of critical methods of education. This information was obtained through self-report given the high rates of false positives that tend to accompany screening for depressive and anxiety disorders in populations with diabetes (Lloyd & Roy 2013). English-speaking ability was required given the focus on dialogical methods within the education programme and the use of discourse analysis for interpreting research



data. Because participation in the educational program primarily involves verbal and visual modes of communication, supports were made available to enable the participation of those with low levels of written language literacy.

### **Recruitment methods**

Recruitment occurred within selected suburbs within the southern metropolitan area of Greater Adelaide. The choice of geographical area was made because of the research institutions' historical involvement with health and social services within the catchment area, relatively high registration rates with the National Diabetes Services Scheme (NDSS) as a non-age adjusted proxy for diabetes prevalence (National Diabetes Services Scheme 2017), and the availability of public transport connecting to a central public transport node. Registration rates with the NDSS ranged from 6.1-7.5% of the total population for each of the 14 included suburbs. In total, this corresponded to approximately 6,000 persons living with diabetes in the recruitment catchment area. Assuming that 85% of this population have T2DM (Tanamas et al. 2013) and 19% experience potentially problematic stigma (Browne et al. 2016, p. 5), there would be an estimated eligible study population of almost 1,000 persons within the recruitment area. Key recruitment methods included:

- advertisement via online diabetes support groups administered within Australia;
- Facebook, email, noticeboard, and in-person advertisement of the research at several local government-funded community centres and libraries;
- news articles and a large paid advert in a printed and freely delivered local newspaper;
- promotion of the research at a monthly group education program for persons with type 2 diabetes;
- advertisement of the research through supermarket bulletin boards;
- paid Facebook research advertisements;
- multiple advertisements through a diabetes member database managed by a state-wide diabetes organisation;
- advertisement of the research in the quarterly published magazine (print and online) of the same diabetes organisation;
- email and print distribution of flyers within several community and faith-based organisations;
- promotion of the research via interviews conducted with a local community radio station; and,
- in-person and interactive promotion of the research at major state events for persons with diabetes.

It is important to note that different recruitment methods were used at different times within the recruitment period, and some methods were revised in hope of improving or re-invigorating interest in the research over time. Throughout the recruitment period, there was a sustained effort to target

PWD through diabetes-specific fora provided by a state-wide diabetes organisation and through online diabetes communities (as listed above). The study flyer formed an important component within these recruitment methods and was used to complement other verbal or written explanations of the research. Originally, the study flyer appealed to emotional states (guilt, shame, and embarrassment), self-appraisals (seeing oneself as different or less valuable), and experiences (being labelled or excluded) that followed accounts of stigmatisation described in qualitative diabetes-stigma research (Browne et al. 2013). Although this approach attracted one participant to the study<sup>10</sup>, it otherwise failed to attract other PWD to participate in the research. This led to a revision of the content of the study flyer to better reflect the desired positive outcomes of the research, which were to develop alternative representations of PWD (i.e. to 'change the way we think and talk about persons living with diabetes'). Drawing from understandings of how patient social movements seek to contest matters of identity (Scambler & Kelleher 2006), it was reasoned that appealing to the agency of PWD in contesting stigmatised identities might offer greater motivation for PWD to participate in the research, whilst not assuming the existence of negative forms of affect, self-appraisal, or experience.

At the same time, paid Facebook advertisements were introduced in an attempt to access PWD that would be less likely to engage with diabetes-specific fora. Advertisements were placed across six rounds (each round lasting approximately two weeks, with 4-8 weeks between rounds), targeting persons aged 45 years or greater residing in postcodes situated within the recruitment catchment area. Because there is a sharp increase in incidence of T2DM amongst persons aged 45 years or more within Australia (Tanamas et al. 2013), targeting by age allowed the advertisements to target those more likely to be living with T2DM. There was initially a good response to these advertisements in rounds one and two of the Facebook advertisements (obtaining four participants); however, there was limited response to the later four rounds. Slowing recruitment led to the decision to advertise the study using a paid half-page article within a local newspaper. At the time, it was hoped that this news print advertisement might access PWD who were less likely to engage with social or electronic media. The content of this news article, like that of the revised study flyer, focused on the desired positive outcomes of the research. It was successful at obtaining a further three participants<sup>11</sup>. Typical of recruitment involving hard-to-reach populations, snowball sampling was also used within this research. Amongst stigmatised individuals, there are those that are socially visible (i.e. attend primary care services, participate in diabetes-related forums, and receive information via diabetes organisations) and those that are less visible (Faugier & Sargeant 1997). Snowball sampling functioned to access what Faugier and Sargeant (1997) refer to as referral chains, which is where the social networks of socially visible persons are used to access those that are less visible, but who also share the characteristic of interest. Therefore, accessing these referral chains was originally thought to help overcome any limitations of other methods of recruitment. In practice however,

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<sup>10</sup> See p.97 for further discussion of how this participant responded to the study flyer.

<sup>11</sup> See p.106 for further discussion of how these participants responded to the news advertisement.

snowball sampling failed to generate additional participants for this research. While most participants knew other PWD, none were noted to live near to the research venue.

These recruitment strategies drew from lessons learned from past research involving recruitment from stigmatised and hard-to-reach populations (Hart-Johnson 2017). Firstly, efforts were made to make the research as transparent as possible, involving an extended process of explanation during the provision of study information and in obtaining informed consent. Secondly, maintaining recruitment flexibility helped to tailor recruitment methods to better match the motivations and communication needs of the target population. In practice, this flexibility was achieved through an incremental roll-out of recruitment activities, with recruitment activities generating insight into what concepts, language, and motivations were driving interest in the research, which in turn informed the development of later recruitment methods and materials. Thirdly, in an attempt to avoid inadvertently reproducing stigmatising language and concepts within recruitment material, all recruitment materials observed language conventions contained within the Diabetes Australia position statement on the appropriate use of language (Speight et al. 2012) and were reviewed by a senior researcher with experience in recruiting from stigmatised populations.

All interested participants were required to contact the doctoral candidate in the first instance to discuss the study, to determine eligibility according to the stated criteria, to distribute study information and consent forms, and to obtain preferences regarding group dates and times. The doctoral candidate then contacted interested participants once the group quota of 5-10 persons had been obtained to confirm their willingness to participate and to arrange a convenient time for interview. All participants were required to provide informed signed consent prior to participating in the initial interview.

### **Analytical strategy**

According to the theoretical premises of this research, if learning has resulted in a critical consciousness of the way that stigmatised identities are discursively constructed, then it is reasonable to expect that discursive changes in representations of diabetes and stigmatising events will also follow. If language for critical theorists is 'central in the formation of subjectivities and subjugation' (Rogers et al. 2005, p. 368), then language will also provide insight into how a stigmatising social reality operates the way it does and how participants form projects that either reproduce or transform this reality. Therefore, the task for this analysis was to relate these discursive changes to evidence of individual learning within a framework of critical consciousness development, and to identify learning processes that might explain variations in outcome between participants. The first stage in the analysis involved a *descriptive characterisation* of how each participant (case) discursively represents PWD and stigmatising events, and their engagement with processes of learning within a framework of critical consciousness development. In a second stage of analysis, this descriptive characterisation then forms the basis for *identifying what has changed* (in relation to

discursive representations and critical consciousness) over the study period, which is then used within a final stage of analysis to *explain* the relationship between critical consciousness development and changes in discourse. A brief overview of these three stages of analysis is provided below.

***Description: characterising discursive representations of persons with diabetes, stigmatising events, and critical consciousness at different time points***

Norman Fairclough's (2003) approach to critical discourse analysis (CDA) formed the basis for identifying, in a transparent way, what had changed between the three interviews with respect to each participant's discursive representations of PWD and stigmatising events. For Fairclough, discourses function to represent aspects of the world in certain ways. Different discourses may be drawn upon by individuals according to their social and personal identities and their standing relative to others, giving rise to multiple ways of understanding the world. Furthermore, discourses can be manipulated to represent alternative possibilities for the 'material', 'mental', and 'social' world, reflecting personal projects for change (Fairclough 2003, p. 124). The advantage of using Fairclough's approach to CDA is that he offers a method of relating linguistic and semantic features of text (i.e., the internal relations of text) to social processes (i.e., the external relations of text) in a relatively transparent, systematic, and rigorous way. This attention to the rigour and transparency of analysis is useful because it helps counter some of the criticism directed at researchers who read their critical social theory into their research data (Rogers et al. 2005).

Identifying the way that participants represent themselves (as PWD) and other PWD offers insight into the discursive regimes that are drawn upon to justify or challenge the existence of stigmatised social identities and inform the way that stigmatised and non-stigmatised groups relate to one another (Fairclough 2003; Toyoki & Brown 2014). A focus on representations of PWD is relevant to the stigma concept because it draws attention to the role of discourse in the construction and management of stigmatised social identities and reflects a process where individuals 'apply societal perspectives in their local worlds' (Toyoki & Brown 2014, p. 717). It is also relevant to the desired learning outcomes within a post-structuralist leaning critical pedagogy, which involves the creation of alternative discourses following a problematisation of existing representations of certain issues or persons (Giroux 2004). Drawing on the approach described by Fairclough (2003), representations of persons with diabetes were examined with respect to *assumptions* about those with diabetes and how *relations of sameness or difference* between those with diabetes and those without (or between sub-groups of PWD) are *legitimised*. Here, assumptions are regarded as tacit beliefs about aspect of the world that are used to form a common ground of meaning. In this way, assumptions can be used to identify hegemony, where certain representations of PWD are privileged to the extent that the truth of these representations is naturalised or taken-for-granted. By examining how these assumptions might change following education, it is possible to identify how hegemony is challenged. Relations of sameness and difference refers to the way in which differences between things may be

emphasised or reduced, facilitating the process of social classification. This classification is central to the operation of stigma, which fundamentally employs over-generalisations to categorise and create separation between members of stigmatised and non-stigmatised groups (Link & Phelan 2001). Therefore, within this analysis the focus is on how separation of those with diabetes and those without diabetes is achieved discursively within interview. *Legitimation* can then be identified in interview text by identifying segments of the interview that offer explanation for the stigmatisation of persons with diabetes, evidenced through reference to the authority of tradition, custom, law, and persons with institutional authority (authorisation), perceived rational forms of knowledge (rationalisation), and value systems (moral evaluation) (Fairclough 2003, p. 98). Because participants would have differing levels of commitment to assumptions about persons with diabetes and the legitimacy of stigmatising relations, the modality of these representations were graded based on their level of commitment to certain truths (epistemic modality) and obligations (deontic modality).

The next object of interest was the way in which stigmatising events are represented. Contained within a report of a stigmatising incident or event is the (conscious or unconscious) decision to represent the event in a certain way as the event is re-contextualised within the interview. Individuals might decide to include or exclude certain information or make this information more or less prominent. For the purpose of this analysis, it was of interest to identify how participants problematise certain stigmatising processes and position themselves as agents within these processes. This analysis was guided by an adaptation of Fairclough's (2003) approach, as described in Table 4.

**Table 4. Describing representations of stigmatising events (adapted from Fairclough (2003, p. 139))**

Processes	Participants
<i>Presence</i> Which elements of events, or events in a chain of events, are present/absent, prominent/backgrounded?	<i>Inclusion / exclusion</i> Which participants are excluded from the event, placed in the background, or made prominent?
<i>Abstraction</i> What degree of abstraction/generalisation is there from concrete events?	<i>Pronoun / noun use</i> How are pronouns (personal or general) and nouns (e.g. diabetics) used?
<i>Arrangement</i> How are events ordered?	<i>Activated / passivated</i> Which participants act or are acted upon
<i>Additions</i> What is added in representing events – e.g., explanations, legitimations, or evaluations?	<i>Personal / impersonal</i> <i>Named / classified</i> <i>Specific / generic</i>

The final step of the descriptive characterisation of cases was to assess their learning against the synthesised framework of critical consciousness development. This assessment of learning was achieved by systematically coding all data sources (interviews, observation field notes, reflective journals) against the coding structure used to construct the framework of critical consciousness development described in Chapter 3. In cases where relevant segments of data did not appear to fit within this organising framework, new categories were (inductively) created to account for these data.

***Interpretation: identifying changes in discourse and critical consciousness development***

The task for this second stage of analysis was to identify what changes in critical consciousness and representations of PWD/stigmatising events occurred over the period of three interviews (pre-group, post-group, and 6m post-group) and five weekly group sessions. Saldana’s (2003) use of framing and descriptive questions were used to analyse changes occurring throughout the study period (see Table 5). At the end of the first descriptive stage of analysis, the Framework Matrix function within the NVivo qualitative analysis software (QSR International Pty Ltd, Version 12) was used to produce a tabulated interpretation and summary of changes for each case, retaining links to original data and annotations.

**Table 5. Questions used to guide the analysis of longitudinal data, adapted from Saldana (2003, pp. 63-4)**

Framing Questions	Descriptive Questions
What is different from one interview through the next?	What increases or emerges through time?
When do changes occur through time?	What is cumulative through time?
What contextual and intervening conditions appear to influence and affect participant changes through time?	What kind of surges/epochal changes occur through time?
What are the dynamics of participant changes through time?	What decreases or ceases through time?
	What remains consistent through time?
	What is idiosyncratic through time?
	What is missing through time?

***Explanation: making inferences about the relationship between critical consciousness development and changes in representations of reality***

The purpose of the final stage of analysis was to explain the relationship between critical consciousness development and changes in representations of PWD and stigmatising events. The central question being asked here is: what are the prerequisite conditions for observed changes in discourse when interpreted against a framework of critical consciousness development and against processes implicated in diabetes-related stigma? This question can assist in identifying relevant mechanisms of learning given that these mechanisms exist within open systems (i.e., environments internal and external to the educational program) involving the interaction of multiple other mechanisms.

This inferential process was supported by use of the cross-case comparison technique described by Yin (2014). Firstly, a thematic analysis was performed to identify and categorise the changes observed in related to representations of PWD, representations of stigmatising events, and critical consciousness development. A table was then constructed (Table 6) to identify how data from each case related to each of these themes. The interaction between critical consciousness development and representations of PWD/stigmatising events was then analysed through use of counterfactual thinking and the study of pathological cases. Counterfactual thinking involved attempting to understand something in terms of what it's not, leading to questions such as: 'how would this be if not....? Could one imagine X without...? Could one imagine X including this, without X then becoming something different?' (Danermark, Ekstrom & Jakobsen 2002, p. 91). The study of pathological cases involved selecting cases where there were notable discursive changes in comparison to others. As Danermark, Ekstrom and Jakobsen (2002, p. 105) claim, it is through the study of pathological cases that 'we can learn about the conditions for the normal by studying the abnormal' (2002, p. 105).

**Table 6. The process of cross-case comparison**

	Case #1	Case #2...etc.	Interaction with Critical Consciousness Development
<b>Changes in representation of diabetes</b>			
<i>Theme 1</i>	<i>Within-case findings</i>	<i>Within-case findings</i>	<i>Use of counter-factual thinking to identify these relationships</i>
<i>Theme 2...etc.</i>	<i>Within-case findings</i>	<i>Within-case findings</i>	<i>Use of counter-factual thinking to identify these relationships</i>
<b>Changes in representations of stigmatising events</b>			
<i>Theme 1</i>	<i>Within-case findings</i>	<i>Within-case findings</i>	<i>Use of counter-factual thinking to identify these relationships</i>
<i>Theme 2...etc.</i>	<i>Within-case findings</i>	<i>Within-case findings</i>	<i>Use of counter-factual thinking to identify these relationships</i>
<b>Changes in critical consciousness development</b>			
<i>Theme 1</i>	<i>Within-case findings</i>	<i>Within-case findings</i>	<i>Not applicable</i>

<i>Theme 2...etc.</i>	<i>Within-case findings</i>	<i>Within-case findings</i>	<i>Not applicable</i>
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***Making inferences about processes contributing to diabetes-related stigma***

Whereas earlier components of the analytical strategy were concerned with using participant data to explain the observed learning outcomes, this analytical activity was concerned with using these same data to make inferences about the processes or mechanisms that constitute diabetes-related stigma. From the perspective of critical realism, these mechanisms of stigmatisation cannot just be ‘mapped or ‘read off’ via [participant] experience’ (Scambler 2006a, p. 274). Rather, the task for analysis is to use participant data, containing accounts of stigmatisation and stigmatised persons, to identify how certain knowledges and concepts are drawn upon to legitimise stigmatisation and what material conditions and practices function to maintain the dominant status of such knowledges. Put simply, this analysis identifies what must exist for participant accounts to be what they are.

Developing such an understanding of diabetes-related stigma requires a process of relating empirical observation to theory, which in turn leads to a new interpretation of the observation – a process that is referred to as ‘redescription’ or ‘recontextualisation’ (Danermark, Ekstrom & Jakobsen 2002, p. 91). Given critical realist assumptions about social reality that cannot be directly or empirically observed, the challenge for interpretation is to make reasonable and rigorous inferences about the generative mechanisms that can explain regularities within empirical data. Therefore, the analysis requires an abductive mode of inference that draws from theories/models/frameworks of stigmatisation (discussed within Chapter 2) in making a judgement about which of these provides the best fit for the data, which helps re-contextualise theoretical understandings of stigmatisation as it relates to diabetes. In this doctoral research, re-contextualisation was achieved by using different thought operations related to *analytical resolution*, *theoretical redescription*, *retroduction*, *theoretical comparison*, and *contextualisation* (Danermark, Ekstrom & Jakobsen 2002, pp. 109-10). In this first stage of analytical resolution, the focus was on eliciting the key dimensions of the complex phenomena of stigmatisation. Because of the fuzziness of the stigma concept, this analytical resolution allows the research to place defined boundaries around the analysis of ‘stigma’ and bracket off related phenomenon, such as biographical disruption (Williams 2000) or diabetes-distress (Hernandez et al. 2020). The next task was to identify what critical theories of health-related stigma (discussed in Chapter 2) might be used to explain participant data in relation to these core concepts (via abductive inference) and use these theories to identify fundamental structures that maintain stigmatisation (via retroductive inference). This process allowed for the revision of theory in relation to diabetes-related stigma. To check the value of this revised theory, participant data was then re-interpreted using this theory to ensure that it could sufficiently explain variation in the data, could be used to relate abstract processes to everyday experiences of stigmatisation, and engaged with key conceptual issues raised within existing diabetes-stigma literature.



### **Attending to researcher reflexivity**

Although reflexivity is an important consideration within all qualitative approaches to research, there is a heightened demand for it when research is grounded in critical social theory. This reflexivity recognises that the researcher is embedded within the social world that is the object of study, rejecting their role as a neutral and objective observer of events and implicating their own implicit biases in any act of data creation or interpretative/analytical activity (Alvesson 2011). Such reflexivity, according to Alvesson (2011), requires ‘conscious and consistent efforts to view the subject matter from different angles, strongly avoiding the a priori privileging of a favoured one’ (2011, p. 106), that is, the ability to step outside of taken-for-granted understandings and explore alternative understandings. This analytical flexibility is particularly relevant to a critical perspective, which claims that knowledge is created through processes of social interaction and experience, but also under the influence of ideology and in serving particular interests (Alvesson 2009). Therefore, as Ellsworth (1989) suggests, any un-reflexive approach to critical education and research is likely to perpetuate relations of power and obscure underlying political agendas, particularly where educators and researchers are ‘implicated in the very structures they are trying to change’ (p. 101) in paternalistic educational projects where ‘the voice of the pedagogue himself [sic] goes unexamined’ (p. 104). Table 7 provides an outline of how researcher reflexivity was prompted throughout different stages of the research process, what data were examined, and what important considerations were taken into account, drawing on reflexive considerations described by Daley (2010), Birks, Chapman and Francis (2008), and Flick (2007).

**Table 7. Reflexive strategies used throughout the research process**

Research activity	Data source	Reflexive prompts
Participant recruitment	Operational memos, maintained from stages of participant recruitment through to the production of research outputs	How did values and ideas contained within recruitment practices influence who was able to participate in the research?  What were the responses to this research and what does this say about stigmatisation and power?
Conducting interviews	Structured post-interview self-assessment that evaluated: <ul style="list-style-type: none"> <li>- Interviewee characteristics and interaction/responses to questioning</li> <li>- Process of interviewer interpretation and construction of meaning during the interview</li> <li>- Development of the interviewer-interviewee relationship</li> </ul>	How power relations manifest within the interview, including how the interviewer and interviewee position themselves and the impact this has on interview narratives. How do these subject positions shift during the interview?  What evidence is there of challenges to the interviewer’s questions and

Research activity	Data source	Reflexive prompts
	Analysis of interviewer-interviewee relations, drawing on later readings and interpretation of interview transcripts	language – e.g., evidence of ‘talk back’?
Conducting observation	Structured observation guide that examined: <ul style="list-style-type: none"> <li>- Participant interaction with learning activities</li> <li>- Participant interaction with the physical learning environment</li> <li>- Interpersonal interactions</li> <li>- Process of facilitation</li> <li>- Communication of social position and intersectionality</li> </ul>	How does power manifest within participant-participant and participant-educator interactions? What evidence is there of challenges to the concepts and language used within the education program? What does dialogue/communication within the group infer about power and identity?
Group facilitation	Structured lesson self-assessment that supported reflection on: <ul style="list-style-type: none"> <li>- Participant learning</li> <li>- Conduct of the session</li> <li>- Educator self-assessment</li> <li>- Future session directions</li> </ul>	How do the identities of the educator and their own frames of reference affect their approach to facilitation and interpretation of session outcomes?
Data analysis	Secondary reflexive analysis of: <ul style="list-style-type: none"> <li>- Coding annotations (description)</li> <li>- Annotations within framework matrices (description and interpretation of change)</li> <li>- Analytical memos used for supporting processes of abductive and retroductive inference (explanation)</li> </ul>	How do the identities, background, and assumptions made by the analyst influence the coding of textual data? What discourses might the analyst be reproducing in their interpretation of textual data? What theoretical biases and blind spots are evident?
Writing up findings	Member reflections on draft findings	Is the researcher reinforcing any problematic discourses through their presentation of findings? Are there alternative perspectives that might explain the findings?

Given that the research is interested in supporting a critique of stigmatised identities, it is appropriate to reflexively examine my own standpoint and how this standpoint might influence educational and analytical outcomes. From the outset of this study, I approached the issue of diabetes-related stigma and critical pedagogy primarily as a dietitian and allied health researcher, but also underwritten by my experiences as a person living with T1DM. Given past professional involvement with PWD, patient advocacy organisations, and practices relating to the care and prevention of diabetes, I was cognisant of the complex forms of resistance to dominant clinical and public health practices and discourses. Having worked extensively with PWD following lower-limb amputation in acute and rehabilitative hospital environments, and later with PWD in primary care settings, I was immersed within an environment where ideas about diabetes-related comorbidity, diabetes risk, and responsibility for self-care, were used to classify, motivate, reward, and scold PWD. At the time, I was aware that these processes were leading to various forms of disengagement with primary care and dietetic services. This form of resistance was very different

to other forms of resistance that I observed in later work with patient organisations and advocates (including persons living with cancer and mental illness), who were better able to articulate and voice their grievances. For me, these observations raised the question of why PWD were unable to 'break free' of the clinical and public health discourses that were handed to them? Perhaps this desire to 'break free' is reflective of my own resistance to dietetic knowledges as a relative outsider within the profession: as a male and a person with chronic illness. Seminally, this resistance to dietetic knowledges was kindled by an engagement with fields of critical dietetics and postcolonial studies, which I encountered following an extended period of working with Indigenous Australian peoples in relation to diabetes care. It was in this space that I became interested in critical pedagogy as a means of engaging in a critique of healthcare and public health practice.

At the outset of this doctoral research, I was cognisant of the potential impact that this personal history might have on my conduct as an educator and analyst. In relation to the educator role, my primary concern was with the level of directiveness that I might reasonably provide to participants. Even though a critical pedagogy is defined by both educator and student assuming learning roles within the group (Tarlau 2004), a certain level of authority on the part of the educator is still required (Giroux 2004). Being fearful of imposing too rigid an interpretation of stigmatisation, especially given under-developed theorising about diabetes-related stigma (as discussed in Chapter 2), Fook and Gardner's (2007) approach seemed to present a good method for allowing participants speak for themselves. In relation to the analytical process, I was also very aware of the risk of inappropriately reading my past experiences (in relation to myself, other PWD, and healthcare and public health practices) into participant data. This concern contributed to my choice of Fairclough's approach to CDA given how it lends itself to a more transparent characterisation of discourse. Taken together, I can appreciate that I possessed an inclination to seek out a position of neutrality in design of this research. Therefore, there was tension between value-oriented aspects of this research (a characteristic feature of critical pedagogy (Kincheloe 2004)) and the desire to present this research as a trustworthy interpretation of reality, drawing from a critical realist philosophy of science. The reflexive prompts contained within Table 7 functioned as useful reminders for navigating this tension throughout the research process, in particular alerting me to areas where my own values or interpretations of participant data might function to obscure other ways of knowing.

### **Quality considerations**

Although it is possible to discuss quality considerations from a range of different standpoints, including with respect to the research's case study design (Creswell 2013; Merriam 1998; Yin 2014), the use of qualitative methods (Cho & Trent 2014), and principles of critically-oriented research (Lather 1986), the discussion of quality considerations will orient itself against a meta-theory of critical realism. As Cho and Trent (2014) argue, evaluation of the quality of qualitative research typically assumes certain ontological and epistemological truths (typically aligned with either

positivism or interpretivism (Ryan & Ruddy 2019)) that then guides methodological evaluation. However, there has been limited attempt to define quality criteria for research conducted from the perspective of critical realism (Ryan & Ruddy 2019). Therefore, the discussion below represents a range of quality considerations that respond to the assumptions contained within critical realism, whilst also cross-referencing a range of quality considerations relevant to case study and qualitative research (Cho & Trent 2014; Creswell 2013; Flick 2007; Merriam 1998; Tracy 2010).

Within critical realism, knowledge of generative mechanisms is seen to be conceptually mediated, meaning that a process of abstraction is required. Such abstraction requires forms of 'synthetic' inference (Danermark, Ekstrom & Jakobsen 2002, p. 84) that can be used to gain new knowledge about reality, that is, the structures and mechanisms that make phenomena possible. The quality of abstraction represents a *key* quality consideration that relates to the goal of *generalisability* within critical realism. *Transparency* in the process of analysis functions to allow others to examine the quality of abstraction, largely achieved through a descriptive characterisation of relevant data using Fairclough's approach to CDA. The quality of abstraction is also dependent on bringing together different data sources and analytical approaches (*triangulation*) to offer a thick description and explanation of underlying mechanisms. Within this research, triangulation was observed in the way that data were collected in different group contexts and at multiple time points (within method triangulation), the way in which multiple sources of data were used to examine different aspects of critical consciousness development (between method triangulation), and the way in which cross-case analysis was used to systematically test alternative theories for explaining the data (theory triangulation) (Flick 2007; Tracy 2010).

In seeking member reflections on the content of research findings, it was hoped that participants might provide insight into how these mechanisms may or may not help explain their experience of diabetes-related stigma. Rather than enhancing credibility through a 'validation' or testing of findings, member reflections were seen to help the researcher develop a more credible analysis through a process of 'reflexive elaboration' (Tracey 2010, p. 844), where the researcher seeks to examine alternative perspectives that might explain the findings (as in Table 12). Specifically, member reflections were invited following the completion of each group, at the time of preparing research progress reports and newsletter updates for the organisation funding this research, and at the completion of data analysis. However, this potential for enhancing the credibility of findings was not fully realised, with participants providing limited feedback on these preliminary findings. Only one participant (C4) offered detailed feedback on these findings, claiming that they provided an accurate representation of her experience of diabetes-related stigma. This participant described her intention to use the content of one of these summaries to help structure future conversations about her experiences of living with diabetes.

The quality of abstraction also depends on the appropriateness and quality of the data itself. Quality of data here refers to the appropriateness of sampling and whether sufficient quantity and richness of data was obtained with respect to the research question (Tracy 2010). As previously discussed, the choice of a self-selected sample, drawing on persons with diabetes who are likely to have experienced stigmatisation, is both ethically and theoretically warranted. In terms of data quality and richness, although the case study involves only eight participants (which itself is not unusual within educational case study designs (Bassegy 1999; Johnson 2014; Merriam 1998), the use of repeat interviews, observational data over five group sessions, and reflective journals offers sufficient depth and breadth of data to support an analysis of individual and group-level processes involved in learning. Furthermore, because the interview, observation, and journal guides were specifically developed to support an analysis of critical consciousness development and changes in discursive representations of PWD and stigmatising events, it was possible to generate a sufficient level of depth of data relevant to the research aims.

### **Ethical considerations and accommodations**

There are two main types of ethical consideration relevant to this research. The first relates to procedural ethics and the second to ethical considerations specific to qualitative and socially critical forms of research. In an Australian research context, the first point relates to the ethical requirements specified under the *National Statement on Ethical Conduct in Human Research* (2007), which is based on principles of justice, fairness, beneficence, and respect. Within this research, principles of justice and fairness have been upheld by removing barriers to participation in the research, including conducting the research in a location well serviced by public transport, providing cash payment to participants on entry into the study to compensate for travel costs, and providing alternative audio-visual learning materials for those with low literacy levels. Through the use of multiple methods of recruitment across different media (in-person, print, online, and email), inequities in the reach of recruitment strategies were also minimised.

Considerations of beneficence relates to efforts to communicate and maximise the potential benefits of the research to participants and the wider community, whilst avoiding or mitigating the risks of harm or discomfort associated with participating in the research. The first point to note here is that this doctoral research is *not* a form of psycho-education for addressing self-stigma. This means that although critical pedagogy may offer individual cognitive-emotional benefits to participants, via psychological catharsis (Ares 2015; Jeanetta 2006; Kased 2013) and improvements in perceptions of self-efficacy and self-worth (Teti et al. 2013), these are not intended outcomes of the research. Rather, the intended outcome of the research is to identify how education might be used in stigma-reduction work in such a way that it supports an analysis of the cultural, social, and political basis of stigmatisation. As outlined in the following chapter, this focus on collective benefit invokes the prevention paradox in public health (Hunt & Emslie 2001) where the research offers potential benefit to a wider population of PWD but potentially limited benefit to individual participants. This bind was

addressed by clearly communicating to participants the intended outcomes and potential use of this research in the context of stigma-reduction work.

At the same time, participation in critical forms of education can also bring about certain harms. These harms include feelings of discomfort (Byrd 2004) and powerlessness (Rondini 2015), which in certain cases might lead to counselling being sought (Wallin-Ruschman 2014). A critical pedagogy also runs the risk of substituting critical reflection and perspective transformation with indoctrination and quasi-religious experiences, which itself acts to reduce capacity for critical reflection (Wallin-Ruschman 2014). Because critical reflection typically requires a certain degree of emotional discomfort (Nolan & Molla 2018; Wong 2004), it is inappropriate to eliminate this risk of harm altogether. Within the group, the likelihood that feelings of discomfort would progress into feelings of distress and contribute to psychological harm was mitigated by allowing participants to control the content and directions of their learning, including the extent to which they wished to confront and challenge personal assumptions. The educational program was also modified to support a greater scaffolding of learning (described in Chapter 6), designed to minimise feelings of frustration and discouragement that can result from performing a difficult task with insufficient support (Rojas-Drummond et al. 2013).

With regards to issues of respect, the *National Statement on Ethical Conduct in Human Research* (2007) infers a deontological concern with recognising the intrinsic value of research participants and a rights-based concern with ensuring privacy and confidentiality is ensured. In relation to the latter point, one of the key issues for this group-based research was limits to privacy and confidentiality. These issues were addressed through the process of obtaining informed consent to participate in the research, with the consent form explicitly stating the limits of anonymity associated with participation in a group setting and the duty of participants to protect the identity of other participants and the confidentiality of group discussions. The confidentiality of participant data was maintained through adherence to university guidelines on the handling and storage of participant data. Formally, research ethics approval for this research was obtained from the Flinders University Social and Behavioural Research Ethics Committee (Project Number 7899).

A relevant criticism of qualitative social research is that it tends to offer little material or real world benefit for research participants or for the broader population from which these participants are drawn (Hammersley & Traianou 2012). This criticism must be taken seriously from the perspective of critical social theory and critical pedagogy, which place special importance on social action and social change following practices of cultural critique or education (Giroux 2004; Steinberg & Kincheloe 2010; Tarlau 2014; Tinning 2002). This research addresses this ethical issue in two ways. Firstly, through a critique of assumptions about diabetes, the education program itself was designed to support a localised critical praxis as former understandings and modes of resistance to stigmatisation (e.g. concealment) are destabilised in order to provide new opportunities for action

(Fook 1999; Fook & Gardner 2007; Healy 1999). Secondly, findings from the group education program were presented to a state-wide diabetes organisation to deliberate on the implications of these findings for future stigma-reduction work (Chapter 12). By communicating these findings to a patient organisation, this research follows Tarlau's (2014) suggestion that there is a need to re-connect critical pedagogy with organisations and social movements as a way of creating real opportunities to realise social change. The following section describes how the findings produced in stage one of this research were used to support this deliberative research involving actors with an Australian state-wide diabetes organisation.

## **Part two: locating critical pedagogy within the landscape of stigma-reduction work**

In part two of this doctoral research, a sub-set of findings produced in part one of this research (contained within Chapter 11 of this thesis) were used to assist a second group of participants to deliberate on the role of diabetes organisations in stigma-reduction work. This research activity is a valuable companion to the earlier research because it can help answer outstanding translational questions regarding where critical pedagogy might be located in the scheme of existing stigma-reduction work and public health practice. This research also fulfils the brief of critical pedagogy, which for Tarlau (2014) involves connecting critical pedagogy with organisations supportive of social change, and for Steinberg and Kincheloe (2010) involves having marginalised voices articulated and included within democratic processes. In this research, a deliberative democratic methodology was used to generate policy options for future stigma-reduction work, involving groups of staff and board members from an Australian state-wide diabetes organisation. The methodology for this second smaller research activity is described below, including an overview of the deliberative democratic methodology, processes of participant sampling and recruitment, methods of data collection, and the analytical strategy.

### **Research design**

The deliberative democratic approach is a methodology used to make policy decisions more democratic. Within this approach, citizens or publics are given the opportunity to participate in policy decisions that affect them, based on an informed and careful (i.e., deliberate) consideration of the issues involved. This approach is often used where there is a need to incorporate public values into the decision-making process, particularly where policy decisions are likely to be ethically controversial and require a fair process for identifying solutions (Abelson et al. 2003; Daniels 2001). As Degeling, Carter and Rychetnik (2015, p. 115) suggest, the need for such an approach occurs in the context of addressing 'wicked issues' where 'technical and normative aspects of a question are profoundly interwoven, including when there is significant technical uncertainty or normative conflict'. Diabetes-related stigma can be considered such a wicked issue given that stigmatising practices were found to be bound up with public health and healthcare practices that seek to prevent and

facilitate improved management of type 2 diabetes, which are practices that can be either justified or rejected given different ethical perspectives. The deliberative methodology used in this chapter has been adapted from similar approaches addressing morally complex and value-laden public health issues, including deliberation on euthanasia policy in Finland (Raisio, Vartiainen & Jekunen 2015), surrogate consent for persons with dementia (De Vries et al. 2010), and embryonic sex selection (Scully, Shakespeare & Banks 2006).

Although there exists a diverse number of methodologies that are subsumed under a deliberative democratic approach, common features include: a) the provision of information about the issue of concern, b) a public discussion of both the information presented and the ideas put forward by other deliberants, and c) making recommendations for action (Abelson et al. 2003). Therefore, deliberative democratic approaches are purposeful in using dialogue to make recommendations for action. In other words, 'formal deliberation is more than a dialogue and not just a debate ... [the] deliberative process extends the thinking of participants beyond their own interests to think about public goods and the collective needs of the community: the aim is to generate recommendations or other advice on a defined topic' (Degeling, Carter & Rychetnik 2015, p. 166). Although there are different traditions from which to view deliberative democracy, notably the Rawlsian liberal tradition and Habermasian critical theory tradition (Hammond 2018; Rostbøll 2008), this chapter approaches the issue from the latter perspective to remain consistent with the assumptions contained within critical pedagogy. At the core of this approach is the belief that publics tend not to be able to *freely* voice their opinions because of the coercive effects of ideology, that is, their opinions are recognised to be 'ideologically constrained' (Rostbøll 2008, p. 721). Deliberation, involving an informed and dialogical exchange of ideas between interlocutors, intends to promote a sense of 'dislocation', which helps 'defamiliarize the familiar' and help 'individuals see the existing reality in a different light' (Hammond 2018, p. 6). Facilitating such dislocation is important given the way (as this research demonstrates) that medical and moral concepts constrain abilities to imagine PWD in alternative or novel ways.

### **Participant sampling and recruitment**

The organisation examined in this research is an Australian state-wide, not-for-profit, and member-based diabetes organisation that had previously contributed funding to this doctoral research. In establishing the context for this research, there are a few important points to make about the mission, values, and scope of practice for this organisation. In formally stating its mission, the organisation is explicit in communicating a central concern with 'supporting', 'empower[ing]', and improving 'outcomes' for PWD and those at risk of developing diabetes. The organisation also makes clear the collective intention of staff, in policy rhetoric at least, to operate in a person-centred manner guided by virtues of *honesty*, *empathy*, *leadership*, and *passion*. At the time of this research, this organisation was actively performing a number of functions for persons with all types of diabetes and those at risk of developing diabetes, including the provision of:



- educational services provided by credentialed nurses and dietitians;
- group self-management education programs and supermarket tours;
- educational seminars on the medical, dietary, physical activity, and psychological aspects of diabetes management, provided by local and national diabetes experts;
- provision of online and print information about diabetes and its management;
- public awareness campaigns, focusing on risk identification and management;
- diabetes prevention programs for at-risk individuals; and,
- fund raising for organisational activities and the funding of research.

The organisation's management and board both agreed in-principle to the broad aims and methodology of a deliberation of research findings and were consulted during the process of developing a more detailed research protocol. Because the organisation had previously contributed funding to this doctoral research, the deliberative method provided a strategic opportunity for the in-depth dissemination of research findings whilst also extending the research to identify how critical methods of education might interface with existing stigma-reduction work at a larger scale. Research participants included members of the organisation's governing board (BRD), healthcare services staff (HCS), and communications and marketing staff (COM), who were approached by the organisation's CEO and health service manager to participate in the deliberative fora. Inclusion of these groups in the research meant that it was possible to explore possibilities for stigma-reduction intervention across different operational contexts, including healthcare interventions, media and communications activities, and policy development, allowing the research to identify interventions that span public health stigma-reduction activities of contact, education, and advocacy (Heijnders & Van Der Meij 2006).

Initially, all staff and board members within the organisation were provided with a 30-minute presentation of research findings by the doctoral candidate, providing an overview of the conceptual model of stigma-deviance relations for PWD (Figure 5, p.148). This brief presentation of findings was intended to establish a more *informed* audience for future deliberation, which served the purpose of facilitating a more deliberate examination of the issues involved, thereby enhancing credibility of the outcomes of the deliberative process (Fishkin, Luskin & Jowell 2000), and providing the opportunity to start to create a sense of dislocation by representing reality in a different light (Hammond 2018). At the end of the presentation, all persons were offered an information and consent form for the deliberative research. At this time, the doctoral candidate made clear the voluntary nature of participation and provided staff and board members with a brief summary of findings and content to be covered within the deliberative groups. Consent forms were completed and returned prior to the deliberative groups.

### **Process of deliberation**

Four two-hour-long deliberative groups (see Table 8 for an overview of participant characteristics and group composition) were performed 1-2 weeks following the initial presentation of findings, adapted from the deliberative method described by Scully and colleagues (2006). Facilitation was performed by the doctoral candidate, with assistance provided by a second post-graduate researcher experienced in research group facilitation and deliberative research methods. For each of the groups, the purpose of the deliberation was firstly introduced, followed by an overview of the process of deliberation and the communication of group norms. Three short vignettes, taken from participant quotes from the case study research, were then presented to each group, each reflecting key issues identified by research participants. These vignettes were presented as follows:

**Vignette 1.** I always hear on the news about how the obesity epidemic is resulting in more cases of diabetes and how diabetes is such a burden on the healthcare system. Plus everyone has a story about someone with diabetes that doesn't watch what they eat, ignores their diabetes, and has lost a foot. It's all so tragic. Sometimes it's hard to remain positive about my diabetes.

**Vignette 2.** I can't say that anyone has treated me cruelly because of my diabetes. But it does annoy me that others feel the need to watch and comment on what I should or shouldn't be eating. It makes me feel like a naughty child for eating the wrong things. I know they probably mean well, but it's none of their business what I eat – the decision and responsibility is solely mine. I mean, we already know our defects, we don't need them pointed out to us.

**Vignette 3.** I used to feel more shameful about my diabetes before I lost the weight. My old GP used to put everything down to my weight, and all the dietitians I went to all just said I needed to eat less and exercise more. Their attitude was that I just wasn't trying hard enough.

After listening to each vignette, group members were asked to: 1) individually note down their initial reaction to each scenario, 2) specify what should be done about the situation from the standpoint of a diabetes organisation, and 3) offer a rationale for their decision. The facilitator then invited participants to share and discuss their response with the group, with the role of the facilitator being to keep discussion on track and moving forward, facilitate participation, and encourage participants to expand upon, evaluate, and critique the proposed actions and reasoning offered by other participants. After all three scenarios had been discussed, all participants were given the opportunity to offer their final opinion on what they think would be the best course of action that diabetes organisations could take for addressing diabetes-related stigma.

**Table 8. Group composition and participant characteristics**

Deliberative group	Relationship to diabetes	Length of service	Gender
Governing Board (BRD)	Advocate/family member of person with T1DM	4 months	Male
	T1DM	3.5 years	Male
	Not specified	3 months	Female
	T1DM	7 years	Female
	T2DM	10 years	Male
	GDM	15.5 years	Female
Deliberative group	Organisational role	Length of service	Gender

Healthcare Services Staff – Group 1 (HCS1)	Diabetes Educator	4.5 years	Female
	Executive Manager, Program Development & Delivery	9 years	Female
	Dietitian / CDE	10 months	Female
	Dietitian	3 months	Female
	Project Officer	9 months	Female
	Dietitian – Priority Areas	6 months	Female
	Research Trial Coordinator	6 months	Female
Deliberative group	Organisational role	Length of service	Gender
Healthcare Services Staff – Group 2 (HCS2)	Evaluation Officer	6 months	Female
	Project Officer	7 months	Male
	Project Officer – Diabetes Management	2.5 years	Female
	Health and Service Delivery Manager	4 years	Female
	Diabetes Educator	10 months	Female
	Dietitian	3 months	Female
	Diabetes Educator	1 month	Female
Deliberative group	Organisational role	Length of service	Gender
Communications and Marketing Staff (COM)	NDSS Training and Assessment Officer	7 years	Female
	Executive Manager Corporate Services	9 years	Male
	Member and Community Partnerships Manager	6 years	Male
	Membership Coordinator	9.5 years	Male
	Marketing and Communications Officer	5.5 years	Female

### Data collection and analysis

Group discussion was recorded using a digital audio recorder and then professionally transcribed. Audio data were complemented by field notes completed by the group facilitator, recording observations of verbal and physical interactions occurring between participants and between participants and the facilitator. NVivo qualitative research software (QSR International Pty Ltd, Version 11) was used to organise and support analysis of all collected data. Data analysis firstly involved a single analyst (the doctoral candidate) scanning the transcripts to identify proposed actions that a diabetes organisation might take to reduce diabetes-related stigma, which were then organised under the typology of stigma-mitigation approaches described by Weiss, Ramakrishna and Somma (2006). Different forms of reasoning attached to these actions, including deliberative critiques and counter-arguments, were inductively coded with reference to themes raised within public health ethics and stigma literature (Bayer 2008; Bayer & Stuber 2006; Bell et al. 2010; Blacksher 2018; Carter & Rychetnik 2013; Childress et al. 2002; Courtwright 2013; Dawson 2009; Holland 2015; Lee 2012; Munthe, Sandman & Cutas 2012; Rossi & Yudell 2012; Spike 2018; ten

Have et al. 2012; Upshur 2013). A preliminary summary of findings was provided to all research participants, who were offered the opportunity to review and suggest amendments to the content, organisation, and interpretation of these findings. Providing allowances for participant review and feedback was an important ethical consideration given that the content of deliberation had the potential to reveal sensitive information that might pose a reputational risk to the organisation and individual participants, particularly given limits on anonymity to participants as visible members within the organisation. Research ethics approval for this project was obtained from the Flinders University Social and Behavioural Research Ethics Committee (Project Number 7899).

In summary, this chapter has described a methodology for explaining how changes in representations of PWD and stigmatising events might emerge through participation in the education program described in the previous chapter, and how such education might integrate within existing stigma-reduction work. As a qualitative and interpretative form of research, a rigorous explanation of learning is possible because of features of the study design (as a longitudinal and comparative case study), data collection methods that facilitate an observation of learning in a comprehensive way, and the use of a systematic and rigorous analytical procedure that is able to characterise discourse, identify discursive changes over time, and relate these changes to processes of learning. The outcomes of this analysis are presented within the following section.

## Section Three: Analysis and Presentation of Research Findings

Up until this point, this thesis has laid a theoretical and methodological foundation for answering the questions posed by this research. The challenge for this section is to use these data to make inferences about the more enduring features of learning and stigmatisation in a way that allows for theoretical generalisation beyond the boundaries of this case study. On one hand, this analysis involves the scientific imperative to articulate the logic relating the empirical data, analytical procedures, and theoretical claims in a transparent and rigorous way. But on the other hand, this analysis also requires the presentation of such a logic within a coherent case study narrative that retains a certain contextual wholeness and complexity (Thomas 2011).

This section approaches these issues by organising key findings against different facets of the analytical strategy used. After providing a descriptive overview of the learners (or cases) and their interaction with the research (Chapter 7), Chapters 8 and 9 focus specifically on what understandings of diabetes-related stigma were produced through participation in the education program and what pedagogical and non-pedagogical processes contributed to these understandings. The first of these chapters (Chapter 8) examines these things in relation to discursive changes in representations of PWD, which provides insight into how discursive regimes are used by participants to construct, legitimise, resist, or transform stigmatised social identities. The second chapter (Chapter 9) then examines these things in relation to changes in representations of stigmatising events, which offers insight into the way that PWD problematise certain processes or structures that maintain stigmatisation. Recognising that the intent of critical pedagogy is to generate socio-political projects for improving the status of marginalised individuals or groups, Chapter 10 identifies what personal projects emerged from this research and how the emergence of these projects might be explained. This chapter specifically draws on representations of personal agency in the context of stigmatising events to examine the role of learner reflexivity in enabling or limiting possibilities for structural elaboration or change. Therefore, the focus of these chapters is on identifying salient features of learning that might facilitate a more critical engagement with the stigma concept.

Chapter 11 then interprets experiences of stigmatisation described by participants to develop a critical theory of diabetes-related stigma, offering a theoretical perspective on stigma that is absent within the diabetes-specific literature. Theorising about diabetes-related stigma in critical terms also helps explain why participants in this research struggled to form counter-hegemonic discourses and projects. Specifically, it helps explain the presence of a narrative that runs throughout the earlier chapters whereby medical knowledge about the chronically ill 'diabetic' body interacts with tacit knowledge about PWD as responsible (health) citizens. This interaction was seen to affect how PWD might come to know themselves and others with diabetes, shaping individual subjectivities and limiting their ability to think critically about and imagine an alternative non-stigmatising reality. It is

such knowledge about the body and moral self that promotes the discursive construction of the stigmatised Other, which in this research takes the form of inter-related sub-groups of *tragic-disabled*, *irresponsible*, and *obese* PWD. Critically speaking however, it is the way in which governments and public health authorities manage health risks (and risky bodies/people) that provide individuals with the moral concepts used to construct the stigmatised Other, a process that is readily adopted in contexts of uncertain futures where PWD are compelled to overcome a natural history of disease progression.

These findings raised a series of important issues regarding the translation of research findings into practice. Firstly, it was apparent that the ability to think about diabetes-related stigma in more critical terms was heavily constrained by the conflation of technical and normative aspects of risk-management. Secondly, critical approaches to education appeared to stand little chance of being integrated into existing public health practice given the instrumental rationality and dominance of existing public health pedagogies. In order to locate a space for critical pedagogy given these constraints, select findings from this doctoral research were then presented to a cross-section of staff and board members within an Australian state-wide diabetes organisation, who deliberated on the implications of these findings for future stigma-reduction work. The findings of this deliberative research are presented in Chapter 12, identifying how movement towards the democratisation of healthcare systems and services provides a promising space for the future practice of critical pedagogy.

These findings are later brought together in Section Four, which identifies several important features of learning that are involved in thinking more critically about diabetes-related stigma and identifies how such learning might be constrained or enabled. This synthesis of findings leads to further discussion about how knowledge generated through this doctoral research responds to contemporary issues around the use of critical pedagogy in public health and stigma-reduction work, why these findings should be trusted and in what ways these findings are limited, and what implications this knowledge has for future stigma research and public health practice.

## 7. IMPLEMENTING THE EDUCATION PROGRAM: WHO WERE THE LEARNERS AND HOW DID THEY INTERACT WITH THE RESEARCH?

The purpose of this chapter is to make transparent the learners and learning activities involved in the educational case study research. This follows the idea that the reporting of a case study should be done in a way that takes ‘the reader into the case situation, a person’s life, a group’s life, or a program’s life’ (Patton 1980, p. 387, cited in Merriam 1998, p. 238), allowing the reader to vicariously experience what it might have been like to observe the research as it unfolded. In providing this overview of participants and learning, this chapter also attempts to preserve the context of each educational group and the participants within each group, recognising that some of this contextual wholeness will be lost in later findings chapters (within Section Three) where rich description gives way to abstractions used for purposes of explanation and generalisation. As a piece of research within the field of public health, the act of distinguishing ‘evidence’ from ‘interpretation’ will also facilitate a more comfortable communication of findings to healthcare and public health audiences (Yin 1999). This is not to say that this chapter assumes a naïve view of qualitative ‘evidence’ as neutral or free of interpretation, but in writing it I have attempted to recount details of the research as honestly and transparently as possible whilst maintaining a coherent synthetic narrative. To support this transparency, I have integrated reflexive memos into the discussion where my influence as researcher and facilitator appears to have shaped the process and outcomes of the research. This attention to researcher/educator reflexivity is an important quality consideration within critical educational research (Chapman 2011; Ellsworth 1989). In this chapter, the discussion of cases is organised according to their assigned group (group one or two) in order to retain a sense of case-group context. For each group, there is a discussion of the fidelity of implementation of the education program against *a priori* lesson plans and how formative assessment influenced implementation, a brief overview of how individual participants interacted with learning activities and others within the group, and a discussion of salient features of researcher-participant interactions.

A total of eight individuals participated in the education program, four in group one (performed from November to December 2018) and four in group two (performed from May to June 2019). Although this research had originally intended to recruit 6-8 participants for each group, a lower-than-anticipated response to recruitment methods meant that the number of participants in each group was truncated given concerns about waiting list attrition and research timelines. A summary of the socio-demographic and diabetes-related characteristics of participants is provided in Table 9. In relation to important variables affecting diabetes-related stigma and educational participation, there are several points to note from this table. Firstly, although this research involved an equal number of male and female participants, there was an asymmetrical distribution between the two groups. This asymmetric distribution is important given gendered differences in the experience of diabetes

and weight stigma (Himmelstein & Puhl 2020a; Liu et al. 2017; Monaghan & Hardey 2009; Tischner & Malson 2011) and the influence of gender on group dialogue (Kaufmann 2010; Lather 1998; Wallin-Ruschman 2014). Secondly, there were also distinct differences between the two groups regarding educational attainment, with the first group featuring two participants with bachelor degrees or higher and none within the second group. This difference is notable given that those with higher levels of educational attainment are more likely to report a felt-stigma in relation to T2DM (Liu et al. 2017), which appeared consistent with the pattern of responses to the DSAS-2 amongst those with higher levels of educational attainment in this study. And thirdly, the second group involved a noticeably older cohort, which is likely to shape the biographically disruptive effect of chronic illness (Williams 2000) and attributions of culpability given that increasing age is a non-modifiable risk factor for T2DM (Bellou et al. 2018). Furthermore, this group had lived with diabetes (following formal diagnosis) for a much longer period of time compared to those in group one. No participant in this research managed their diabetes with exogenous insulin, which is a notable absence given the possible influence of public insulin injection on the perception of stigmatisation (Schabert et al. 2013). No participant in this research identified as having an indigenous or first nations ancestry.



**Table 9. Participant/case characteristics**

	Group One				Group Two			
	C1	C2	C3	C4	C5	C6	C7	C8
Sex	Female	Female	Male	Female	Male	Male	Female	Male
Age at time of entry into study (years)	51	63	61	69	77	78	57	84
Country of birth	Australia	Australia	Australia	Australia	England	Australia	USA	England
Highest level of educational attainment*	Bachelor degree	High school	Bachelor degree	Cert I/II	Primary school	Cert I/II	Cert I/II	High school
Employment status	Retired	Retired	Disability pension	Retired	Retired	Retired	Disability pension	Retired
Years since diabetes diagnosis	9	4	2	9	24	28	13	17
Current medical management	Oral hypoglycaemic agent(s)	Oral hypoglycaemic agent(s)	'Diet only'	Oral hypoglycaemic agent(s)	Oral hypoglycaemic agent(s)	Oral hypoglycaemic agent(s)	Oral hypoglycaemic agent(s)	Oral hypoglycaemic agent(s)
Diabetes education attended in past	Diabetes seminars (several)	None	None	Diabetes seminars (several)	None	Diabetes information seminar (1990)	Structured 6-week lifestyle program	Diabetes education group
DSAS-2 score (total)	70	61	62	65	61	46	62	44
<i>Self-stigma</i>	16	21	6	26	12	11	16	7
<i>Blame &amp; judgement</i>	32	24	31	23	33	24	27	20
<i>Treated differently</i>	22	16	25	16	16	11	19	17

\* With reference to the ABS Australian Standard Classification of Education (ASCED), 2001 (Australian Bureau of Statistics 2001)

## Group One (cases 1-4)

Interestingly for this group, most participants (C1, C2, and C3) first came into contact with the research via paid online advertisements on Facebook, either directly (C1, C3) or indirectly through third party sharing (C2). Although C1 and C2 requested study information and quickly signed up to the research, with their motivations for participating in the research becoming more apparent during interview, early email correspondence between me and C3 shed some light on his motivations for participating in the research. Entering into the research, C3 was cognisant of 'a stigma attached to illness', which he had experienced prior to his diabetes diagnosis due to a chronic inner ear disorder that adversely affected his gait. According to C3, reactions of others towards his unusual gait had sensitised him to similar 'stigma' related processes affecting PWD.

I agree that there is a stigma attached to illness in general, which I have noticed regarding my Meniere's ("oh, look at that man...staggering and unbalanced drunkard and it's only 10am in the morning.."). As the T2 is "new" to me I have also noticed this with others who have it, the aspersions cast by general society and to a degree some of their own views on themselves. (C3 – email correspondence)

The other participant in this group (C4) first came into contact with the research via a study flyer that was distributed electronically to members by a state-wide diabetes organisation. This participant called me directly, emphatically claiming that the description of 'stigma' contained within the study flyer (original version) closely reflected her own feelings of embarrassment, shame, and guilt towards her own diabetes. Despite C4 living approximately one-hour drive away from the study venue, she was adamant that she would be able to fulfil all requirements of the research given that participation in this research project was 'exactly what she needed at this time' (C4 - operational memo). Case 4 arrived early to each session, despite commuting across peak traffic conditions each time.

### Implementation of the educational program

With the exception of one session in which C3 was absent (session four); all participants completed each of the five group sessions. Facilitation of this first group remained roughly consistent with the *a priori* lesson plans, with minor changes made to address issues raised in formative assessments of learning.

#### Session one

The first session was designed to provide participants with an overview of the education program and develop a foundation for thinking about diabetes-related stigma in more socially critical ways. Specifically, the session's objectives were to help participants: i) recognise the personal relevance of critical reflection in helping them make sense of and contest diabetes-related stigma, ii) understand what was expected of them in the upcoming group sessions, and iii) manage anxieties related to group participation. In reference to facilitation styles described within ethnographic studies of critical pedagogy in Health and Physical Education (HPE) classrooms (Fitzpatrick 2013;

Fitzpatrick & Allen 2019), my role as a facilitator within this session was to facilitate the development of learning relationships within the group ('building the environment'), interact with participants in ways that communicated my role as a reflexive co-learner as well as a group facilitator ('embodied criticality'), and focus on issues of marginalisation and power as they relate to the stigma-concept ('studying critical topics' and 'deconstructing power'). Reviewing field notes from this session, I was observed to provide an overview of models of stigma (specifically drawing from conceptual models of health-related stigma developed by Link and Phelan (2001) and Scambler (2006a)) and critical reflection whilst allowing participants to freely voice their reactions to the content with minimal probing or questioning. These frameworks appeared to have an immediate appeal to several participants. During the session, both C1 and C2 engaged in lively discussion about the importance of weight stigma within their own lives whilst noting their struggle in articulating what was driving this stigma and what they could do to address it. After the group, C3 described to me how he was in need of a 'framework' to help him make sense of his diabetes.

Three of the group members (C1, C2, and C3) frequently used the term 'stigma' in describing their experiences in relation to their weight, diabetes, and other chronic illnesses. It was recognised that the experience of stigma is dynamic and does change over time, citing examples of epilepsy and Down syndrome. Interestingly, C2 and C3 both expressed concern that they couldn't think of any specific critical incident relating to their diabetes. This feedback was surprising to me given that both had described rich experiences of what I would regard as stigmatisation. I advised that even mundane experiences were useful and encouraged them to draw on the experiences discussed during the group or during the pre-group interview. While I felt that my explanation of concepts of stigma and critical reflection were satisfactory, in retrospect this discussion may have benefited from a more active educator voice, incorporating my own interpretations, values, and emotional response to diabetes-related stigma. Offering a reflection on his own engagement with critical pedagogy over several decades of teaching HPE, Tinning (2020) suggests that this directiveness is required in developing a sense of urgency and agency for change amongst novice teachers within the neoliberal classroom:

I still remain committed to the ideal that Spodek (1974) expressed all those years ago, namely that all teacher education (and schooling) is ideological and our job as teacher educators is to make this explicit to our students and to help them understand why it is necessary to take up the challenge of critical pedagogy to help young people to negotiate their lives with an understanding of the scope and potential for their own agency and conditions necessary of a more just and equitable world. (Tinning 2020, p. 987)

### **Session two**

In session two, the intention was for participants to be able to: i) articulate implicit assumptions or knowledges used to make sense of their critical incident, ii) begin to think about the ways that these assumptions and knowledges relate to specific practices, and iii) identify how these assumptions and knowledges are experienced and manage to 'get under their skin'. Although most participants were able to identify relevant assumptions, there was limited discussion regarding the latter two

points. The focus for participants appeared to be on trying to alleviate the storyteller's (perceived) anguish by coming alongside and recognising that these perspectives were shared amongst others in the group. Thus the group took on a support-group like function at times. However, this supportive environment came at the expense of a more critical engagement with participant incidents. As a consequence, I shifted my facilitation style towards a greater emphasis on coaching and modelling, with the hope of supporting a more critical analysis of the presented critical incidents. Cognitive modelling specifically involved me drawing on the cognitive tools provided in the participant workbook (Appendix 5) to articulate the 'reasoning (reflection-in-action) that learners should [or might] use while engaged in the activities' (Jonassen 2009, p. 231). Coaching on the other hand involved a process of providing explicit feedback regarding participant reflections and encouraging a more critical reflective performance. This coaching and modelling approach required a more directive facilitation style, adopting elements of what Fitzpatrick and Allen (2019, p. 649) refer to as the practice of 'deconstructing power', involving 'the verbalisation and overt challenging of power relations'. The focus was on articulating the medical and moral concepts that shaped the consciousness and identity of PWD. However, I noted that participants were slow to warm to this critically reflective 'habit of mind', preferring instead to develop a sense of solidarity through a communication of shared experiences. It is possible that my bias towards developing techniques of critical thinking, consistent with Tinning's (2020) emphasis on rational critique within critical pedagogy, may have overlooked the needs of participants to first validate their experiences as a shared phenomenon.

### ***Session three***

Session three offered participants the opportunity to suggest alternative ways of thinking about PWD, using the critical incidents described in the previous session to identify how different ways of thinking about PWD might open up possibilities for alternative ways of acting. As participants took turns re-imagining their critical incident within the group, there was a consistent re-iteration of the assumptions and knowledges identified in the previous session. However, in exploring alternative ways of acting, participants appeared to fall back on familiar strategies of stigma avoidance, as raised in the pre-group interviews. In response to this movement in learning, I initiated discussion about the relationship between stigma, power, and human agency, drawing on the ideas discussed in Chapter 2 of this thesis. These ideas sparked a discussion amongst participants about what they termed the 'power of ideas' (a term proposed by C3 and taken up by other participants) and how this 'power' was reinforced by practices of coercion, reward, and punishment within healthcare settings. Despite this revelation, participants again turned to tried and tested strategies of stigma avoidance (discussed in more detail later within this chapter) as a solution to this issue.

As was the case for the previous session, this session required a significant amount of coaching and guidance to help participants move from a critique of knowledges used to stigmatise, to devising alternative knowledges and courses of action. Reflected in field notes from this session, it

appeared that participants had struggled to identify alternative knowledges about PWD, contributing to a stalled discussion when imagining alternative non-stigmatising practices. Reflecting on this observation, it appeared to me that there was a missing piece in the educational method - at least in relation to its use for examining health-related stigma. The assumption was that a critique of the knowledges used to understand PWD would lend itself to alternative ways of knowing and acting. However, these alternative ways of knowing did not appear to emerge spontaneously for participants. Reflecting back on my own personal and professional history and returning to literature characterising diabetes advocacy work and interactions within online diabetes communities (Basinger, Farris & Delaney 2020; Holland 2018) I struggled to identify any well-defined alternative representation of PWD. In writing up the formative assessment for session three, I left a memo to myself as a reminder to discuss these thoughts with participants in the next session.

#### ***Session four***

In this session, the intention was for participants to refine and test the ideas developed over the past sessions, using Forum Theatre as a testing ground for these ideas. It also provided a good opportunity to shift the facilitation style in a more 'playful' direction. This 'playfulness', according to Fitzpatrick (2013), is thought to help diffuse tension around an issue and help learners to view the issue from multiple perspectives without being too invested in any one perspective. Two 'acts' were developed for this session, each constructed to closely resemble the issues raised by participants within the group (primarily) and pre-group interviews (secondarily). The first act featured a series of exchanges between a PWD (as a hospital in-patient) and medical, nursing, and food service staff within a hospital ward, whereas the second act involved a discussion of diabetes and PWD around the meal time table, with participants seated around the table as if participating in the shared meal. Participants were clearly nervous about the prospect of acting out change within this simulated environment, which detracted from the playful intent of the activity.

There appeared to be strong emotional reactions to the content of both acts one and two, which further detracted from this playfulness. Cases 1 and 4 in particular were quick to express outrage regarding the actions of the 'stigmatiser' in both acts, stating a concern with what they both saw as being paternalistic attitudes and behaviour directed towards PWD. At this point, I encouraged participants to think about ways that PWD might be represented so to challenge this paternalism. This tact was designed to help address the concerns raised following the previous session about a lack of clarity around alternative representations of PWD. Both C1 and C4 emphatically declared that PWD should be regarded as 'adults' who could decide for themselves an appropriate course of action. When invited to suggest an appropriate re-enactment, no participant felt comfortable to re-enact the scenes. Rather, C1 and C4 both offered curt and emotive responses directed towards the stigmatiser, which primarily functioned to deflect stigmatisation away from the PWD. Throughout the session, participants seemed to revert back to defensive responses to

stigmatisation, attempting to deflect stigmatisation without using their critical thinking skills to better understand and challenge this process. Given that there was limited cross examination of ideas within the group, possibly due to there being smaller numbers in this session (C3 being absent), I adopted a stronger coaching role within this session. The purpose of this coaching was to illustrate how different elements of critical reflection might be used to recognise stigmatising practices, develop counter-narratives, and develop alternative strategies of resistance. By the end of the session, I felt that participants appeared to have an appreciation that their initial responses to acts one and two may have been less than helpful.

### ***Session five***

The final session offered participants the opportunity to review their learning and identify changes in thinking that occurred through their participation in the research project. The session assumed a focus group-like feel as I guided participants through the learning activities and model of critical reflection, posing questions to participants at frequent intervals. Drawing from field notes, it was apparent that C1 and C3 were dominant participants within this session. Relative to the other participants, it seemed likely that this focus group-like format played to their strengths as confident verbal communicators and more conceptual-analytical thinkers. All participants were able to clearly articulate assumptions informing their experience of diabetes-related stigma, which was a marked improvement from the first session. Although there was less clarity around an articulated plan of action, there were some novel insights (initiated by C3 and later affirmed and developed by other participants) about the way in which a person's own knowledges about diabetes and PWD must change prior to challenging stigmatisation. However, there was limited discussion about how these learnings had informed the everyday practices of participants.

As anticipated in the lesson plans, the final session was also used by participants to establish a sense of closure. I noted how the female participants (C1, C2, and C4) exchanged gifts with one another, and one even provided me with a small gift. Each participant thanked myself and the observer for our work during the course of the research. I finished this first group eager to perform the post-group interviews, curious about what discursive and behavioural changes I might observe. At this point, the process of education and the observed learning outcomes felt messy and opaque, warranting further examination through interview and a review of collected data.

### ***Journal writing***

Despite me emphasising the value of journal writing, explaining in detail how to complete the journals, providing a worked example, and discussing learner-generated issues with journal writing at the start of each session, only three participants completed any journal entry (C1, C2, and C4), only one completed all five entries (C4), and only two wrote in a manner consistent with instructions provided in the journal writing guide (C1 and C4). Despite having completed reflective journals during the course of her social work practice, in session two, C1 expressed her dislike of journaling because the mental work and heightened self-consciousness that comes with written reflection. Case 2 also shared in session five how she found journal writing uncomfortable, stating that 'reflective journals are difficult to write when you know they are being read, but reflecting without judgement [by the

reader] may be easier' (C2 – post-group interview). Never having completed a reflective journal before, C4 also discussed in the post-group interview how she hated completing her reflective journal, but regardless found that it had helped her to organise her thoughts and support a recall of fleeting thoughts or ideas. For her, reflective journaling 'was a big thing coming out of it [the group]', noting that although she only wrote one or two sentences in the first entry, she was 'writing a fair bit by the end' (C4 – post-group interview).

### **Interactions between participants and learning activities**

Within the education program, learning centred around the selection and analysis of a critical incident that each participant felt offered insight into their experience of stigmatisation. Therefore, it is important to make explicit in this section exactly what these incidents involved and how these were used and interpreted throughout the educational program. For C1, there was a thematic focus on the evaluation and control of deviant behaviour. During session two, C1 angrily described an incident whereas a hospital in-patient she was refused a sweet biscuit during food service, being told 'diabetics can't eat that'. She described the feeling of annoyance that came with what she saw to be a violation of her personal liberties. For C1, this incident was symbolic of other interactions where PWD are seen as 'out of control' and that diabetics need to be controlled because they can't be trusted to control themselves. In suggesting how she might think or behave differently should she encounter the same incident again, she suggested that she would tell the individual to 'bugger off', as abruptly as possible, to let the stigmatiser know that they had violated her 'adult' right to dietary choice (session 3 – observation). In a similar way to session three, in session four C1 reacted angrily to the evaluation of eating behaviour of overweight persons, playing out aggressive responses that communicated to the stigmatiser how they had violated personal liberties.

For C2 the critical incident involved two utterances made by her daughter (a practising nurse), one following her diabetes diagnosis ('well, you're surprised?') and one shortly after in response to her perceived lack of effort towards dietary restraint, exercise, and weight reduction ('we'll come visit you with your wheelchair and your foot removed'). In session two, C2 reasoned that the utterances made by her daughter were informed by the assumption that overweight is informative of personal laziness and a lack of willpower. Although she didn't explicitly relate this assumption to obligations for disease prevention (including both the prevention of diabetes and the prevention of diabetes-related complications), these obligations were clearly implied in remarks made during the group and in narratives presented in each of her interviews, suggesting that she must take 'greater responsibility' for reducing weight and managing her diabetes. She even claimed in the post-group interview that a motivation for participating in the research was to motivate herself to take better care of herself. In session three, C2 continued to dwell on her emotional response to her critical incident, unable to suggest alternative ways of thinking of behaving in response to the incident, claiming that she was not very good at 'thinking on the spot'. Neither C2 nor any other participant in the group were able to critique the notion of individual responsibility and self-motivation – these obligations were seen to

draw upon a logic of self-preservation. In session four, C2 reflects on the act of hiding her research workbook from her daughter, feeling that she didn't want to discuss her diabetes with anyone until she had demonstrated her ability to better manage her diabetes, which would be evident through successful weight reduction. This earlier claim that she was unable to 'think on the spot', might explain why she also avoided participating in the forum theatre activity in session four. It may also reflect an individualisation of stigmatisation as a personal problem, reflected in her claim in session five that group discussion 'made me realise I don't need to be validated by other's perspectives and that I only need to validate my own beliefs'. She went on to claim that these beliefs related to personal responsibility for behaviour change and the importance of self-motivation, beliefs which remained largely untouched through her participation in the research.

In his critical incident, C3 focused on his cognitive and emotional response to his diabetes diagnosis, feeling culpable for the onset of his diabetes given that his father had been diagnosed with T2DM at an early age and subsequently died from advanced complications of diabetes. He stated that 'I should have known better' and 'it's my own fault', describing how the self-blame associated with a diabetes diagnosis is built on the assumption that PWD have failed, by their own volition, to identify health risks and to proactively act to reduce these risks. He expands on this idea within session three, claiming that 'diabetes is never blame-free', which he uses to suggest that the moral evaluation of others is a natural human tendency and that the appropriate response to self-blame is to absolve oneself of blame by acting responsibly. Although absent for session four, C3 offered a detailed critique of the blameworthiness of PWD in session five, raising issues relating to scientific uncertainty regarding T2DM aetiology and the role of culture in constraining individual behaviours. Later in the session, he offered a synthesis of the group discussion, explaining that stigmatisation emerges from the reduction of diabetes aetiology to one factor (obesity) and that de-stigmatisation requires a recognition of aetiological diversity and needs amongst PWD. He then claimed that stigmatisation is also driven by the assumption that PWD are responsible for their diabetes (i.e., 'they caused it') and that PWD are considered as either lazy ('won't change') or weak-willed ('can't change'). The group consensus at this point was that these assumptions apply both to PWD and those that are very overweight, which create potent forms of moral evaluation for PWD that are also very overweight. Appealing to ideas about the relativity of knowledge, he goes on to suggest that participation in the group had emphasised that 'others will have different perspectives' and that 'no perspective is necessarily right or wrong, but just different.' He then went on to claim that although he doesn't see himself differently as a consequence of his participation in the research, he does see others differently.

As a striking account of stigmatisation, C4's critical incident captured the attention of co-participants within session two and provided content that provoked further reflection in post-group interviews by C1 and C2. This incident involved details of C4 losing consciousness due to hypoglycaemia in the presence of a small group of friends, requiring emergency treatment by a paramedic. On regaining



consciousness, C4 states how she asked the paramedic not to make her diabetes status known to her friends. She describes the overwhelming feeling of shame associated with her diabetes, although at this point she was unable to locate the source of this shameful emotion. In session three, C4 struggled to identify an appropriate alternative way of thinking or behaving should she encounter the same incident again. She acknowledged that the deeply emotional and highly shameful feeling evoked by the incident made it hard to consider other ways of thinking or behaving. It was not surprising then that C4 reproduced her original response (described in session two) in the Forum Theatre activity in session four. In this activity she calls 'stop' when a (fictional) nurse walks into the room to hang up a sign reading 'diabetic diet'. She shares that she felt the sign acted as a public mark of disgrace and suggested that an appropriate response would be to ask the nurse to take it down, at least just before her friends were due to visit. In a second theatrical act, C4 identifies a stigmatising act suggesting that she would be 'fuming' as the stigmatised target. But like in the earlier act, she responds to the incident by opting (by self-admission) to 'fume' in silent. And in session five, she seems to accept rather than challenge attributions of blame, suggesting that the appropriate course of action would be to 'get over myself'.

### **Interaction between participants**

In contrast to group two, interpersonal conflict was notably absent from interactions between participants in group one. Rather, participant interactions tended to function to offer affirmation and create a sense of solidarity amongst participants, which had the effect of creating a safe environment for dialogue. This sense of safety and group harmony was described by several participants in interviews following the group.

I really enjoyed it [the education program]. It was a good forum and everybody seemed to get on well. I was a bit sort of worried, I mean, because of my past profession and the study I've done too and work we've done, I've been involved in a lot of the sort of groups and forums and that and sometimes, it can be, if you get two clashing personalities, that it can become quite yeah, it's not – yeah. But I think we all sort of mesh, even [C3], who's quite an ongoing anarchist. (C1 – post-group interview)

I enjoyed the other women. I was more comfortable. Nothing against [C3], but I enjoyed [C1's] directness and openness. You can identify. When she was talking about her daughter and that was nice. I'm not saying I felt alone with it, but it was nice to have validation. And [C1] was very good at validating. We're Facebook friends now. (C2 – post-group interview)

Not discriminatory at all towards them [co-participants]. I just feel in sync with them. Yeah...I felt comfortable. Comfortable. Yeah. (C4 – 6m post-group interview)

By session two, participants had begun to enter into established group roles. Dominant roles were played by C1 and C3, with C1 providing emotional support and affirmation for other group members and C3 assuming the role of the analyst (much like his role within the pre-group interview), connecting experiences to abstract concepts for himself and for others in the group. This distinction played out in the style of discourse used by participants, with observations in session one describing the way that C3 communicated his ideas through advanced concepts and terms (e.g. by drawing on notions of 'social control' and 'social stigma') and C1 using a more personable, emotive, and

colloquial language. In the post-group interview C3 suggests that the role he played was that of an encourager to others in the group, supporting those that he perceived to possess lesser 'self-worth'. Within the group, C2 and C4 played supporting roles, contributing content but playing a less prominent role in the critique and construction of knowledge compared to C1 and C3.

### **Interactions between participants and the doctoral candidate**

There was a remarkable difference in the relationship established between participants and me as researcher-educator in groups one and two. In group one, I was perceived as a co-learner in the research process. Individual participants frequently attempted to understand my motivations for conducting the research, my understanding of the problem of stigmatisation, and my own hopes for the research. This was most pronounced for C3, who from the pre-group interview adopted the role of a co-analyst in the research. In session five, he responded to my questions (as educator) regarding perceived educational outcomes, asking if I had 'got something out of the sessions'. In the 6m post-group interview, he would also go on to suggest that me (as researcher) and him were both 'nexialists', borrowing the science fiction term to describe how both of us were drawing on knowledge from multiple (social) scientific fields to understand the problem of stigmatisation.

A key feature of educator-participant interactions, as already discussed, involved the influence of instructional supports of coaching and modelling. These supports occurred largely in response to high levels of emotional support being offered by certain participants in the group, led by C1. Although this support did act to create a sense of solidarity and a safe environment for dialogue, it was also observed to truncate a more detailed analysis of experiences of stigmatisation. In performing coaching and modelling roles in sessions two and three, I would interject where discussion was unduly dwelling on a description of experience and its emotional impact, or where discussion had stalled. Reflected in assessment notes, at times this coaching and modelling led to me feeling that he was being overly 'intrusive' in the learning process. This intrusiveness was particularly apparent in session three, in which C2 and C4 were unable to identify alternative thoughts or behaviours and where discussion had stalled. In both cases, I stepped in to provide examples of potential alternatives, explicitly describing the logic informing the selection of these alternatives. This action was performed so to provide some tangible actions for each participant to reflect upon following completion of the group. Although this intrusion wasn't ideal, it was considered to be better than leaving the discussion open and with no sense of closure. Given these concerns, it was helpful to receive explicit feedback from participants about the process of facilitation, which overall appear to suggest that participants were cognisant of and satisfied with the approach taken by me as educator.

I thought it was a good group of people and it was run well and I really admire your skill of moving things along. Not everybody has that ability when you've got obvious time limits and you've got a program to get through, but it can, when you've got a group of talkers, which obviously you did have ... but you're very good at moving it along to the next stage. Which is a very good skill to have. You should be proud of that (C1 – post-group interview)

I guess, when I think of myself in the meeting, sometimes I'm a work orientated person, a job orientated, so once I've started on I get on with it. Probably some of the discussions were repetitive over the weeks, the stories or the discussions similar, and possibly just a little bit too long when I could see you wanted to get this on with. You, kind of, got where you wanted to go but you gave people plenty of time to talk, and that probably took most of the time too. But you are questioning people all the time, so they want to answer. And you – because you're doing that work that you have to do, so you really want to get under, under the surface. (C4 – post-group interview)

## **Group Two (cases 5-8)**

Most participants (C5, C6, and C8) within group two first came into contact with the research via a study advertisement placed in a local print newspaper. Importantly, the content and style of this newspaper advert had changed considerably from the earlier version that was encountered by participants in group one. Rather than using terms reflecting the emotional experience of stigmatisation to gain the attention of potentially suitable participants, this newspaper advertisement adopted an approach that focused on the role that potential participants might have in challenging current representations of PWD. This change in tact appeared to attract a very different cohort of PWD compared to earlier recruitment methods, attracting an older group of men who described themselves as having significant co-morbidity.

As the only female participant in group two, C7 responded to same Facebook advertisement as participants in the first group. At the time, she identified this educational research as a form of advocacy work that sought to challenge current representations of PWD. She went on to explain that her motivation to participate in the research originated from her awe of personalities within the online diabetes advocacy community, mostly featuring persons with T1DM in North America. For C7, she saw the research's aims as being congruent with her own small-scale project of dismantling some of the fear associated with diabetes.

I always feel like I'm teaching people about living with diabetes and that it's not a horrible thing, and that you can live well ... That as long as you can manage yourself, and a lot of people talk about managing it but it's more - in my case, managing myself and saying no to another cookie, which I don't really actually want but the first one was good. Just try to learn all that you can about it, because the more that you learn about it the less it - the less you have to fear. Because a lot of people are like, oh yeah, that's scary, you can never have sugar again. Bullshit. (C7 – 6m post-group interview)

## **Implementation of the educational program**

In group two, C6 and C8 completed all research activities in their intended form, including individual interviews, group sessions, and reflective journaling. Case 5 participated in all of these activities with the exception of session two, in which he participated in a telephone discussion of his critical incident with me as the educator. Also participating in a telephone discussion with me in session two, C7 suspended her participation in the research following completion of session two. Despite her absence from later group sessions, she agreed to participate in the final 6m post-group interview.

Compared with group one, issues related to behaviour management featured prominently within most sessions for group two. Even within session one, it became clear that C5 (and to a lesser extent C8) had entered the group with a firm sense that there existed certain truths about diabetes and PWD and that he had a role in communicating these truths to others within the group. Given the early identification of concerns with C5's behaviour, reflected in pre-interview memos and the formative assessment of session one, I spoke individually with C5 between sessions one and two, discussing how his behaviour (i.e., interrupting others and forcefully communicating claims about diabetes and PWD) was problematic given the aims and norms of the group. In the remaining sessions, the facilitation of the sessions was modified to support a more structured turn-taking behaviour, which allowed each participant to contribute without fear of interruption. As the following discussion illustrates, my role as facilitator within these sessions focused heavily on creating a safe and suitable environment for critical dialogue (what Fitzpatrick and Allen (2019) refer to as an environment building role). Throughout the formative assessments, I noted how my pre-occupation with creating a suitable learning environment detracted from my ability to exercise the more playful and critical embodied style that I performed at different points in the first group. Furthermore, the reticence of participants to engage with ideas around the relativity of knowledge made communication difficult when dealing with critical topics or deconstructing issues of power.

### ***Session one***

Following my explanation of diabetes-related stigma and critical reflection in the first session, I struggled to identify exactly how participants received the explanation. When invited to contribute their thoughts about the explained content, participants sought to re-iterate the narratives and experiences described within the pre-group interviews, lacking specific reference back to the concepts or ideas presented in the preceding summary. Additionally, I felt that the session struggled to reduce or manage anxieties related to group participation. Early within the group, C5 was observed to frequently interrupt other participants as he sought to explain or account for the observations and claims being presented by others. As an experienced group facilitator in healthcare and public health settings, I had frequently encountered this type of group behaviour and recognised it to be destructive to group learning. Drawing on these past experiences, I stepped in early to manage these interruptions given concerns that they might generate hostility within the group. Within the first session, I was observed to use re-directions and summaries to manage these interruptions, although I concluded in the formative assessment that I should have intervened earlier and more explicitly to establish ground rules relating to C5's unacceptable behaviour. Following on from my assessment, I did arrange of telephone call with C5 shortly after the session to discuss these issues in private and suggest ways of behaving that were consistent with the established group norms.

### ***Session two***

In preparing for session two, I was very aware of the need to create a safe environment for reflection and to address some of the issues identified in the previous session. Therefore, my strategy for

session two was to adhere to a close discussion of the presented critical incidents (thus focusing on the study of critical topics) whilst trying to limit the extent to which participants might address unrelated issues or re-iterate former experiences without further critique.

All but one participant (C5 being an exception) presented their critical incident using the format provided in the study workbook (see Appendix 5). Presentation of their critical incident was performed in an entertaining storytelling style and with a degree of spontaneity by C7 (via phone discussion) and C8, whereas C6 attempted to read off his notes, which led to a disjointed and difficult to understand account of his incident. Case 5 (via phone discussion) used the opportunity to present an incident taken from his pre-group interview, offering an account of the activity without further critique. By presenting their incidents, participants appeared to be providing a fairly matter-of-fact account of their experience and actions.

Within the group, the matter-of-factness of these accounts appeared to discourage deliberation and critique amongst other participants, which led to me taking a more active role in modelling how participants might examine these incidents. This modelling was similar to the approach taken in session two for the first group; however, I was much more involved in this process for the second group. The low number of participants attending the group in person (C6 and C8) also impacted negatively on the quality and range of responses to the presented incidents, instigating a more active involvement on my part. The incidents presented by C6 and C8 also seemed to be relatively uninteresting or peripheral to the stigma concept, contrasting the rich experiences of stigmatisation described in their pre-group interviews. With more relevant incidents, the deliberative process may have turned out differently, both in relation of inviting more relevant questions from others and creating enthusiasm about the relevance of stigma to PWD. I also noted in the formative assessment a feeling of closed selfhood amongst participants, where illness was understood as an individual rather than social phenomenon. The one exception was C7, who provided an interesting critique of the way that PWD function to maintain and enforce moral codes of self-care. Unfortunately, C7 left the group at this stage following the death of a family member, leaving only three participants to continue with the group program.

Within my formative assessment, I felt that the next session would benefit from a more focused discussion on stigma-related processes, trying to minimise distractions relating to talk of self-management regimes. Important themes that had begun to emerge included the fear of being excluded from food-related rituals, the internalisation of moral codes of conduct, shifts in responsibility for diabetes self-care onto PWD, and the powerful influence of medical knowledges about PWD.

### ***Session three***

Session three offered participants the opportunity to suggest alternative ways of thinking about PWD, using the critical incidents described in the previous session to identify alternative ways of thinking about and responding to specific stigmatising events. Following an explanation of the exercise, participants were in turn invited to reflect on their critical incidents. A difficulty emerged in facilitating the session when participants increasingly used their critical incidents to validate their original interpretations and courses of action in response to the incident. Suggested changes were generally minor and involved small scale personal projects such as better educating oneself about diabetes management so to help others avoid developing diabetes-related complications (C5) and being more empathetic towards others that are overweight-obese, struggle with diabetes management, or struggle to maintain a positive sense of self (C6 and C8). There was a building narrative within this group that diabetes-related stigma is a problem that belongs to someone else, which was a narrative that supported and took-for-granted personal projects designed to alleviate the suffering of others. Other than this central narrative, there was limited evidence that members were actively listening and responding to the contributions of others, with the exception of a couple of instances where C8 reflected on the points raised by C5.

Consequently, I felt like the group was losing touch with the central aim of the research, which was to develop a critique of the way that stigmatised identities are formed and maintained. During this session, I was either trying to manage issues of dominance within the group (primarily involving C5) or to redirect the discussion back to concepts related to stigma. Case 8 certainly picked up on this lack of clarity when, towards the end of the session, he noted that the group had deviated from a discussion of diabetes-related stigma. Again, participants appeared to struggle with a critique of their incidents given that these incidents were unclear examples of stigmatisation. At this stage, I felt that the Forum Theatre activity in the following session might offer clearer and more evocative examples of stigmatisation for participants to examine and critique. Reflected in my formative assessment, I hoped that these new texts might re-align group discussion with the intended aims of the education program.

#### **Session four**

In preparing for session four, I spent considerable time reviewing field notes and pre-group interviews to identify suitable themes and interactions from which to construct two theatrical acts. I felt that the success of this session would largely depend on how *clearly* the learning material might relate ideas about diabetes-related disability, self-care, and weight-stigma (as raised within the group and interviews) to everyday practices encountered by participants. Given these considerations, I constructed two theatrical acts, one involving interaction between a primary care physician and PWD within a primary care practice and the other acting out a morning tea involving several participants from a senior citizens group.

After explaining the purpose of the Forum Theatre activity and completing act one in its original form, participants were invited to critique and re-create the exchange in a subsequent performance. Like for group one, participants in group two preferred to offer critique rather than perform or act out the changes themselves. A defining feature of the group was the tension (more passive aggressive than overt) between C5 and C8. In attempting to avoid open conflict, I noticed that these participants tended to present their contributions to me as the facilitator, rather than to other participants within the group. There was also limited deliberation occurring within the groups, with C5 and C8 appearing to read into the acts thematic ideas around the tragedy of diabetes (for C5) and more positive features of living with diabetes (for C8). Case 5 also continued to raise issues related to diabetes self-management, which occurred despite frequent attempts by me and C8 to refocus discussion back onto the issue of diabetes-related stigma. The continued drift towards issues of self-management made it difficult to maintain a focused discussion. This drift was particularly noticeable within act one, which focused on interactions occurring between the PWD and primary care physician. Case 5 tended to focus on what clinical parameters and management strategies were most appropriate, which avoided the more relevant issue of how medical knowledges about PWD were used and privileged within the interaction.

The observation that there were no 'stop' points within either of the acts suggested that the participants generally approved of the strategies used by the fictional characters in response to the stigmatising event, representing either avoidant or passive responses to stigmatisation. At the end of the session, I felt that rather than re-invigorate a critique of the production of stigmatised identities, the session provided another forum for participants to assert certain representations of PWD in the face of what they perceived to be misrepresentation. For C5, his grievance was with PWD failing to see themselves as moral agents inhabiting a vulnerable body, whereas C8's grievance involved the misrepresentation of PWD as sufferers and victims of personal tragedy. In light of these observations, I was interested in how these ideas might be communicated within the final session, in which participants are asked to reflect on their learning through the group program.

### ***Session five***

The final session was intended to support participants to reflect on the learning that occurred over the course of their participation in the research. The session was delivered in a similar way to group one, where I provided an overview of the model of critical reflection and the learning activities used over the previous four weeks. I then posed questions to participants at specific points throughout this overview so to help structure their reflection on learning. Case 8 appeared to follow this aim most closely, describing how participation in the group contributed to a realisation that he and other PWD need to be more empathetic towards other PWD and be more attentive to the different perspectives through which others view their diabetes (in later interviews, he would refer to the role

that C5 played in facilitating this learning as someone that was intolerant towards alternative perspectives). Alternatively, C5 tended to re-emphasise points made earlier within the group program and during the pre-group interview, with no explicit reflection on processes of learning. Case 6 volunteered limited discussion during this session and typically did so only after being invited to contribute. Aside from C8 claiming that he intended to be more empathetic towards other PWD, there was no evidence that any participant was planning on incorporating any learnings into broader projects of stigma reduction. Participants appeared to listen attentively to my discussion of opportunities for future advocacy work; however, none provided any comment in relation to these opportunities.

This group certainly wasn't cohesive, so it seemed that there was no real need for closure, at least in relation to personal bonds that may have formed over the course of the group. I perceived that participants may have been relieved to have finished the group, particularly given the tension between C5 and C8 and C6's reticence towards open participation. Prior to this session, I was concerned that C5 and C8 might be more forthcoming with their feelings or thoughts towards one another. I felt that this contributed to me being reasonably structured in my facilitation style, asking questions and providing participants with the opportunity to answer the question before progressing to the next question. While my approach may have acted to limit opportunity for dialogue, interactions occurring over the past four sessions provided evidence that such dialogue was unlikely to occur spontaneously.

### ***Journal writing***

Although most participants (C5, C6, and C8) attempted to maintain a reflective journal, the content of these journal entries were often very brief and made little reference to specific events and learning occurring within the group. For C6, journal entries were completed after sessions one and four, functioning as a repository of key ideas collected over the group sessions. While C5 tried to follow the semi-structured journaling guide more closely, the precise content and meaning of these entries were difficult to interpret given the brevity of writing. Take for example the following entry produced by C5 following the first session.

**Question:** Describe in detail what you learned from this session?

**Response:** 1. There is still an enourmose amount of missinformation [sic] or lack of information that needs to be changed.

**Question:** what might have contributed to this learning? E.g. was there anything that triggered this learning; how did interactions with other group members or the researcher contribute to this learning; and how has my own past experiences influenced this learning?

**Response:** 1. Nothing and everything. 2. Just as expected, everyone needs it to work but without the practicle [sic] experience it must be very difficult. 3. Greatly. (C5 – reflective journal – session 1)



Maintaining a detailed journal after each session, C8 used the reflective journals in a manner more consistent with its intended use. His journal entries built on an emerging theme of the role of self-stigma. Specifically, his interactions with C5 featured prominently within these journal entries, providing evidence of a 'self-stigmatising group of diabetics' (C8 – reflective journal – session 3). In later journal entries, he made reference to his 'psychological immune system' (C8 – reflective journal – session 4) and how this functioned to help him maintain a positive sense of self despite a fear of diabetes-related complications and a concern with being regarded as 'inferior' by others because of his diabetes. His journal entries closely reflected the content of discussion raised within the group sessions, suggesting that he was using the journal to help guide his thinking for later sessions.

### **Interactions between participants and learning activities**

Given his absence from session two, C5's critical incident was discussed with me as educator via telephone. Drawing from an event described in his pre-group interview, C5 recounted how his general practitioner (GP) reacted angrily (i.e., he went 'ballistic') to his blood glucose level of 27mmol/l, threatening to revoke his licence unless he returned to the medical clinic for review later that day. Following questioning by the educator, C5 surmised that this GP's reaction was based on assumptions about his lack of responsibility for his diabetes, itself seen as evident because of his excessive weight. He then went on to describe how this doctor would continue to attribute other medical complaints to his diabetes and his weight, and that the GP was able to do so because 'he went to university' and possessed expert status given his specialist knowledge. For C5, this privileging of expert knowledge had the effect of discounting his knowledge of diabetes and self-management strategies that worked for him. In session three, C5 presented his critical incident again, relating this incident to the feeling of being controlled and threatened. He claimed that this coercion led to him losing a large amount of weight following his diabetes diagnosis. On being asked what he would do differently if he encountered the same issue again, he broadly claimed that he would devote more time to educating himself about diabetes, without specifying the exact content or purpose of this self-education and precisely how self-education would function to address processes involved in stigmatisation. He also raised similar issues in the forum theatre activity within session four, which featured an act involving a medical consult between a PWD and his GP. Although not relevant to the script in this act, he again raised the issue of his own GP threatening to take away his licence if he did not comply with their rules<sup>12</sup>. Ironically, although C5 began with an incident reflecting his concerns with the blame applied to PWD in relation to self-care behaviours, he

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<sup>12</sup> This refers to historical general practice guidelines that required persons with diabetes to maintain a HbA1c below 9% in order to maintain their drivers licence. Although participants in this research believed that the guideline was still current, the guideline was revised in Australia in 2016. Rather than focusing on HbA1c as a criterion for fitness to drive, the focus now is on major safety risks that include hypoglycaemia and end organ effects such as impaired vision (Austroads & National Transport Commission Australia 2016).

appeared to engage in a project of blaming other PWD for inadequate self-care, a project that became particularly pronounced in the latter half of the group program.

Likely reflective of his lower DSAS-2 score relative to most other participants in this research, C6 presented an appropriate incident but struggled to identify how his incident might contribute to stigmatisation. In his incident, he described visiting a friend in hospital where he was told that nursing staff no longer placed a sign reading 'diabetic' above the patient's bed and that PWD were no longer offered a special 'diabetic diet'. Following further group discussion and questioning, he noted the prominence of self-education in contemporary diabetes care, with responsibility for tasks of self-management increasingly being placed on PWD within a hospital setting. In this session, I noted that C6 rarely engaged in improvised or spontaneous discussion, but rather preferred to follow the guide contained within the program workbook. In session three, he suggested that his incident wasn't a great example of his experience of stigmatisation, presenting a second incident in this session that involved interaction with a stranger experiencing diabetes-related hypoglycaemia but who appeared drunk at the time. Reflecting on his incident, he suggested that in the future, he will try to pause and reflect on his own biases before 'pre-judging'. At this point, he presented a rather confusing narrative regarding how he might respond if someone asked him about his diabetes, claiming that he would say 'bugger off and go and read a book about it'. He also claimed that he would tend to avoid persons that are 'negative or stigmatise' and focus on trying to 'feel better' about himself. Although C6 only participated in a limited way within the forum theatre activity in session four, he did contribute content regarding the way that healthcare services have become less personalised over time, contributing to an increasing reliance on stereotypes to inform clinical decision-making at the neglect of eliciting and responding to the patient narrative.

Interestingly, C7's critical incident focused on the way that C5's utterances about the importance of dietary self-restraint infiltrated her own thinking about responsibility for diabetes self-care. During her grocery shopping, she described how she began to feel guilty for choosing certain foods and fearful that she might encounter C5 or other participants in the group, who she imagined would look into her trolley to evaluate her food choices. Following further discussion regarding the incident, she claimed that this sense of guilt was the result of feeling evaluated against an unattainable gold standard of diabetes management, which contributed to the construction of dualisms of good and bad forms of self-management. Reflecting further, she suggests her thinking has its origin in historical forms of dietary education, based on dietary guidelines that implicitly suggest that there are good and bad foods. Although she dropped out of the group program at this point, she demonstrated further evidence of reflection on this incident in her interview six months following the group.

People are a lot kinder than what we give them credit for, I think. And a lot of people probably don't even think, "She's diabetic, she shouldn't have that". Whereas some people who are kind of locked in with this, they get that mindset. Then it makes you feel self-conscious. I had that when I left here after one of the sessions and went grocery shopping. I kept thinking I was

going to run into one of the other participants and have my cart judged by them. I think it's not just other people. Some of the stigma is what other diabetics give other diabetics. I don't remember anything directly being said, but it was Mr Know-It-All-Talk-It-All. Yeah. But it was odd to have that feeling at the grocery store. (C7 – 6m post-group interview)

The critical incident chosen by C8 occurred in the context of a party and involved him rejecting an offer of an alcoholic drink for reasons unrelated to diabetes. To his annoyance, the offerer responded to this rejection by saying 'that's right you can't have it because you're diabetic'. After some exploration and discussion of the incident by the educator and C6, C8 suggests that in the context of social rituals involving eating and drinking, it is better to justify non-participation for reasons other than diabetes or otherwise risk opening up what he describes as 'Pandora's box'. By opening up Pandora's box, he meant that others will treat him as if diabetes were a master status, raise questions about his diabetes status, and/or treat him differently in the future as a PWD. He reasoned that others knowing about his diabetes will contribute to what he refers to a sense of 'superiority' where others feel that they can do things that he can't. He explicitly stated that there exists assumptions about how PWD should behave, rejecting the truth of this assumption on the basis that 'you can't generalise how people have to look after their diabetes'. In the forum theatre activity in session 4, C8 played a lead role in identifying assumptions contained within the script of act one, which involved interaction between a PWD (as patient) and his general practitioner. He identified the way that assumptions made about the weight-pathology relationship were informing diabetes care decisions and the way in which the interaction produced feelings of shame regarding the sick body. Following his analysis of this interaction, he claims that 'you need to do something so you don't have to leave the doctor's office feeling self-stigmatised'. And in act two, which involved acts of dietary segregation, he returned to the idea that PWD are subject to evaluation against a tacit code of conduct. In both acts however, C8 was unable to identify alternative courses of action.

### **Interaction between participants**

Participant interactions within group two were very different to those that occurred in group one. Specifically, C5 had quite a strong influence on the way that other participants engaged with learning activities, how they interacted with one another, and how discussion was facilitated within the group. This influence was felt in two main ways by participants and myself as educator. Firstly, C5 tended to stifle dialogue through frequent interruptions of other participants (albeit less so in later sessions due to educator intervention) and the declaration of infallible truths about diabetes, PWD, and diabetes management. The effect of C5's behaviour on group function was well summarised by C6 in the post-group interview.

C6: When you listen you should be a good listener and listen to who – you brought the subject up, you should listen to what they say, instead of you imparting your knowledge. And that was what the whole course was about. It's mainly dealing with questions, you know, listen to their problems rather than you say, well, I think you shouldn't worry about that, listen about it.

I: How do you think listening played out in the group?

C6: Oh, C5 and the other chappie [C8] he handled it very well – ‘I’d like to finish, please’. And then C5 would understand ... C5 wasn’t a good listener. C8 was listening to everyone, you know, I thought he did. And he had some good points too. Very good. C5 wasn’t a good listener. He was thinking about his own idea and then saying it, even if he cut you off. And C8 used to – I don’t think he got cross with him, but he said, “I’d like to finish, please.” And then C5 would say, “Oh, that’s”. And C8 was a formal chairperson in various groups so I think he knew how to conduct himself and to hold the stage. (C6 – post-group interview)

His self-proclaimed credentials for offering such advice was that he was 'one of the survivors. I'm one of the guys who got through' (C5 – 6m post-group interview), referring to the reformation of what he regarded as his past transgressions of poor diet, inactivity, and obesity. At times, his narratives around the reformation of self-care also meant that C5 redirected focus away from processes relevant to stigmatisation towards matters of diabetes self-management, which disrupted broader narratives related to stigmatisation. As C8 remarked in sessions three and five, this meant that the discussion at times failed to address matters relevant to their experience of stigmatisation. There was clear push-back by C8 in response to C5’s behaviour, who tried to enforce group norms by talking through C5’s interruptions or asking if he could be allowed to finish. Although not culminating in openly disrespectful behaviour or conflict, frequent interruptions by C5 led to a rather tense relationship between C5 and C8, which added a slightly competitive and aggressive edge to learning activities in a way that detracted from creation of an environment suitable for dialogue. The crux of the tension involved matters of representations of diabetes and PWD, where C5 was acting to represent diabetes as a master status (informed by strict obligations for self-management), whereas C8 was seeking to represent diabetes as a peripheral aspect of his identity.

This conflict between C5 and C8 led to a tussle for dominance that overshadowed the more passive stances adopted by C6 and C7. In the context of a facilitated process of turn-taking, C6 would participate in contributing content when offered dedicated time to do so, but otherwise contributed little to the discussion. As C8 suggested in the post-group interview, ‘He didn’t say much. He was sort of - I think he found it hard to get involved.’ From my perspective as educator, the questions and comments raised by C6 in response to group dialogue had an obligated feel, as if he should contribute content rather than personally seeing the value of doing so. Accordingly, his contributions were often tangential to the meaning of preceding discussion, acting unintentionally to interrupt and re-direct discussion away from matters of stigmatisation. When he did ask a question, he appeared to follow ideas contained within the question guide (Appendix 5), which meant that sometimes his comments or questions failed to closely relate to the content of the speaker’s story. Although only present in person for the first session, C7 also expressed after the group that she felt somewhat ‘marginalised’ within the group as the sole female participant amongst a cohort of older men. In the 6m post-group interview, she stressed how C5 (or ‘Mr-Know-It-All-Talk-It-All’) in the first group created an environment where she felt that she was being judged or evaluated, that is ‘I really kind of felt like, particularly the man next to me [C5] was more of a judger - he not only judged himself but he also judged other diabetics.’ (C7 – 6m post-group interview).

## **Interactions between participants and the doctoral candidate**

Participants within the first group maintained a curious interest in me as a researcher and adopted a stance where both the researcher and participant were learners examining the issue of diabetes-related stigma. In group two, there were very different relationships occurring between the researcher-educator and participants. For C5 and C8, their role was that of the expert, with the researcher assumed to be a relatively naïve instrument through which to record their experiences. Despite regarding both as challenging participants and learners, I feel I had developed a high level of rapport with C5 and C8, largely motivated by the early identification of these individuals as likely to contribute to issues of dominance. This rapport was helpful as it allowed me to be relatively blunt in identifying and correcting unhelpful behaviour occurring within the group whilst avoiding defensive reactions. I also had a high level of rapport with C7; however, this rapport was driven more by our sense of shared purpose to improve the status of PWD, something that she identified with given her past exposure to diabetes advocacy groups. The effect of this rapport was that I felt that I could trust her to participate authentically in the learning activities and with other participants, contrasting my sense of distrust regarding the motives of other participants in group two. In contrast to C5 and C8, C6 perceived himself to be naïve regarding issues of stigmatisation, often asking me whether his interpretation of a certain situation or experience was correct. For example, after providing an interpretation of the vignette used in the pre-group interview, he asks 'is that the right answer?' Over the course of his participation in the research, we maintained a fairly formal researcher-participant relationship, which meant that it was often difficult to access more private accounts of his experience relating to his diabetes and stigmatisation.

As previously discussed, conflict occurring within this group contributed to a facilitation style that emphasised turn taking (introduced in session two and maintained throughout later sessions) in order to ensure participants were able to contribute to the discussion without fear of interruption or correction. This facilitation style reflected a broader concern with behaviour management and the enforcement of group norms, which acted to detract from a focus on learning and the critique of ideas. As a result of this challenging behaviour, discussion would frequently wander from the purpose and scope of each learning activity, requiring me to truncate participant narratives and re-direct discussion by either acknowledging this deviance or by employing facilitation strategies of summaries and re-directive questions. However, at times I felt this approach risked participants feeling that their contribution was 'wrong' or that there were implicit expectations regarding appropriate answers or ways of answering the questions that were posed. The following memo, containing a formative assessment of learning and facilitation in session four, illustrates some of the frustration experienced by myself in managing this tension, which I saw as detracting from learning.

I felt like this session was largely an exercise in re-directing focus back on the topic of stigma and managing group behaviour ... As a consequence of issues of dominant behaviour, I tended to enforce turn-taking behaviour quite strongly, which I felt came across a little heavy handed at times and itself acted as a barrier to dialogue. I feel that I've reached a low point in

this group with respect to their ability to think critically about their experiences with diabetes, not necessarily because they aren't capable but because they appear preoccupied with asserting (as truth) their representations of diabetes and PWD within the group, largely build on ideas about responsible self-care, which is done in the face of what they see to be erroneous competing representations. (Formative assessment – session 4)

In summary, this chapter has offered insight into the conduct of this educational case study research along two main lines: who were the learners (or cases) and what were the prominent features of their participation in the educational research. In writing this chapter, I was cognisant of the way that the reporting of critical education work in public health contexts (as observed in Chapter 4) frequently involve grand and universalising claims about learning, claims that appear out-of-step with the challenges involved in the critique of hegemonic or taken-for-granted knowledges. Therefore, this chapter functions within this thesis to lay bare the messy and complex process of education and learning, as observed within this research. Drawing upon a meta-theory of critical realism to help make sense of this complexity, the follow chapters explain how features of learning, education, and knowledge work together to shape discursive representations of PWD and diabetes-related stigma.

## 8. REPRESENTING PERSONS WITH DIABETES: RELATING THE SELF TO THE STIGMATISED OTHER

This chapter draws on an analysis of how PWD were represented by participants in this research, how these representations changed over time, and how these changes might be explained. Through this analysis, an interesting finding emerged that challenged existing ideas about precisely who is stigmatised. In this chapter, I make the argument that the construction of the tragic-disabled *Other*<sup>13</sup>, largely symbolised by the amputated or ulcerated leg, functions as the cornerstone of diabetes-related stigma. It is with reference to this cornerstone that the construction of related *irresponsible* and *obese*<sup>14</sup> sub-groups of PWD occurs. This othering of tragic-disabled, irresponsible, and obese sub-groups of PWD emerges from a medicalised understanding of the 'diabetic' body as inherently risky and vulnerable to a natural history of decay, recognising that diabetes has undergone a historical transition from an acute life-limiting illness to one that can potentially be managed through medical treatment and self-management (Feudtner 2003). This process of othering, which is dependent on taken-for-granted medicalised understandings of the 'diabetic' body and their role as responsible citizens, allowed most participants in this research to re-cast themselves as 'normal' in comparison to the stigmatised Other. This chapter develops the idea that future stigma-reduction work would benefit from a more specific examination of the process of othering and its role in eliciting the moral concepts used to stigmatise. However, being cognisant of the moral concepts used to stigmatise is in itself insufficient to promote a further critical analysis of stigmatisation. In fact, the opposite was true for most participants in this doctoral research. For these participants, participation in the educational program functioned to elicit moral concepts that were then used to legitimise the inferior status and poorer treatment of the stigmatised Other, truncating a further critical analysis of diabetes-related stigma. Rather, the ability to contest the concepts used to stigmatise, spurred on by a sense of unfairness and moral outrage, allowed for further dialogue regarding the production of the stigmatised Other.

In this chapter, I start by firstly identifying how PWD were discursively represented by participants in this research and how these representations changed over the course of the research. For most participants, these representations functioned to differentiate between the 'normal' self and tragic-disabled, irresponsible, and/or obese Other. Interestingly, these representations mostly remained

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<sup>13</sup> A theoretical examination and clarification of the Self-Other distinction is provided on pp.121-123. In capitalising the 'O' in Other, I am referring simultaneously to categories of PWD who are made different and the practice of objectification via dominant ideological frameworks. This approach differs from a Lacanian-inspired convention within post-colonial studies that distinguishes between the other (as a colonised person) and Other (as the empire and the imperial discourse through which the subject attains a sense of self) (Ashcroft, Griffiths & Tiffin 2013, p. 187). Despite referring to specific sub-groups of PWD in this analysis, my use of the term 'Other' seeks to avoid tying down PWD to certain categories. Rather, the intended focus is on how participants discursively construct these categories and how these discourses are ideologically conditioned.

<sup>14</sup> In this chapter, use of the term 'obese' reflects the language used by participants to describe fatness.

static over the course of the research, with some minor exceptions. By comparing the learning of participants that did and did not demonstrate such change, it appeared that discursive changes seeking to reconcile the relationship between Self and Other could be explained by the way that these participants drew on alternative concepts (here, in relation to the fat body) to contest the fairness of applying certain moral concepts to PWD. This analysis is appropriately placed within this findings section, as being able to identify exactly who is stigmatised (eliciting salient moral concepts and concepts about the nature of the body) and recognising stigmatisation as being unfair were observed as important antecedents for sustaining a critical dialogue. As is thematic throughout these findings chapters, critical dialogue always rests on tenuous ground in the face of an omnipresent medicalised and moralised risk discourse, which is drawn upon to sustain stigmatisation.

## **Discursive representations of persons with diabetes: relating the Self and Other**

A noticeable sore point for several participants in this doctoral research was the idea that PWD as a united group are stigmatised (C6, C7, and C8) or that they as individuals possess a stigmatised identity (C3, C5, C6, C7, and C8). At first, this observation appears odd given that participants entered this research with experiences of stigmatisation and scored sufficiently high on the DSAS-2 to indicate a 'potentially problematic perceived and experienced diabetes stigma' (Browne et al. 2016, p. 2145). However, this apparent contradiction makes sense when read in the context of changes in representations of PWD amongst participants that functioned to distance participants' own sense of self from the stigmatised Other. As illustrated in Table 10 (p.122), representations of PWD coalesced around categories or sub-groups of PWD seen as particularly detestable: those with advanced diabetes-related complications, those deemed to possess irresponsible characters<sup>15</sup>, and those that are obese. Othering played out amongst participants in this research through changes in representations of PWD as members of a relatively homogenous group to increasingly differentiated forms of representation. The term 'differentiation' here is taken directly from C8's reflection on the stigma concept, evident within the following interview excerpt.

C8: To me it's not a stigma. So differentiation, that's a much better word.

I: Differentiation. Are you able to elaborate on what you mean by differentiation and why it's a better word?

C8: We differentiate between people. You meet people – all right, I go into a group and say look, are you a – they're all diabetics there. Some of them, they're over the top. She is in that class there. I look at – oh, there's one. She's in that class there, because she is over 80, over in those. And she is obese. Not because she's diabetic – she's not diabetic fortunately. But if there is a diabetic who is obese and eats all the wrong stuff, that's in that area there. And that's how I differentiate. People who are serious about being a diabetic, but they keep that to them – well, you know, they sort of don't wear a flag and say I'm a diabetic. They don't

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<sup>15</sup> Here, the focus was on the enduring dispositions or character traits of 'irresponsible' PWD, which were observed via the fleeting practices of inappropriate self-care by these 'irresponsible' persons. In this way, inappropriate self-care behaviours are taken to be subjectively informative of irresponsible moral character (Uhlmann, Pizarro & Diermeier 2015).



broadcast the fact. So to separate them, that area there, where they get on with their lives.  
(C8 – 6m post-group interview)

As can be observed in Table 10, participants either entered the research with a developed sense of this form of identity thinking, or developed such identity thinking during the course of the research. As it is used here, the term ‘identity thinking’ draws on Adorno’s idea that such thinking is a distortion of experience, whereby the subject comes to fully identify objects through the ideological concepts that are applied to them (O’Connor 2012). Although alternative social psychological terms such as stereotyping might also be drawn upon as a label for this process, Adorno’s critical theory orientation and his work in relating identity thinking to capitalist market principles and attempts to overcome nature (Gunderson 2020) have special relevance to the theoretical orientation of this research and to diabetes-related stigma, a point that is developed later in this chapter. What is apparent from the content and function of the discursive representations of PWD in Table 10 is that this identity thinking led to the articulation of certain categories of PWD that were *Other* to the ‘normal’ *self*. For each participant in this research, ideas about the self (or *true* self for C2) in relation to diabetes emerged from understandings of what one is not – i.e., the Other. This othering was particularly evident in the way that participants responded to the interview question: ‘how do you see yourself as a person with diabetes?’ Here, attempts to articulate one’s sense of self were made largely with reference to the stigmatised Other, characterised by their bodily deformity and irresponsible dispositions. The way in which participants contrasted ideas about oneself in relation to the stigmatised Other is well illustrated in the interview excerpts provided below.

Interviewer: Can you describe to me how you see yourself as a person with diabetes?

C6: I see myself ... this other person I know who had chronic diabetes he said to me, “I always check my extremities, so I don’t get sores, you know, because they don’t heal.” Now I always thought, you know, I check in places that I haven’t got something coming up, you know, with too much sugar and that’s the only thing that worries me because I’m very conscious of that and I haven’t got, sort of, boil things coming up on the neck and face, and other places.(C6 – post-group interview)

Interviewer: Can you describe to me how you see yourself as a person with diabetes?

C5: Human being, and that’s all I can describe myself as. I’m not different. My mother – you’re talking about bad diabetes – if you stick your finger in the fire you are going to get a burnt finger, and whose bloody fault that she stuck the bloody finger in the fire in the first place? It’s not the bloody fire. It’s nobody else’s finger, it’s your finger, your control. Diabetes is exactly the same. If you don’t listen and do as you’re bleeding told it’s going to kill you, and if you’re really lucky you will die, because if you aren’t the end is not a pretty sight, believe me. My grandmother was a diabetic and you couldn’t tell my grandmother anything. When I was growing up she would have weighed 15 or 16 stone, when she died she weighed six stone minus. My mother, when she would have been in the 16 stone range easily; [my wife] used to take her shopping and she’d come home with kilos and kilos of lollies and chocolates and it wasn’t the kilos of chocolates, it was the diabetes that was at fault – oh fuck off. (C5 – pre-group interview)

Therefore, participants' sense of themselves were intimately tied to their membership of a 'normal' dominant majority of 'health promoting' and 'responsible' PWD. Table 10 provides evidence for this claim, illustrating how representations of the self and of 'normal' PWD failed to exist outside of the shadow of the Other. Before examining how othering was achieved discursively by participants in this research, a brief overview of theory related to the Other and how such theory relates to the stigma concept is warranted.

Fundamentally, stigma and othering are ways of conceptualising reactions to human difference. However, the concept of othering and the distinction between self and Other contains important theoretical assumptions that have tended to be glossed over within theorising about stigma and hold special relevance to the narratives of participants in this research. Despite frequent references to processes of othering in health-related stigma literature (for example, Deacon 2006; Hatzenbuehler, Phelan & Link 2013; Ranjbar, McKinlay & McVittie 2016; Van Breda 2012), few arguments have been presented for why concepts relating to the Other (also othering or otherness) are being drawn upon and how this othering might relate to the non-stigmatised self. One notable exception is Lupton (1998), who draws from psychoanalytic theory in claiming that othering functions as an unconscious defence mechanism to help people manage negative feelings that is likely to be destructive to the self. This would include feelings such as anxiety and fear, feelings that are more likely to present themselves amongst PWD compared to the general population (Kuniss et al. 2019; Smith et al. 2013). These defence mechanisms then function to transfer these unacceptable aspects of the self onto others, who are then regarded as 'bad' and not us. For Lupton (2013b), this process of othering becomes particularly salient in contexts of health-related risks and where there is a crossing of culturally-defined bodily boundaries. This symbolic perspective, reflecting the work of Mary Douglas (1966), suggests that risk plays an important role in helping individuals maintain a coherent sense of their world by maintaining boundaries between 'us' and 'them'. This idea assumes a more critical edge when interpreted through the lens of post-colonial theory, which asserts that the process of othering can only be understood in contexts of power and dominance, which give rise to essentialised knowledge about the Other (Ashcroft, Griffiths & Tiffin 2013; Varisco 2007). In this context, the Other functions to provide 'the terms in which the colonized subject gains a sense of his or her identity as somehow 'other'' and becomes 'the ideological framework in which the colonized subject may come to understand the world' (Ashcroft, Griffiths & Tiffin 2013, p. 187). In this way, othering emerges from ideologically conditioned ways of knowing, which to some extent forces conformity onto the Other.

**Table 10. Changes in representations of persons with diabetes (PWD)**

Representations of PWD	Case							
	1	2	3	4	5	6	7	8
There exists a sub-group of irresponsible PWD	Emphasised following research participation	Maintained to be true	Emphasised following research participation	Maintained to be true	Emphasised following research participation	Maintained to be true	Maintained to be true	Emphasised following research participation
There exists a detestable sub-group of obese PWD	Maintained rejection of the truth of this	Maintained to be true	Emphasised following research participation	Maintained to be true	Emphasised following research participation	Emphasised following research participation	Maintained rejection of the truth of this	Emphasised following research participation
Persons with diabetes-related complications as detestable	Not evident in the data	Maintained to be true	Maintained to be true	Maintained to be true	Emphasised following research participation	Maintained to be true	Not evident in the data	Not evident in the data
There exists a sub-group of PWD who responsibly manage their diabetes	Emphasised following research participation	Emphasised following research participation	Maintained to be true	Maintained to be true	Maintained to be true	Maintained to be true	Emphasised following research participation	Maintained to be true

Within this thesis, a post-colonial interpretation of the 'Other' is privileged when talking about the 'stigmatised Other'. This theoretical orientation is justified firstly by the critically-oriented aims of this doctoral research, which like post-colonial studies seek to challenge hegemonic ways of understanding oneself and others (Ashcroft, Griffiths & Tiffin 2013). Secondly, the experience of living with chronic illness reflects a Habermasian 'colonisation' of the 'lifeworld' by social systems (Fredriksen 2003; Scambler & Scambler 2010), whereby open debate or communication about illness is stifled by strategic actions (led by bureaucratic power and/or market mechanisms) that come to dominate how individuals think or act in relation to illness. It is in this context that health-related social movements emerge, with these movements engaging in projects of lifeworld de-colonisation (Scambler & Kelleher 2006). Putting these two things together, a post-colonial understanding of the 'Other' offers insight into how social systems (elaborated on within Chapter 11) provide an ideological framework that condition ways of knowing about PWD. However, a symbolic perspective also offers insight into how this lifeworld colonisation is maintained.

Categories of otherness described by participants in this research closely followed a logic of risk management. However, the ultimate aim of this risk management was to avoid encountering 'disgusting' bodily states of obesity and amputation. Throughout the analytical process, it was the recurrent narrative of the disgusting nature of obesity and diabetes-related complications and the medically-defined at-risk body that initially drew attention to theory relating to the Other. Take the following utterances for example:

I wasn't grossly overweight. I was overweight. Not medically obese but I was overweight. Obese is like, you know, you turn sideways to go through the door and it doesn't make any difference. That's gross. (C3 – post-group interview)

There's this guy who come out [of the hospital], he was skinny as a rake and he looked like he was dead anyway, that greyish pale, that – smoking like a bloody chimney. And he was in a wheelchair with a leg missing. And you think, well, if that doesn't make a person think I better stop doing this, but you see, their thinking is they're so far gone, it doesn't matter anymore. And realistically, they're fairly right. They can't come back. But surely, if they show the general population that have just become diabetic, sent along to where they can meet these people, that might say oh, I don't want to go down there. So, if I could do something now, I won't get there. (C5 –post-group interview)

Othering along these lines also suggests that the term 'diabetes-related stigma' is a misnomer. A reading of the extant diabetes-stigma literature suggests that PWD as a unified group are unfairly labelled according to overgeneralisations (i.e., stereotypes), which are based on a narrowly applicable set of beliefs about diabetes aetiology and disease progression (Abdoli et al. 2018; Benedetti 2014; McNaughton 2013). Findings from participants in this research suggests that this reading of 'diabetes-related stigma', as experienced by 'normal' PWD, is more of what has been referred to as courtesy or associative stigma (Corrigan, Watson & Miller 2006; Goffman 1963; Phillips et al. 2012). Here, PWD can be said to fear becoming associated with tragic-disabled, irresponsible, and obese persons, which form more precisely defined stigmatised groups. Further discussion of the construction and legitimisation of these stigmatised sub-groups of PWD is provided below, starting

with examination of the tragic-disabled sub-group of PWD. This discussion takes into account participants who either maintained or increasingly emphasised these stigmatising representations over the course of the research, offering explanation as to why these representations emerged and were maintained.

### **Constructing the tragic-disabled sub-group of persons with diabetes**

What is clear from participants in this research is that the tragic PWD with advanced diabetes-related complications functions as a *cornerstone* status within diabetes-related stigma. In architecture, the cornerstone is a stone within a structure that is laid first and used as a reference from which to position the other stones. In this way, the disability and bodily disfigurement resulting from disease progression is the necessary antecedent for developing ideas about the shameful body or blameworthy person. For those participants that made reference to PWD living with diabetes-related complications (C2, C3, C4, C5, and C6), all maintained representations of such persons as symbols of suffering and tragedy, provoking feelings of disgust, fear, and pity. When talking about diabetes-related complications, each of these participants dwelled on lower limb pathology (ulceration and neuropathy) or amputation, reflecting the asymmetrical focus on amputation observed within existing research examining fear of complications (Wukich, Raspovic & Suder 2017). Other important macrovascular or microvascular complications, such as retinopathy, nephropathy, stroke, or cardiac disease, were notably absent from participant accounts. In addition to signifying a state of suffering, to have diabetes-related complications also threatened to signify that the person had not adequately cared for themselves. In other words, the person is perceived to be both physically and morally corrupt, premised on the taken-for-granted logic of the self-care-biomarker-complications (S-B-C) causal relationship (C1, C2, C3, C5). This logic was apparent in the way that these participants frequently drew on rationalisations paired with moral evaluations as a discursive strategy to legitimise the inferior status of these ‘tragic’ PWD, such as observed in the below interview excerpts:

Both of them [two male work colleagues] didn’t do anything about it for five years and sort of, you know, just said we ignored it, and they’ve got the worst complications. (C4 – 6m post-group interview)

If you don’t accept diet, the diabetes can kill you. Then forget it. If I point a gun at your head, it’s not the gun that’s going to kill you, it’s me pulling the bloody trigger, then you’re going to be dead. And the trigger here is look after yourself. If you can’t look after yourself, then I promise you, your future’s horrible. (C5 – post-group interview)

Given its relevance to the S-B-C relationship, it is important to recognise the pervasive nature of discourses of risk that were embedded within interviews and group dialogue. Narratives of the experience of living with diabetes and experiences of stigmatisation depended on implicit assumptions about the ‘at-risk’ person<sup>16</sup>. Specifically, it was presupposed that PWD are *always* at risk of bodily breakdown or decay (in the form of diabetes-related complications), requiring *constant*

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<sup>16</sup> The notion that the ‘diabetic body’ is inherently risky was also brought to my attention by several PWD following public health communications portraying PWD as a vulnerable population group in the early stages of the COVID-19 pandemic (personal correspondence, June 2020)

vigilance to manage this risk. Thus, the 'diabetic' body was considered inherently risky. However, presumed knowledge of the association between certain behaviours and risk of complications (mediated by blood glucose level and other pathophysiological biomarkers), meant that risk-management was possible via acts of self-care. Reminiscent of notions of bio-power and governmentality, medical imperatives of self-care (or self-governance) were re-enforced by disciplinary measures of surveillance, normalisation, and correction, grounded in medical knowledge about the 'diabetic' body (Kendall et al. 2011). This interplay between risk, self-care, and medical surveillance, and how this functions to distinguish the self from the tragic-disabled Other crystallises within the following excerpt, taken from a post-group interview with C5:

Now, how do you find diabetics? Simple. You go to [major acute care hospital]. They've got a floor there with diabetics with arms and legs missing because of diabetes, okay? Because that's really what diabetes does. You end up – there's lots of things you can't eat, so obviously, you're going to cut down food. Then, you know your time's limited, so if I keep eating this, I'm going to make things worse. So, you know it's as simple as that. So, you then live on this record book [recording daily blood glucose levels] that everybody hates...I'd be watching my food and I really do watch what I eat and all of a sudden, my numbers are up higher, the eight, 10, 12 range. Eight, 10, I'm happy with, 12, 14 I am not happy with. Something's not working, blah, blah, blah. So, go back. So, you cut out an item. If no change, put it back in. Cut out another item. No change? Put it back in. All of this, you've heard many, many, many times. Well, the doctor will tell you that all the time. Okay, so what's causing the problem? So, you look through, look through, look through and you find something. Yeah. One of my triggers is I have to have a three-monthly long-range blood sugar test, okay? Otherwise, I lose my licence. So, this is something you need to get through to everybody or you're going to lose your licence when the long-range number gets to nine. (C5 – post-group interview)

What is apparent from this excerpt is the way that identity thinking emerges from the imperative to avert a natural history of bodily decay, which leads to the identification of certain attributes (in relation to self-care behaviours and disease biomarkers) that holds particular instrumental value in preventing diabetes-related complications. This observation is reminiscent of Adorno's assertion that identity thinking emerges in contexts where objects are interpreted in instrumental terms, following the capitalist 'exchange principle' where there occurs is 'a levelling of qualitative differences between objects into commensurable equivalents for the market' (Gunderson 2020, p. 5). As in the previous interview excerpt, it is possible to observe how C5's value as a 'patient' with diabetes is constructed around the metric of the blood glucose level and his behavioural response to this metric.

What is also apparent from this excerpt is that lower-limb ulceration or amputation signals a discrete point at which the body has irreversibly broken down. Although no participant in this research possessed such advanced pathology, several (C2, C3, C4, C5, C6) perceived their body to always be on the verge of such breakdown, creating a sense of uncertainty and urgency for improved diabetes self-care. For several of these participants (C3, C5, C6, and C8), this meant subjecting themselves to the advice of experts (largely in the form of endocrinologists and diabetes researchers, but also general practitioners, diabetes educators, podiatrists, and dietitians), who were seen to possess specialised knowledge regarding appropriate treatments (clinical care) and self-care behaviours (self-management) to manage the risk of complication development. Here, there was a

division of labour where experts assumed responsibility for directly managing the 'externally imposed' threats to health (i.e. non-modifiable risk factors for diabetes progression) and PWD assumed responsibility for managing risks seen to be 'internally imposed' (Lupton 1995, p. 77), requiring the PWD to actively manage themselves through acts of self-care. Part of this urgency for self-care was stoked by the fear of and feelings of disgust towards states of lower limb amputation and ulceration, such as that evident within the following interview excerpt.

God forbid, I would never want to lose a limb. I'm always very grateful when the podiatrist gets a good pulse. I do - yeah, so in that sense, I'm not in denial. I do the health checks. I regularly see a podiatrist. I - I went and bought old lady diabetic shoes even. It was just - I'd put socks on - I put black socks on and wore them on the plane because they were just so comfortable, so yeah. Yep, that was - that was my reality check, having - not that I'd worn high heels, I don't - I wear comfort shoes, but I - I had to go and buy it in my experience, old lady diabetic shoes, the velcro kind, just because the podiatrist kept saying, "You can't wear these any more. They're not supportive enough. You need - yeah. Yeah, you can't - can't - you can't strain your feet basically. You've got to take care of your feet, and - so yes, I have - I have three or four - three out of the five, at least, visits on the care plan are with a podiatrist, yeah. (C2 – pre-group interview)

Disgust is a well-documented affective response to amputation (Burden et al. 2018; Rohrmann et al. 2009), potentially developing in response to the threat of bodily decay and death (McGinn 2011). However, at a sociocultural level, the emotion of disgust is thought to play an important role in managing difficulties in categorisation, what De Block and Cuypers (2011) refer to as the problem of 'categorical ambiguity' or 'categorical fuzziness'. Here, solidifying boundaries around categories functions to minimise feelings of uncertainty (such as that observed amongst participants in relation to the threat of diabetes-related complications) while also promoting forms of behaviour that avoid transgressions against cultural standards. In other words, disgust has been 'co-opted to play auxiliary roles in the sociocultural domain' (De Block & Cuypers 2011, p. 476), which is done with the purpose of managing threats to a known and predictable social order and in doing so protects one's own sense of their world whilst also preserving the existing social order (Douglas 1966). In public health contexts, disgust is used as an educational strategy in preventative health campaigns, which functions to manipulate the affective response of the public with the intent of motivating behaviour change (Lupton 2014; Morales, Wu & Fitzsimons 2012). For participants in this research, the emotion of disgust was used both to motivate self-care behaviour and to solidify the boundaries between 'us/me' and 'them', boundaries that are inherently 'fuzzy' given the universal riskiness and vulnerability of the 'diabetic' body and the uncertain nature of one's own future in the face of such risks.

Although disgust may be supportive of an adaptive social order, it also reflects important ethical, moral, and political dimensions precisely because 'all types of disgust centre on distinctions between Self and Other' (Lupton 2014, p. 10). Therefore, the disgusting qualities of the stigmatised Other should offer a fertile site for analysis within critical pedagogy. What then can explain why a critical examination of the othering of persons with tragic diabetes-related complications did not occur within either group in this doctoral research? Reasons for this omission might include the reticence of

persons with advanced complications to participate in research or the repression of fear-provoking thoughts about the development of complications. This is a reasonable claim given observations of repressive coping amongst those with health conditions that require heightened levels of self-control, including diabetes (Myers et al. 2008; Sadeghzadeh et al. 2019). This repressive coping style was hinted at by C8, who claimed that he often busied himself with activities to avoid dwelling on the negative consequences of his diabetes and other health issues. Case 4 also suggested that she avoided diabetes literature because of its frequent reference to the consequences of (poorly managed) diabetes. It is also not surprising that representations of tragic PWD were maintained throughout the research given that there were very few references to diabetes-related complications or a disabled sub-group of PWD within the group sessions, other than for the instrumental purpose of motivating desirable self-care behaviour. Take C5 for example, who drew heavily on texts of disabled PWD in the post and 6m interviews, spurred on by his perception that C8 was reckless and ignoring this advice (as a 'bloody idiot' and 'stupid bastard') and that he was going to face the consequences or 'suffer horribly' as a result of this behaviour (C5 - post-group interview). These interviews provide evidence of the way that C5 reproduced an othering discourse that established disabled PWD as an inferior sub-group of PWD whose status is justified because of a failure of self-care, itself symbolic of poor moral character. The inferior position of the tragic-disabled PWD is necessary in order to motivate a change in behaviour and dispositions towards self-management, a point that is evident in the following statement:.

All I'm saying with diabetes, that's a unique situation in that the aftermath of having diabetes is all these other things we're hearing about. Can you imagine what that's doing to somebody just arrived in hospital for the first time? That would be terrifying. Think about it. You turn up at hospital. You've got diabetes. We're going to send you to hospital to get balance. Who are these people? Don't worry about them. They've lost limbs from diabetes. You put your mind to work on that little problem [of diabetes self-management]. (C5 – 6m post-group interview)

Taken together, the strong emotional effects of disgust towards disabled and disfigured bodies and the use of the tragic-diseased Other to motivate behaviour change appeared to limit learners' capacity for critical reflection. The reticence of participants to examine the status of persons with diabetes-related complications might be explained by observations that certain disease-avoidance mechanisms operate automatically at a psychological level, distinct from more conscious and controlled aspects of stigmatising thoughts and behaviour (Lupton 2013c; Park, Faulkner & Schaller 2003). To reflect on one's own beliefs and feelings towards disabled and disfigured persons may be so emotionally threatening that it cannot be ethically accommodated within education work given the likely distress raised by such discussion amongst an 'at-risk' group of persons. Here, the diseased Other is feared precisely because it represents a perceived future state to which the PWD will conform unless preventative action is taken. This logic would explain why participants in this research privileged acts of self-care as an appropriate response to the threat of stigmatisation. Intimately connected with notions of the at-risk body, an irresponsible sub-group of PWD emerged



as those persons fated to assume the status of a tragic-diseased PWD should they continue their course of action.

### **Constructing the irresponsible sub-group of persons with diabetes**

All participants in this research either maintained (C2, C4, C6, C7) or elaborated on (C1, C3, C5, C8) representations of a sub-group of PWD who fail to adequately manage their diabetes, attributed to some form of person character deficit or defect. This character deficit might express itself through voluntary acts of wilful defiance of self-management responsibilities (i.e., they are wilfully irresponsible) or the inability to exercise self-discipline over dietary and exercise behaviours (i.e., they are weak-willed). Take for example, the below excerpt, which uses the factive verb 'we already know our defects' to presuppose that diabetes is the consequence of certain character defects. It is apparent from this excerpt that the focus of evaluation is on the (defective) character of the participant, who is cognisant of her being perceived as silly and childlike for not managing her diabetes appropriately.

It puts you on a defensive stance immediately, when health practitioners treat you that way. Because they treat you like you're obviously defective, you must be a bit silly and so, they treat you a bit like how I would have treated my kids if they didn't do their homework. It's not a nice feeling. I mean, we already know our defects, we don't need them pointed out to us.  
(C1 – post-group interview)

The relevant question for this research is how did ideas about the irresponsible character of PWD emerge and in what way was this representation subject to a critical analysis? The emergence of this theme was most pronounced in group two, which appeared to be largely driven by C5's preoccupation with the S-B-C causal relationship and his explicit adoption of a teaching role within the group. This role appeared to emerge from a complex biographical and illness narrative that constructed himself as a subject who, by virtue of his own moral character, was able to 'conquer' his diabetes following a long history of having a self-declared poor disposition towards care of his body (pre-diagnosis) and diabetes (post-diagnosis). This narrative is consistent with what Lucherini (2019) describes as bright siding in his analysis of the autobiographies of persons with type 1 diabetes. Here, bright siding focuses on the socially sanctioned narrative of 'overcoming of loss and failure', which acts to marginalise the chaos narratives of those that 'fail to do illness properly' (Diedrich (2007), cited in Lucherini 2019, p. 11). Bright siding creates contrast between the 'heroic and confident diabetic subject' and those Others who struggle 'to reconcile diabetes and other aspects of life into a stable identity' (Lucherini 2019, p. 14). A similar bright siding self-appraisal was observed amongst other participants who had lost large amounts of weight and reformed their dispositions towards self-care, particularly C3 and C8. In this way, these participants approached the analysis of stigmatisation from the standpoint of the formerly stigmatised Other but now transformed or

assimilated 'normal' PWD. In other words, they demonstrated a self-directed movement from the stigmatised out-group to non-stigmatised in-group (Ranjbar, McKinlay & McVittie 2016, p. 214) as a consequence of conquering their diabetes and overweight bodies. On the basis of assumed differences in moral character, this shift in moral status led to each of these participants engaging in the act of dissociating themselves with those that fail to adequately manage their diabetes, drawing on observations of obese bodies and inappropriate food choices. It is here that it becomes apparent that the characteristics of the 'bad' Other (as those that had failed to reconcile diabetes into a stable and *productive* 'diabetic' identity) reflect detestable characteristics of the formerly 'bad' self, as C5 claimed in his post-group interview.

'My problem has been eating wrong. My problem has been not exercising and you've got all that in black and white ... if you don't fix it, you're paying, you're going to run into it. Then you're in trouble. You get heart, liver, the whole box and dice. And that's why they're trying to get through to you, they say listen, get it down now. In 10 years' time, it's not going to be better, it's going to be worse. But if you've got it down now, you can approach in a safer manner. But if you keep going oh, I could eat this, that, god knows what – believe me, it's not going to change. Your attitude has got to change and that attitude is what you eat, what you do, your exercise, the whole box and dice.' (C5 – post-group interview)

This excerpt also reflects a pre-occupation with managing disease risks and maintaining physical health, something that was taken-for-granted by participants in this research. It was taken-for-granted precisely because of the belief that such action is taken simply for reasons of self-preservation, perceived to be a fundamental human motivation. Consequently, irresponsibility was then attributed to deficits in human motivation. Although C1 and C3 both identified factors that might constrain the ability of PWD to engage in appropriate acts of self-care, including constraints imposed by culturally defined roles and histories of trauma, the ability of most PWD to act in a relatively free and unconstrained way on (presupposed) motivations for diabetes self-care was largely assumed within their interviews. The following excerpts demonstrate how an irresponsible sub-group of PWD was constructed, based on implicit assumptions regarding obligations for risk-reduction, motivational deficits amongst 'irresponsible' PWD, and the capacity of PWD to freely act upon imperatives for self-care:

Look, an older generation like us tend to feel that we go to the doctor and fix it. Well, that is not necessarily going to work is it?" So that sort of highlighted my sentiments of that because I think that's just foolhardy and that's like standing out in the road and expecting a car not to hit you. (C3 – 6m post-group interview)

Because at nine [HbA1c > 9%], they take your licence away, until you get your numbers down, then you can get it back. So surely, if I want to maintain a licence, I don't go out and binge on chocolates and burgers and things like that. It's self-defence. So I don't. It's no good saying, I'm early stage diabetes or I'm late stage diabetes. That's like saying, I'm doing 10 miles an hour or 110 miles an hour. See, you've got control of the pedal. Bring it down. (C5 – 6m post-group interview)

We've got the goodies, the hard, the ones that are genuine and the idiots who walk around; they don't look after themselves. They say, "I'm a diabetic, can't do anything about it." They're foolish. (C8 – 6m post-group interview)

Pulling these points together, it appeared that participation in the research functioned to fortify rather than critique the construction of an irresponsible sub-group of PWD. A good example of how the category of irresponsible PWD was re-enforced through participation in the research is contained within C2's analysis of her critical incident. She described being retorted by her daughter (i.e., 'we'll come visit you with your wheelchair and your foot removed') in response to her perceived lack of effort made towards dietary restraint, exercise, and weight reduction. Rather than engaging in a critique of this utterance, the act of raising this incident within the group functioned to emphasise her motivational deficit. She described her response to the education program in the post-group interview, noting that the 'decision to become more proactive [regarding matters of diabetes care and weight reduction] has become even stronger. The decision and responsibility is solely mine. I regret that I've not taken action sooner.' In a similar way, C1 and C4, identified that participation in the educational program functioned to increase their motivation to better manage their diabetes, evident in the following interview excerpts:

I started – I check my blood sugar regularly now, I never used to. I might do it once a week, but now I thought, well, really, it's up to me how I manage my diabetes and it's better to know. So that has changed for me which is probably good; it's probably a good thing for me that I now manage it better. (C1 - 6m post-group interview)

I still think that the value of it [the research group] was having other people there to hear their stories, but was taking that time out of your life to do that, and discussing these sorts of things. The role play I enjoyed. I remember that. It was the time, the content and the time to take time out for yourself to look at your life. Now probably if I'd been working, I probably wouldn't have done that. I'd been retired 12 or 18 months by then. And it was another thing I added to help me with diabetes. I'm thinking of it in a more – not in such a bad way. It's given me - while at times my eating hasn't been – so, I thought that it makes me more conscious of diabetes and what I should be doing, so I have that time, but also, as that story, about it being shame, you know, I've dealt with some of that. (C4 – 6m post-group interview)

Although seen to be positive outcome for participants in group one, this was an unexpected and disappointing outcome for me as an educator at the time, as it suggested that participants did not engage with a critical analysis of the logic of irresponsibility or the mechanisms that maintained this logic. A key constraint to furthering a critical analysis of irresponsibility appeared to be the perceived infallibility of the logic used to evaluate irresponsibility, tacitly drawing from powerful medical knowledge about the S-B-C relationship, assumptions about the unconstrained freedom of PWD to engage in acts of self-care, and the assumption that the self-preservation of health exists as a universal and desirable human motivation. Although the aim of the education program was to unsettle or destabilise taken-for-granted assumptions about PWD (Fook & Gardner 2007), it would appear that these assumptions remained firmly in place even after participation in the educational program. A key contributor to this stasis appeared to be the way that knowledge about the 'diabetic' body and the role of PWD as a moral agent is legitimised by both the healthcare provider and PWD on the basis that these things function in the best interests of the PWD. In this way, medical and moral authority over PWD can be seen to be maintained by voluntary means rather than as a subjugating or oppressive force of domination (Lupton 2012b). In doing so, there is a layering of

knowledge about the body and of responsible citizenship, constructing PWD as consenting *bio-citizens*. Use of this term, drawing from Rose (2007), suggests that one's experience of illness is shaped by notions of citizenship that give rise to prescribed forms of social and political engagement. Within their role as bio-citizens, PWD are obliged to take personal responsibility for care of their body/diabetes, a role that governments and public health actors 'have committed intense political energy and considerable financial resources to constructing' (Halse 2009, p. 57). For example, this energy is evident in a past joint Diabetes UK-Tesco diabetes awareness campaign, where campaign material strategically sought to amplify the danger of diabetes and the grief associated with it, whilst also personalising notions of risks and personal responsibility for diabetes prevention (Brookes & Harvey 2015).

The notion of bio-citizenship is especially relevant to PWD given the centrality of biomarkers of diabetes control and progression (i.e., within the S-B-C causal relationship) in making inferences about moral (ir)responsibility and identity. These biomarkers act in a similar way to the use of the body-mass-index in inferring irresponsible citizenship, whereby 'the assignment/adoption of BMI metaphorically erases the heart, soul and history of human subjects, substituting in its place a (numeric) entity devoid of personal or social identity on which the state and its allies can inscribe a new persona—that of the (virtuous) bio-citizen' (Halse 2009, pp. 49-50). This logic also explains why in this research, the medicalisation of fatness (i.e., obesity) as a risk factor for diabetes and diabetes-related comorbidity and its visibility as a marker of irresponsible bio-citizenship resulted in the construction of a stigmatised obese sub-group of PWD. The following section examines this sub-group as a distinct target for stigmatisation, although this group is also subsumed under the sub-group of irresponsible PWD.

### **Constructing the obese sub-group of persons with diabetes**

Although participants felt that their diabetes status was rarely brought to attention in everyday interactions, excess adiposity or fatness was drawn upon by all participants as a socially visible and meaningful attribute. It was observed through excessive displays of flesh, in the form of 'overhanging gut[s]', 'sumo wrestler'-like roundness, and poorly fitting or revealing clothing. For participants in this research, being labelled (or labelling oneself) as fat/overweight/obese signified that the person is sexually unattractive, disgusting, unhealthy, less capable, and possessing flaws of character – either for being unwilling or incapable of exercising self-control over eating and exercise behaviours. The first point to make here is that this meaning was applied to obese persons regardless of their diabetes status, reflecting a broader weight stigma (Puhl & Heuer 2009; Puhl et al. 2008). However, knowledge of a persons' diabetes status served to emphasise irresponsibility on top of the meaning already ascribed to them as an obese person. Take for example the following excerpt.

Because stigma of diabetes, it is there, but it's very definitely individual, and it's a direct line to one type of diabetic; and the word I use is obese. That is the only place where you see

stigma. And the common stigma is look at that fat bugger, no wonder he's a bloody diabetic, he should start losing some weight. (C8 – 6m interview)

Several participants (C1, C2, C3, C4) expressed how being very obese provided seemingly irrefutable proof of their culpability for their diabetes diagnosis, reflected in C1's statement that 'it's not the diabetes stigma that concerns me, it's that people will think how I got diabetes' (C1 – post-group interview). Therefore, obesity is taken to be subjectively informative of an irresponsible character amongst PWD. Here, there is a rational presupposition that in the face of widely accepted knowledge about the health risks associated with obesity, the obese person with diabetes (OPWD) has either failed to act in a way that might reduce this risk or lacks the psychological capacities to do so. By this same logic, OPWD who demonstrate sizeable weight reduction may be let off the hook and as a result might be more able to reject their stigmatised status as an 'irresponsible' PWD. Interestingly in the 6m interview, C4 claimed that as a result of the group, she 'no longer [felt] shame about [her] diabetes', precisely because she had successfully lost and maintained her excess weight, which she claimed was proof that she 'did what [she] could' to avoid diabetes. Several participants had lost significant amounts of weight (> 30kg) following a diabetes diagnosis (C1, C3, C4, C5, C7, C8), which had the effect of promoting distance between the reformed self and the (still irresponsible) OPWD as Other. Like observed elsewhere (Brandheim 2018), this othering was largely achieved through a process of 'animating' desirable characteristics of the self, which was used within interview narratives in order to implicitly ascribe undesirable traits to OPWD and portray this sub-group as being in crisis because of their obesity. Take the following interview excerpt as an example of how participants compared their own desirable dispositions and behaviours to those of OPWD:

The problem is not the overweight, the problem is not the diabetes, the problem is within themselves. Gosh, there's so much about me that has brought me to this point in life. I always used to teach martial arts when I was up to your age, I used to run my own school and all sorts of things and I was fairly competent in all of those things, and that's also given me the strength of character to be able to say, I'm me, I don't care what other people think because it doesn't matter. And it's given me that sort of confidence to deal with people in whatever capacity ... when you can help them understand those things, then you understand that that change can only happen within you and once you make that change, then you can change your physical attributes and you can reduce some of your body weight and help yourself, but what you have is a situation where they may well be overweight because they've always been overweight, they've always been overweight because people give them a hard time, because people give them a hard time, they lack self-worth and self-confidence so they eat to compensate which has given them an overweight situation which, of course, perpetuates the situation so you've got to break that cycle. (C3 – pre-group interview)

For certain participants this othering was also directed inwards, producing a logic of self-blame due to failed attempts of securing membership within a thinner, healthier, and more self-disciplined caste. Case 2 provided an interesting example of this self-othering as someone who had not been able to reduce her weight despite her best efforts. This participant drew heavily on comparisons between herself as an obese person (and as an OPWD) and other OPWD who had successfully managed to reduce their body weight. Note how in the following excerpt, C2 portrays her own obese body as Other to her authentic sense of self. Following her participation in the education program, it was her

comparison with co-participants (who had all successfully reduced their weight) that brought attention to her irresponsible nature:

And in one of our accommodations there was a whole mirror wall. True mirror. You can't get away from it and you just wake up going, who is that fat person looking back at me? ... I spoke two weeks ago about a woman I worked with was size 20 and I was, like, "Oh, God, if I ever got to that size I'd do something about it." And guess what size I am now? Twenty. And I've done nothing. Everyone else has managed to lose weight [referencing others in the group]. I've indulged. (C2 – 6m post-group interview)

For both groups, discussion of the role of obesity in diabetes-related stigma was dominated by a critique of the obesity-diabetes causal pathway. The issue with this discussion was that it was unfruitful in promoting a critique of the status of OPWD. Despite recognising that the probabilistic (epidemiological) notion of risk could not be explained using linear causal thinking, participants were left at an impasse whereby they and other PWD were still deemed at least partly responsible for their diabetes diagnosis given a personal history of obesity. By examining the obesity-diabetes causal pathway on medical grounds, issues relating to the medicalisation of fatness and failures of bio-citizenship were left untouched by participants. Although dominant within this research, this thinking was also challenged by two participants, C1 and C2. For these participants, the medical and moral concepts that were uncritically used to understand fat/obese persons evoked a sense of outrage and unfairness. This finding is explored in further detail in the following section.

## **Challenging the legitimacy of stigmatisation with notions of unfairness**

What the findings from this chapter demonstrate so far is that the pervasive medicalisation and moralisation of diabetes and fatness has created a situation where it is difficult to mount a rational (medico-scientific) argument against the creation of stigmatised groups of disabled, irresponsible, and obese PWD. In this way, a common-sense morality of bio-citizenship (reflected in discursive legitimation by moral evaluation) was embedded within a rational medical logic of the S-B-C causal relationship, with the former backgrounded against the latter. This discursive pattern follows the assertion by Salmon and Hall (2003) that medical knowledge is often naively perceived as being neutral and value-free, which ignores how patient identities are shaped by the tacit needs of healthcare providers and healthcare systems. For Salmon and Hall, the relative invisibility of normative aspects of healthcare becomes particularly pronounced in relation to chronic disease, which presents a special challenge to medicine given its bio-psycho-social complexity. For participants in this study, diabetes-related stigma appeared to reflect an interplay between medicalised notions of the at-risk body, giving rising to feelings of bodily imperfection, and the submerged moral concepts used to evaluate one's management of the risky body. For the majority of participants in this research, the moral concept of personal responsibility for diabetes self-care took the form of *common-sense morality*. Common-sense morality here contains ideas about what is a '*just or fair* distribution of well-being to individuals with moral status' where individuals receive 'the degree of well-being that they *deserve*' (Persson 2013, p. 199, emphasis in original). This

common-sense morality was carried within the medico-scientific logic of the S-B-C relationship to make inferences of deservingness for adverse diabetes-outcomes. This common-sense morality produced an interesting finding whereby a majority of participants entered the research with broadly stated grievances about cultural understandings of diabetes and PWD, yet left the research legitimising the inferior status of the stigmatised Other. However, two participants (C1 and C7) were observed to challenge the legitimacy of moral concepts applied to obese persons (but not PWD), warranting further examination of learning processes that might have contributed to this outcome.

In their rejection of the inferior status of obese persons, C1 and C7 demonstrated an emotional outrage regarding what they saw as being the *unfair* treatment of obese persons. This finding brings to mind Tinning's (2002) claim that critical pedagogy is best served when rhetorical styles of *thymos* (containing rage against injustice from the perspective of the marginalised) and *mythos* (reflecting a personal mode of storytelling) compliment a more conventional logical critique of the status of marginalised groups. Likewise, this observation resonates with calls for critical educational scholars to be more attentive to 'extra-rational', 'spiritual', and affective processes in facilitating learning about the status of marginalised groups (Dirkx, Espinoza & Schlegel 2018; Taylor & Cranton 2012; Watts, Griffith & Abdul-Adil 1999). The following excerpt provides an example of the emotional response (*thymos*) generated in response to the idea that OPWD are unfairly stigmatised. What this statement of outrage does is to sideline a logic of culpability, which might otherwise legitimise this treatment as deserved and thus fair, and bring to the fore how the status of OPWD is unfairly ordered along political-economic lines. In this way, moral and ethical concepts are applied to systems of government rather than to the obese individual.

It's acceptable to pick on people because they're fat and that goes into it's acceptable to treat people with diabetes type 2 as lazy and slothful and that really upsets me. It does. It upsets me and it makes me quite emotional because it's not right and it's not fair. It's not fair to treat people like that. I don't believe it's my fault I have diabetes any more than it's someone's fault if they fall over and break their leg going down the stairs. Then you, of course, fat people are a burden on the taxpayer and the health system and so are alcoholics and they're not banning alcohol. (C1 – pre-group interview)

There is limited data to explain precisely how the group functioned to develop a sense of unfairness about the status of obese persons for C1 and C7. In pre-group interviews however, both participants communicated a concern with the status of members of other marginalised social groups by gender, race, and sexuality, drawing upon their own personal experiences of marginalisation (in relation to weight for C1 and in relation to sexuality for C7). However, findings from this doctoral research suggests that in itself, the ability to draw from personal experiences of marginalisation and use these experiences to understand other forms of marginalisation was insufficient to generate this sense of unfairness. Although C1 and C7 entered the group with extensive histories of exposure to weight prejudice, so did C2 and C4. However, whereas C1 and C7 emphasised the unfairness of the devalued status of obese persons given the way in which their embodied identities were colonised by medical and moral concepts, C2 and C4 both legitimised the application of such concepts. This

is where exposure to texts communicating alternative representations of fat/obese persons or OPWD appeared to play a role. For C1 this exposure may have been a consequence of her social work training and consumption of popular feminist and fat activism literature, and for C7 this exposure may have been related to her consumption of online blogs written by fat activists and members of a fractured diabetes advocacy community. These exposures meant that prior to entering the research, these participants were already aware of alternative subjectivities and associated concepts used to understand the fat body. For both participants, the fat body was observed to be the product of genetics, illness, and histories of caring and motherhood, representing a form of bodily diversity that could not be adequately understood with reference to its medicalised risky nature or personal moral deficits. This is apparent in the following interview excerpt where C1 recounts the 'cuddliness' of her body as perceived by her grandson, which is an understanding of fatness that is at odds with dominant cultural understandings.

I take my grandson to school and stuff and there was always that fear in the back of my head that they would be embarrassed by me. And they're not. They come running out of their class hugging me, "Grandma." And the little one, he's four and he'll cuddle me. He'll go, "You're fat Grandma." And I'll go, "Yeah." "I love your fat." He cuddles into me. So it's like a positive thing to him. It's like I'm snuggly 'cause I'm fat. I think, well that's not a bad thing. But when he says, "Oh, you're fat Grandma," he doesn't say it in a derogatory way. He says it, it's just like a fact of life. Like, you wear glasses Grandma. (C1 – pre-group interview)

However, the problem here is that while a sense of rage and injustice emerged in response to the generalising concepts applied to fat/obese persons, such outrage was not observed in relation to other stigmatised sub-groups of PWD, including those with advanced complications or those deemed to be irresponsible. Both C1 and C7, like the other participants, continued to legitimise the concepts used to understand these sub-groups of PWD. The embodied reality of managing one's diabetes and preventing diabetes-related complications meant that medical and moral concepts, drawn upon to both manage one's illness and construct identity, were not easy to subject to critique. Difficulty in looking beyond this embodied reality is evident in C1's reflection on her beliefs towards diabetes self-care, as illustrated in the interview excerpt provided below. Here, her identity as a responsible and self-disciplined 'adult' is tied up with the imperative to 'control' her diabetes, which itself threatens to produce further disease and disability unless personal action is taken. Although she explicitly seeks to avoid the categorisation of PWD along moral lines, she nonetheless engages in a discursive process of othering as she plays off stereotypes of laziness against the reality of caring for one's diabetes. For C1, just like the other participants, there were no alternative subjectivities or concepts that could be drawn upon as a resource for challenging the generalising concepts applied to PWD, as was the case for understanding fatness:

I don't ever think that it's my own fault that I got diabetes, but it is my own fault if I let it get worse without controlling it. That part of it is on me. I'm an adult, no one else can manage it for me really, so yeah, I think it made me understand that I need to have control of it rather than it having control of me, if you get what I mean? I mean, if you let it get out of control and don't look after yourself, you can get really sick being a diabetic ... If you can't be bothered to take care of it well then it's sort of true, so, yeah, I am too lazy to take care of it and that's why I'm in hospital now. It's like if you had an open wound, you wouldn't not clean it and dress it



and take care of it, and then when it gets really infected, go, well it wasn't my fault. You wouldn't do that, would you? Because it would be your fault, you need to take care of it, and yeah, I think it proves that theory of, oh, laziness, because everybody, or most people do. They combine diabetes, especially type 2, with laziness, you were too lazy to exercise or eat properly or not go through the drive-thru and cook a meal, or whatever, and it's true. If you don't take care of it, well, that makes it sort of true, but yeah, you're too lazy, no one can do it for you. (C1 – 6m post-group interview)

For now, this chapter has identified the centrality of othering in relation to experiences of diabetes-related stigma and how this othering emerges from powerful forms of knowledge that interpellates PWD to know themselves as medical and moral subjects. By engaging in a critique of diabetes-related stigma through use of these dominant medical and moral concepts, participants tended to legitimise stigmatisation. However, it was the ability to draw on alternative concepts to understand fat/obese persons that generated a sense of outrage regarding the misrepresentation of such persons. Therefore, in terms of pedagogy, stigma-reduction education would benefit from firstly engaging with questions of who *precisely* is stigmatised and whether stigmatised statuses can be regarded as being *justified* or *fair*? By focusing their analysis on the stigmatised Other, participants in this research brought attention to salient medical and moral concepts drawn upon to construct the Other. More problematic was the way in which participants tended to justify the legitimacy or fairness of the application of these concepts, enabled by a common-sense morality and the embodied reality of diabetes care. Drawing on observations of challenges to the legitimacy of weight stigma, providing exposure to alternative representations of PWD may plausibly play a role in providing learners with the conceptual resources that might be used to challenge the fairness of stigmatisation. This finding suggests that such scaffolding is likely to be required in order to counter the medical and moral hegemony that was observed to dominate the thinking of PWD in this research.

## 9. REPRESENTING STIGMATISING EVENTS: IDENTIFYING STIGMA PROCESSES THROUGH A TEXTUAL ANALYSIS

This chapter moves on from an analysis of how stigmatised statuses are defined and legitimised towards an analysis of the processes involved in stigmatisation. This analysis is relevant for stigma-reduction work, which must be able to 'identify its injuries and to articulate its grievances' (Hoy 2005, cited in Beckett & Campbell 2015, p. 271). The problem evident within diabetes-stigma literature is that this injury or grievance is presented in fairly broad terms, which makes it difficult to identify exactly what mechanisms of stigmatisation are being problematised and whether these mechanisms are considered to operate in unfair ways<sup>17</sup>. For example, Kato, Yamauchi and Kadowaki (2020, p. 73) suggest that stigmatisation results when PWD feel 'judged, blamed, and shamed because of the[ir] diagnosis, feedback (either from glucose monitoring devices, blood test results, or their healthcare providers) revealing inadequate glycaemic control, and diabetes-related complications associated with the performance of their daily self-care behaviours'. This grievance may be interpreted in at least three different ways. The first way is to problematise the emotional response of PWD to their illness and self-care requirements, effectively re-branding diabetes-related stigma as diabetes-related distress (Robinson et al. 2018). The second way is to problematise the terminology used when discussing matters related to a diabetes diagnosis, diabetes surveillance technologies, and diabetes-related complications. Such an approach can be found within diabetes language position statements, which largely address the language used by healthcare providers in the provision of diabetes care (Banasiak et al. 2020; Diabetes Australia 2016). The third way is to problematise the ideologies and practices that infuse PWD with special meaning regarding the sick, enterprising, and responsible self (Williams 2010). Clearly then, diabetes-related stigma-reduction work is in need of a method for better articulating the grievances of PWD. This chapter contributes knowledge about such a method, describing how different texts function to draw attention to different mechanisms of stigmatisation, thus producing different grievances regarding stigmatisation. This knowledge is vital to stigma-reduction work within a critical paradigm given that the inappropriate choice of text(s) used to support an analysis of stigmatisation may inadvertently lead to a personalisation of stigma, leaving analysis of the cultural, social, and political basis of stigmatisation relatively untouched.

In analysing how participants in this research represented stigmatising events, I was able to recognise that some texts were better suited than others in drawing attention to the cultural, social, and political processes that produce stigmatised sub-groups of PWD. Drawing on their *critical incidents* as a text for examining stigmatisation, participants in this research represented stigmatising events in a way that increasingly problematised individual psychologies. Here, stigmatisation was

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<sup>17</sup> This is also true of stigma-reduction work more broadly, with Deacon (2006, p. 420) claiming that stigma-reduction work relevant to persons living with HIV/AIDS has been hampered by a fractured understanding of stigmatising processes, which has resulted in a 'mixed bag of anti-stigma interventions'.

said to occur because of any combination of; motivational deficits (opening oneself to legitimate attributions of blame for negative outcomes), inappropriate interpretations of paternalistic treatment, and a lack of personal resilience in the face of negative beliefs, attitudes, or practices directed towards PWD. Despite this individualisation of diabetes-related stigma, there was a sense that the stigmatisation of PWD has its basis in and is legitimised by powerful forms of medical knowledge, which become visible in public health pedagogies of health education and health news. Although this sense contributed to a nascent critique of health news and the deployment of medical/nutritional knowledge by healthcare experts, this critique was truncated by what was perceived to be the unassailable and 'natural' logic of biomedical knowledge about the vulnerable and risky body, following the logic developed in the previous chapter. In this chapter, I firstly examine exactly how stigmatising events were represented by participants in this research and how these representations tended to draw central attention to a perceived self-stigma. I then examine how different texts functioned to draw attention to different processes involved with stigmatisation, thus shaping these representations, and what potential these texts have for facilitating a critical analysis of diabetes-related stigma.

### **Individualising diabetes-related stigma through experiential texts**

Table 11 provides an overview of the ways that different participants problematised diabetes-related stigma. From this table, it can be seen that the first two forms of representation conceptualise diabetes-related stigma at an individual psychological level, whereas the latter two forms of representation focus on practices that communicate knowledge used to understand the fat body and obligations for dietary self-care. This section specifically examines how a focus on psychological processes of stigmatisation emerged within this research, thus individualising the stigma concept, and how this tendency towards individualisation relates to texts drawn upon to support an analysis of diabetes-related stigma. The following section then examines the latter forms of representation in a similar way.

Within this research, the notion that stigmatisation is a self-inflicted phenomenon was either maintained (C1, C3, C4, C5) or emerged (C2, C7, C8) within participant discourse. This understanding of stigmatisation was remarkably similar to psychological notions of self-stigma typically described within the mental illness stigma literature (Mittal et al. 2012). Here self-stigma focuses on the stigmatised persons' cognitive, emotional, and behavioural response to stereotypes and prejudice affecting members of the stigmatised group (Herek 2007). Within the diabetes-stigma literature, the concept of self-stigma is frequently drawn upon to explain the operation of diabetes-related stigma. Here, a trope is evident along the lines that (stigmatised) PWD sense that society blames those with diabetes as bringing about their own condition and for failures in self-management, resulting in feelings of culpability and negative self-image as they blame themselves for disease progression (Broom & Whittaker 2004; Browne et al. 2016; Earnshaw & Quinn 2012;

Kato et al. 2017; Kato et al. 2016b; Schabert et al. 2013). Reflecting broader observations of the way that the stigma concept is used, the consequence of this type of thinking is that the stigmatised individual is 'viewed as the primary locus in which stigma processes take place' (Yang et al. 2007, p. 1526), reproducing the tendency to conceptualise stigma in 'individual psychological terms' (Deacon 2006, p. 420). Whereas some participants presented the idea of self-stigma in a generic or fuzzy way, several participants (C2, C3, C6, C7, C8) elaborated on the notion of self-stigma by drawing on concepts analogous to psychological constructs of resilience or coping, evident in the following interview excerpts.

Talk to the hand. I don't care. I mean and I say that in a very offhand sort of way. I don't mean I don't care but I actually don't care what they think about that. It is not their business. I don't go through life thinking what other people think of me. I really don't care anymore. I have become a successful old fart ... Well, they stigmatise me but I don't give a rat's so it doesn't matter. (C3 – 6m post-group interview)

You have to learn how to deal with it, like plastic wrap. Let it slide off. Like the slime that it is ... Just let it slide off, because it's not you. If somebody's giving you the evil eye for you and your diabetes, it's that person that has the problem, not you, generally. But you can get wrapped up in it if you take it all so personally. (C7 – 6m post-group interview)

This finding is not surprising given how psychological approaches to self-care have firmly embedded themselves within the rubric of diabetes self-care activities. This point is made clear within the AADE7 Self-Care Behaviors® framework (American Association of Diabetes Educators 2020), which places 'healthy coping' within the centre of their concentric circles diagram of self-care behaviours. Healthy coping here is described as being 'critical for mastery of the other 6 [self-care] behaviors', claiming that 'psychosocial factors that interfere with a person's ability to self-manage the disease and achieve desired metabolic outcomes greatly influence diabetes and other related conditions' (American Association of Diabetes Educators 2020, p. 141). In this way, 'health coping' or resilience can be seen as an extension of the instrumental rationality of diabetes self-care, where the ability to cope with illness is valued to the extent that it enables the practice of behaviours appropriate for the prevention of diabetes-related complications. However, there was also evidence that the use of experiential texts, in the form of critical incidents and informal observations of co-learners/participants, also functioned to favour an individualistic interpretation of diabetes-related stigma.

**Table 11. Changes in representations of stigmatising events**

Representations of stigmatising events	Case							
	1	2	3	4	5	6	7	8
Problematised the process of self-stigmatisation	Maintained focus on this process	Emergent focus on this process	Maintained focus on this process	Maintained focus on this process	Maintained focus on this process	Not evident in the data	Emergent focus on this process	Emergent focus on this process
Problematised diabetes-related stigma as a lack of resilience	Not evident in the data	Emergent focus on this process	Maintained focus on this process	Not evident in the data	Not evident in the data	Maintained focus on this process	Emergent focus on this process	Emergent focus on this process
Problematised weight bias within healthcare practices	Maintained focus on this process	Not evident in the data	Not evident in the data	Not evident in the data	Not evident in the data	Not evident in the data	Not evident in the data	Not evident in the data
Problematised the categorisation of PWD using medical concepts	Maintained focus on this process	Not evident in the data	Maintained focus on this process	Emergent focus on this process	Maintained focus on this process	Not evident in the data	Maintained focus on this process	Maintained focus on this process

An overriding problem with the use of experiential critical incidents was the way in which a retelling of these incidents frequently came under attack by a logic of self-care. Dialogically, this obligation for self-care was observed to disrupt or fracture any emerging critical analysis of stigmatisation, such as with the following exchange that occurred within group two. Case 8's use of Pandora's box as a metaphor for the consequences of disclosing one's diabetes status, potentially a rich source of content for analysis, quickly gave way to imperatives for self-care that were made explicit by C5 and C6. Similar findings were also observed in group one. Even rich incidents of stigmatisation, such as that contained within C2's critical incident (being retorted by her daughter, who stated 'we'll come visit you with your wheelchair and your foot removed'), gave way to a logic of self-care. Put simply, participants entered the research with poorly defined grievances regarding their status or treatment as PWD, but by the end of their participation in the research several (C2, C5, C6, C8) had discredited these grievances given how these grievances detracted from master imperatives for self-care.

C8 says 'where the stigma comes in is that I felt that I had to make excuses for not wanting a drink' – the stigma is there when you have to start telling lies. Case 5 responds – 'the way I've dealt with that is that I DO NOT DRINK...but but but...I DO NOT DRINK'. Case 5 notes the importance of PWD not drinking alcohol. Educator redirects discussion back to C8, who goes on to note how it is best just to say no and not to explain oneself, otherwise you open Pandora's box. Case 6 adds that the stigmatiser in C8's critical incident might be a food pusher – someone that pushes others to eat. He claims that he has mentioned that to a friend – that they are a food pusher and they shouldn't do it ... Case 5 mentions that when you say in a group 'I don't drink, I don't smoke' people in that group tend to follow this good example – 'I promise you'. He goes on to present an example of children influencing the behaviour of parents, suggesting that social pressure helps PWD to 'eat sensibly'. (Field note – group 2, session 3)

For those that maintained their grievances regarding the stigmatisation of PWD (C1, C3, C4, C7), critical incidents discussed within the group were used drew attention to individual perpetrators of discrimination (i.e., the stigmatiser) whilst backgrounding processes that might have enabled these acts. The following interview excerpt from C1 offers insight into how group discussion functioned to solidify her grievance towards these perpetrators of discrimination.

And if you do educate yourself against people against those things, you can then say when they go should you be eating that? You can then say, yes, I can eat this because A, B, C, you know, and really, if you're not a diabetic you don't really understand diabetes, you only understand what you read, but you have to find some courage to do that, and I think doing this little study thing sort of helped me because a few years ago, if that guy would've said that to me I would've kept walking with my head down, I wouldn't have said anything, because I feel like – well, I felt like I didn't have any right to say anything. But after hearing other people's experiences and doing the little role plays we did and stuff, I feel like now that I do have the right to say that. He's got no right to talk to me like that just because I am fat. (C1 – 6m post-group interview)

Building from a critique of the 'conceptual inflation' of the stigma concept, Deacon (2006) suggests a need to differentiate between inter-related concepts of stigma, discrimination, and disadvantage. Like for that observed for PWD and other stigmatised conditions (de-Graft Aikins 2006; Saunders 2014), stigma can adversely affect the self-concept and behaviours of stigmatised persons, regardless of whether they experience mistreatment because of their stigmatised status. The use of

critical incidents by these participants had the effect of conflating stigma and discrimination, which reduced the visibility of other processes contributing to diabetes-related stigma. Providing examples of these alternative processes, relevant to stigma affecting persons living with HIV/AIDS, Deacon (2006, p. 421) argues that:

...in understanding stigma as a social process we do not need to define it in terms of discrimination to appreciate the importance of social power relations. We can define stigma as a social process in which:

1. Illness is constructed as preventable or controllable;
2. 'Immoral' behaviours causing the illness are identified;
3. These behaviours are associated with 'carriers' of the illness in other groups, drawing on existing social constructions of the 'other';
4. Certain people are thus blamed for their own infection; and
5. Status loss is projected onto the 'other', which may (or may not) result in disadvantage to them.

What is apparent from this list is that a certain level of abstraction is required to relate personal experiences contained within a critical incident to these social processes. The use of critical incidents in stigma-reduction work may therefore require learners to become better acquainted with a critical theory of stigmatisation prior to the reflection on experience. This idea follows the logic of traditional approaches to experiential learning, which suggests that an academic component of learning precedes an action (experiential) component that is then followed by a structured reflective component (Breunig 2005; Wisnewski 2015). However, one of the limitations of the diabetes-stigma literature is that there currently exists no articulated critical theory of diabetes-related stigma to draw upon for this purpose, a limitation that is addressed in Chapter 11 of this thesis.

The focus on the role of critical incidents as an experiential text has so far ignored the influential role that informal texts played in shifting or re-enforcing representations of stigmatising events. Whilst participants were engaging with the critique of personal experience in the form of formally stated critical incidents, a *black market* production and interpretation of texts was also taking place. This involved a process whereby the utterances of co-participants, often hinting at their dispositions towards diabetes self-care, generated novel texts that other participants drew upon to produce special insights into stigmatisation. Metaphorically speaking, it was a black market exchange in the sense that these texts were being used to secretly evaluate the conduct and character of co-participants, thus violating stated group norms, only to emerge in the confidential context of post-group interviews. These informal texts were especially influential in shaping changes in representations of stigmatising events, particularly through their use in bringing attention to processes of self-stigma. Use of these texts occurred in two main ways. Firstly, certain participants experienced this self-stigma first hand, instigated by interactions with others in the group who communicated personal achievements in the form of weight reduction, well-controlled blood glucose

levels, or the strict adherence to self-care behaviours. These interactions led C2 and C7 to compare themselves with others, with C2 falling short of others in relation to weight reduction and C7 falling short of others in relation to dietary self-control. Such interactions are illustrated in the following interview excerpts:

I need to change that [weight] to be healthier. I don't have a lot of self-restraint. And everyone else [everyone else]– C3 lost a lot of weight ... And I've done nothing. (C2 – post-group interview)

Some people who are kind of locked in with this, they get that mindset. Then it makes you feel self-conscious. I had that when I left here after one of the sessions and went grocery shopping. I kept thinking I was going to run into one of the other participants and have my cart judged by them. I think it's not just other people. Some of the stigma is what other diabetics give other diabetics. (C7 – 6m post-group interview)

Secondly, the evaluation of the dispositions or behaviours of others functioned to problematise the way in which others responded to their diabetes diagnosis, which became particularly pronounced in the context of conflict between C5 and C8 in group two. In the below excerpt, C8 describes the way in which C5 represents PWD as being at risk of bodily breakdown and suffering (symbolised by the diabetes 'monster') as the epitome of self-stigma:

If I can be rude I'll say yes, and that was C5 and I thought he was a bloody idiot. If anybody is asking for stigma he was and he definitely changed a lot of my thoughts on it because I do not think of it as the monster, the bad thing that's going to get me. But I realised there are people like him that do and it's not their fault. It's what they have been - they've been listening to the wrong people I think. Where does C5 get his ideas from? Who told him it's a monster? You've got to go back to square one and say, "All right, when were you told you were a diabetic and what did they say diabetes was going to do to you?" That's where it begins. (C8 – post-group interview)

These findings suggest that a reflexive analysis of these informal evaluations might provide a fertile site for analysing the construction of the stigmatised Other in future educational work, something that this doctoral research was unable to capitalise on at the time. By focusing attention on characteristics of the stigmatised Other, it is possible to elicit salient concepts used to categorise PWD and engage in a more deliberate process of determining whether it is fair to apply these concepts to PWD. However, other pedagogical texts were observed to provide a more stable and transparent platform from which to examine the discursive production of the stigmatised Other. These texts, including nutrition/diabetes education and health news, were drawn upon by participants to problematise forms of knowledge used to shape the identity of PWD.

## **Representation, ideology, and public health pedagogies**

Up until now, I have focused on texts drawn upon within the learning environment of the educational case study. However, it was apparent that in representing stigmatising events, participants were also drawing upon a variety of other texts that although were discussed within individual interviews had failed to establish themselves within group discussion. Throughout the interviews, a commonly expressed idea was that stigmatisation is maintained through representations of PWD by health



news and social media and through the moral language and educational practices of healthcare providers (HCPs) and other non-medically trained persons. The focus here remained on language and how it is strategically (in the case of health news) or tacitly used (by HCPs and the public) to represent PWD in inaccurate or unfair ways. For example, C8 maintained a critique of news media as contributing to the representation of PWD as tragic victims of disease, which he attributed to media organisations attempting to sell sensationalist stories of tragedy and suffering to their audiences. Cases 1 and 4 also described the way in which images of obese persons were strategically used within news stories about diabetes (and vice versa) to appeal to a moral public concern regarding obesity and diabetes ‘epidemics’, evident in the following interview excerpt:

I saw a show they did, it was a documentary, it was American and they went to this – apparently the fattest people in the world live there, and I mean these people were hugely obese, some of them were 500 pounds, I don't know how they even lived. It was awful. And of course they all had diabetes, and some had lost their feet and – you know, because of it, and it was just, like, oh, look at all these fat diabetic people. I'm pretty sure there's skinny diabetic people too, but they didn't show any of them. (C1 – 6m post-group interview)

Such recognition of the stigmatising function of health news by members of stigmatised groups has been previously reported by Holland (2018) in her research involving persons with mental illness. For Holland, such persons were observed to be cognisant of the way that health news discursively functions to re-inforce medical authority and the patient-consumer ideology<sup>18</sup>. This observation can be understood using the concept of *biocommunicability* (Briggs & Hallin 2007, 2010, 2016), which recognises the ways in which news media performs a pedagogical function to reproduce cultural understandings of health, disease, and citizenship. In other words, news media teaches:

‘ ... the public about what counts as valuable health knowledge, who produces it, how it circulates, and who receives it. Health news is thus performative and pedagogical in the sense that it interpellates different actors to take different positions toward health knowledge and socializes the audience in specific ideas of what counts as biocommunicable success (accepting ascribed positions) or biocommunicable failure (failing to take up or challenging ascribed positions) (Van Beveren et al. 2020, pp. 1363-4).

Briggs and Hallin's (2010) assertion that health news reporting possesses the status of a *boundary object* may explain why participants entered the research cognisant of its potentially stigmatising effects. They suggest that the communication of health news functions as the gateway through which biomedical authority and notions of the healthy neoliberal citizen might influence broader ideologies, structures, and social practices. For Briggs and Hallin (2010, p. 150), this means that health news offers an important text for examining how stigmatisation might occur given that these texts (as boundary objects) ‘often make clear to us tensions and ambiguities that may exist more generally in social practices, but not sharply enough for us to notice them easily’. The reason why participants in this research did not further their analysis of the stigmatising function of news media is likely the consequence of using personal experiences as formal texts upon which to reflect. Reflecting an intuitive concern with the internalisation of negative stereotypes and attitudes and interpersonal

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<sup>18</sup> These categories approximate earlier references to the medicalised self and bio-citizenship (Chapter 8)

interactions between the stigmatised and stigmatisers, the chosen critical incidents failed to engage with media representations of diabetes that featured so prominently within the interviews.

There were certain exceptions, however. At the beginning of session 3, C8 produced a newspaper clipping of an article written about an individual with type 1 diabetes (see below excerpt). Upon presenting the article to me, C8 described how the text produced an 'unnecessary' separation between persons with type 1 and type 2 diabetes, a separation that was implicitly premised on beliefs about the culpability of persons with type 2 diabetes for their diagnosis. He noted that although he usually avoided reading articles about diabetes, he thought that he would read this article given his participation in the group.

Norton has type 1 diabetes, an auto-immune condition that affects around 130,000 Australians and occurs when the body's defence system mistakenly attacks beta cells where the hormone insulin is produced (type 2 diabetes is linked to poor diet and obesity). (Scott 2019, underline by participant)

Texts that proved useful in the critical analysis of stigmatisation also included those that contained examples of resistance to dominant discourses. Although not explicitly used within the group environment, such texts were used extensively within interviews provided by C1 and C7, who drew on online blogs produced by fat activists and diabetes advocates as examples of challenges to the medicalisation of the fat body and PWD. These online environments can be seen to represent political spaces where the medicalisation of the body can be contested and alternative subjectivities expressed. In this way, PWD transition from consumers or spectators of knowledge, to producers of knowledge, albeit in ways that can sometimes produce 'biocommunicable cartographies in which different models combine and intersect in complex, sometimes contradictory ways' (Van Beveren et al. 2020, p. 1364). Neglecting a further analysis of these texts was a lost opportunity, and perhaps an indication that this short educational program at times failed to engage learners as co-creators of the educational process (Wisnewski 2015).

Again, being omitted from group discussion despite its prominence within individual interviews, the analysis of stigmatisation in healthcare contexts tended to take aim at the status of biomedical knowledge and its role in constructing the 'diabetic' subject and subjecting the PWD to a regime of professional and self-governance. Particularly prominent was the role of dietitians, who were portrayed by most participants (C1, C3, C5, C6, C7, and C8) as playing an important role in communicating and enforcing the expected behaviour and bodies of PWD. To put this in perspective, a total of 89 discrete and unprompted references were made to the role of dietitians across 18 of the 23 interviews. These participants consistently described how the dietary education provided by dietitians reinforced the moral imperative for PWD to change their dispositions towards eating and the body. Some participants saw this dietetic imperative as unproblematic (as in the first excerpt below), whereas other participants could be seen to actively resist what they perceived to be an unwelcome imposition of beliefs about lifestyles and health (as in the latter excerpts). In the last

interview excerpt, C1 uses the metaphor of 'baggage' to describe the moral burden that dietitians place on OPWD to achieve a healthier (or thinner) state.

And the other thing with diabetes, and so many other things in this world, you look at something and say, oh, I'd like this, I'd like that, I want this, and I want that. But if you look at it from a diabetic or many other things as well, I mustn't eat this. So if I don't want to eat it, don't put it in the cupboard. Don't put it in the fridge. I'm starving. I'll have an apple. Why? You know what's in there ... the dietitians will tell you, how much meat you've got to eat. They'll tell you how much vegetable you've got to eat. What type of vegetable you've got to eat. (C5 – 6m post-group interview)

He's [the vignette character with diabetes receiving dietetic education] going to need to diet, he's going to need to exercise, he's going to need to do that, he's got to become a different person, and that's when you change. That's the first - how can I say - stepping stone in diabetes. (C8 – post-group interview)

But her [bariatric surgeon] whole attitude, it was like being back at school. You go in for your appointment and if you haven't lost the five kilos you were meant to lose, it was like you were naughty. You can do better. You're not trying. I feel like I am trying. I felt like, I don't know, I just felt like she was, you know, typical fat person, doesn't try. That's the attitude I got from her. It could have just been me, but I did. And I've had that from dietitians as well. You just need to eat less. Actually no I don't need to eat less. It's like, I'm already carrying enough weight around. I don't need your extra baggage. (C1 – pre-group interview)

What is apparent in these excerpts is that nutritional knowledge or expertise possessed by dietitians acts to manage PWD by establishing forms of self-discipline, whereby dietitians function to provide PWD with the means to modify and control their dispositions, dietary behaviours, and bodies, and thus know themselves as 'ethical subjects' (Coveney 1999, p. 28). For participants in this research, such acts of self-discipline were subject to an ongoing process of professional surveillance in the form of routine assessment of weight, dietary behaviours, and blood glucose results. The following excerpt illustrates how surveillance practices seek to embed themselves into the daily lives of PWD. In the context of diabetes care, dietetic education and practices<sup>19</sup> may therefore function in a similar way to health news as a boundary object. This idea recognises that dietetic practice establishes a space where biomedical understandings of the body, notions of healthy citizenship and self-care, and professional surveillance intersect (Gingras & Brady 2019; Morley 2019). This is not to say that similar spaces do not also exist within other healthcare practices, but that dietetic practice appeared to function more effectively in making visible the 'tensions and ambiguities' (Briggs & Hallin 2010, p. 150) involved because of its reliance on self-care over direct professional intervention, its focus on bodily and behavioural surveillance, and the politicisation of nutritional science (Scrinis 2013).

I've been to dieticians that, they do, oh, aren't you naughty, and they make you keep a food diary, which nobody writes in honestly, because yeah, I've kept food diaries but I left out that I had a chocolate éclair or a Mars Bar. I'm not going to write that down there so the dietician can go, well, you shouldn't be eating that. I already know that I shouldn't be eating that. People do not write the truth in there - they don't. Only people who are very fit and a normal size keep an honest food diary and they don't need dieticians. People don't tell the truth because they think they're going to be judged for it. (C1 – 6m post-group interview)

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<sup>19</sup> Participants in this research also identified similar issues within structured diabetes education programs and medical consults where lifestyle (diet and exercise) modification was a prominent aspect of discussion.

In this chapter, I have provided evidence that participants in this research drew on a variety of texts in order to construct their own understanding of 'diabetes-related stigma'. However, the problem with this free-range selection of texts is that the stigma concept became individualised – either as property of the stigmatised target or the stigmatiser. In a way that was not anticipated during the design of the educational research, the curated use of formally stated critical incidents came under attack from the logic of bio-citizenship, which re-directed focus away from a critical analysis and towards obligations for self-care, and by informal evaluations of co-participants. However, what this chapter also demonstrated was that certain texts, in the form of health news and nutrition/health education, offered certain participants a glimpse of the way in which medical and moral concepts infuse certain representations of PWD. Whereas the use of experiential critical incidents may require the articulation of a critical theory of stigmatisation in order for participants to better relate personal experiences to more abstract stigmatising processes, health news and nutrition education seemed to provide a more direct route for engaging in a critique of the ideological basis of knowledge used to understand diabetes and PWD.

## **10. FORMING PERSONAL PROJECTS FOR STIGMA-REDUCTION WHILST STRUGGLING TO IDENTIFY AN ALTERNATIVE NON-STIGMATISING REALITY**

Up until now, the focus of the analysis has been on identifying and explaining changes in the way that participants understand stigmatisation. For critical pedagogy however, such understanding is not an end in itself, but rather is useful to the extent that it might guide actions aimed at improving the status of marginalised groups. This action, it is suggested, evolves in response to a critical praxis that involves an ongoing synthesis of reflection and action (Kincheloe 2004). A critical praxis is ongoing because there is always the potential to revise and re-construct former understandings, particularly given dynamic changes in the mechanisms of marginalisation or stigmatisation (Hatzenbuehler, Phelan & Link 2013, p. 817) and because it is not possible to engage in a wholesale critique of one's assumptions about reality (Roberts 2000). But as the literature review in Chapter 4 has demonstrated, public health knowledge about the development of a critical praxis and its relation to improvements in the status of marginalised groups is currently lacking. This gap in knowledge is particularly problematic as it means that critical pedagogues in public health are unable to argue on empirical grounds about the precise impact that their educational work is having. If an alternative paradigm of diabetes education is to justify its existence alongside the dominant self-management paradigm of education, which itself is supported by considerable evidence of effectiveness (Deakin 2011; Jarvis et al. 2010; Loveman, Frampton & Clegg 2008; Urbanski, Wolf & Herman 2008; Worswick et al. 2013), then this empirical evidence is essential. A key methodological constraint in generating this knowledge is that the vast majority of existing studies (as reviewed in Chapter 4) have used cross-sectional case study designs, typically drawing from data collected immediately after conclusion of the educational intervention. In using a longitudinal case study design, involving data collection spanning the period before, during, and six-months following the education program, this doctoral research was able to identify actions occurring over an eight-month period and relate these actions to features of individual learning.

In examining the relationship between individual actions and features of learning, this chapter draws on a set of assumptions about the nature of human agency and its relationship to culture and structure. Specifically, the work of critical realist Margaret Archer (Archer 2002, 2003, 2007, 2010, 2015) and its use in the study of health inequalities and stigmatisation (Scambler 2013a, 2013b, 2018b, 2019) is drawn upon to examine how individual reflexivity, in part influenced by learning occurring within the educational intervention, functions to mediate what is assumed to be analytical distinct phenomena of structure and agency (Archer 2010). These processes are captured within Archer's theorising about morphostatic/morphogenetic sequences, which offers explanation about how human reflexivity might lead to the reproduction or transformation (i.e., structural elaboration) of conditions that constrain or enable future action. Here, human agents are firstly confronted with

ontologically real material-structural and cultural properties of the social world, which possess generative powers to constrain or enable certain forms of thought and behaviour. Reflexivity then is the internal psychological process where agents are able to form personal projects in response to these antecedent conditions (Archer 2007). These assumptions are appropriate for examining the operation of human agency within this educational case study given shared critical realist assumptions about the ontologically real nature of mechanisms producing stigmatisation and assumptions made about the function of human reflexivity within the adopted educational program (Fook & Gardner 2007).

In this chapter, I specifically draw on participant data contained within discursive representations of stigmatising events, focusing on the way in which participants position themselves and others as agents within these events. From an analysis of these data, I identify two broad forms of action, involving self-education and maintaining personal resilience in the face of stigmatisation, and examine how these outcomes relate to individual learning and group interactions. Far from the emancipatory discourse found within the studies reviewed in Chapter 4, actions taken by participants were largely concerned with avoiding or deflecting the threat posed by stigmatisation, emerging either from oneself (self-stigma) or from others (discrimination). These findings are consistent with observations that stigmatised persons tend to manage their stigmatised identity primarily through *deflections*, rather than *challenges* to the social order (Manago, Davis & Goar 2017). These findings revealed an inability of participants to envisage an alternative reality where PWD are not stigmatised, limiting opportunities to challenge this social order. By interpreting participant data alongside a broader literature describing challenges to stigmatisation observed within disability and fat advocacy movements, this chapter helps identify some of the constraints involved in identifying this alternative reality, and to a lesser extent some possible enablers.

## **Challenging and deflecting stigmatisation through self-education and personal resilience**

With some notable exceptions, two very different approaches to stigma-resistance were observed amongst participants within groups one and two. Within group one, the actions taken by participants were largely motivated by a desire to avoid being labelled as irresponsible by others. These actions involved seeking out further knowledge about the self-care requirements for diabetes, using this knowledge to guide a more appropriate practice of diabetes self-care and/or to correct erroneous beliefs about diabetes self-care held by others. Within group two, changes were more cognitive in nature, reflecting a concern with maintaining a personal resilience to stigmatisation. These stigma-resistance strategies are highly reminiscent of those strategies employed by persons living with mental illness, which are distinguished as either acts of *deflection* or *challenge* (Thoits 2011). Whereas deflection strategies are used to dissociate oneself from the stigmatised group and are typically cognitive in nature, challenge strategies typically lead to behavioural responses that are

motivated by a recognition that stigmatising stereotypes are untrue for others as they are for oneself. Where strategies of deflection tends to preserve stigmatising arrangements, strategies of challenge are thought to challenge these arrangements (Manago, Davis & Goar 2017; Thoits 2011). This section examines how the different forms of stigma resistance enacted by participants might be explained in relation to the characteristics of learners and the educational intervention.

Within group one, a clear feature of dialogue was to lend credence to the *shared* reality of processes of *weight* stigma (distinct from diabetes-related stigma), particularly those processes related to the evaluative gaze applied to overweight persons (C1 and C4) and shared experiences of being blamed by others for their lack of responsibility for self-care of the body (also C1 and C4). As C1 and C4 claimed in their post-group interviews, 'we were all on a similar page' and were all 'in sync' with one another. This sense of connection appeared to be largely driven by C1 and her empathetic role within the group, likely the consequence of her past social work practice and experience in facilitating therapeutic and support groups. Drawing comparison to Archer's ideal types of reflexivity, dialogue involving C1 and C4 appeared to promote a tendency towards communicative reflexivity, where the internal conversations of participants required completion and confirmation by others before ideas might be acted upon (Archer 2007), working towards the outcome of consensus (Scambler 2013b). This speaks strongly to the idea that challenge strategies are motivated by collectivist thinking, where there is a shared sense of being treated unfairly (Thoits 2011). This is in contrast to deflection strategies, which are premised on the idea that others are deserving of their stigmatised status. A good example of an outcome of this type of thinking lies in C1's response to a stranger calling her a 'fat fuck', in which she locates the problem of weight stigma in the beliefs and attitudes of the stranger. In her six-month interview, C1 suggests that it was the 'group discussion' that gave her the 'courage' and 'confidence' to confront stigmatisation in this way, reacting against the fat slur emerging from the evaluative gaze of a stranger:

I went to Woolworths, and I went in, my husband was in the car, I come out and there was a guy, some scraggy looking guy, sitting in front of the shop having a smoke. As I walked past him, he said to me, "Fat fuck." He actually said that to me. Now, I think your study helped me a bit because six months ago I would've kept walking, but I didn't. I turned around and said to him, "What did you say?" He goes, "Oh, you're okay." I'm like, yeah, I'm okay, but you're not. And he went really red and looked away and I just walked off. It really – it did upset me but I thought to myself, no, no, I'm not putting up with that anymore. (C1 – 6m post-group interview)

At this point, it might appear that ideas about the shared experience of stigmatisation and collectivist thinking counterpose the earlier assertion that processes of othering tend to create divisions of identity amongst PWD. However, it is important to recognise that this sense of solidarity only emerged in relation to weight-stigma, in which C1 and C4 engaged in a process (typifying the communicative reflexive) of conforming to and completing a dominant narrative whereby fat persons are unfairly watched and judged by others. By others in the group completing or validating this narrative, C1 describes feeling more 'confident' to act on this sense of unfairness. A more complex picture can be observed in Table 12 (p.153), which provides an overview of exactly what acts of

deflection or challenge were observed amongst participants in this research. What is apparent from this table, besides the asymmetrical use of deflection/challenge strategies by members of the two groups, is that none of these strategies dealt with challenging the way in which PWD are medicalised or represented as bio-citizens. Differences in the forms of resistance exercised by participants in each group masked similarities in their beliefs about the immutability of cultural attitudes and beliefs about the culpability of PWD, grounded in medical understandings of the at-risk body. Whereas Thoits (2011) interprets the act of educating others about mental illness and its medical management as a form of challenge, this doctoral research would suggest that this well-intentioned act of resistance applied to PWD would inadvertently reproduce representations of PWD as medical objects and biological citizens. From the perspective of a critical theory of stigmatisation, the acts of resistance that were characteristic of each group might better be referred to as deflections (perhaps with some collateral benefit to 'normal' PWD) given that they generally failed to challenge the ideological basis of stigmatisation. For those in group one, the attempt to re-define norms against which irresponsibility is evaluated means that only those that act responsibly might be let off the hook for stigmatisation, doing little to challenge the moral concepts drawn upon to stigmatise. This re-working of ideas about irresponsibility is evident in an incident described by C3, which involved him challenging the assumption that *all* PWD must also be overweight or obese. While this action might function to divert attributions of culpability away from thinner PWD, it fails to address the moral evaluation of fat bodies and how this relates to the evaluation of OPWD.

The moment you mention diabetes, I have diabetes, people automatically say that's because you're overweight and fat but I'm not anymore, you see? They go, "Mmm, oh, this does not compute, god, it's a nice day today, isn't it?" ... their argument's just been dashed. (C3 – pre-group interview)

Within group two, there was an overwhelming focus on avoiding stigmatisation through acts of self-care and the exercise of personal resilience. This focus on self-care appeared to be related to a heightened process of othering occurring within the group, largely instigated and maintained by C5. Throughout the research, C5s discursive representations of PWD and stigmatisation were remarkably stable. He maintained the logic that: a) persons with advanced diabetes-related complications were particularly detestable, b) that PWD possess the agency to avoid this detestable state through acts of self-care, and c) that the PWD is obligated to exercise this agency towards the avoidance of diabetes-related complications. Although incongruent with the aims of this education research, it emerged later in the research that he participated in the research as an opportunity to motivate others to take better care of their diabetes. Explicitly, he suggested that this motivation was driven by his own act of reformation regarding his disposition towards and practice of self-care, or as he stated in his 6m post-group interview 'I'm one of the one's that got through ... that conquered my diabetes'. Reflecting the focused autonomous reflexive (Scambler 2013b), C5 communicated a single-minded pursuit of health, grounded in a fundamentalist ideology of self-care. For him, stigmatisation could be avoided if others would also adopt similar fundamentalist beliefs about diabetes care. This thinking was relatively insulated from interactions occurring with others within



the group, evident in the way that group dialogue functioned to confirm prior beliefs and the way that the evaluation of co-participants was used to further fortify this position. In this way, there was no attempt to think outside of the concepts used to distinguish the self from Other or acknowledge the peculiar features of other PWD, evident within C5's post-group interview:

So, what I'm trying to get at is if you're going to try and educate people, think about what that person's thinking about it. I've got away with it this far I'm X age, done it all my life, it's not going to change. Pardon, it has changed already. You've been told you're diabetic. Start looking after the diabetes. Treat your diabetes with respect, not disrespect. And isn't that what C8 was doing? He doesn't respect diabetes, he'd been told. As far as I'm concerned, diabetes is one of the best things I've got. Why? Because it made me fucking grow up. Made me realise there's two and two, they make four. Not whatever you want it to make. You've got to comply or face up. (C5 – post-group interview)

The effect of this behaviour was for C5 to provide other participants with evidence (or informal texts) suggesting that stigmatisation was largely the consequence of an inappropriate psychological response to obligations of self-care handed to PWD. This narrative was apparent in the post-group interviews provided by C7 and C8, who each demonstrated an increasing emphasis on processes of self-stigma (as established in the previous chapter). For both participants, C5 and his notion of diabetes as a 'monster' became representative of the self-stigmatising PWD. Both participants contrasted themselves against C5 on the basis of their personal resilience to the internalisation of stigmatising beliefs and attitudes, which for C8 was a consequence of his strength of character (what he describes as his 'psychological immune system') and for C7 was a consequence of introspective projects of reflective journaling and online blogging. In a similar way to C1 and C4 in relation to their narratives around fatness, C7 and C8 drew upon interactions with C5 to complete narratives about the role of personal resilience in managing the illness experience, a narrative than can be found within research examining the illness experiences of PWD (Livingstone, Van De Mortel & Taylor 2011; Lucherini 2019) and within models of diabetes care (American Association of Diabetes Educators 2020).

Therefore, it appeared that participants acted in ways to avoid being categorised as Other, which they did by drawing upon existing narratives that either required completion and validation by others in the group or could be sustained regardless of group involvement. Because these narratives focused on individual or interpersonal transgressions, actions were also directed along these lines, precluding a more 'community' or 'other' orientation (Scambler 2013b, p. 151). As the following section demonstrates, it was the inability of participants to imagine an alternative non-stigmatising reality that constrained their ability to engage with alternative narratives, such as those narratives that might draw attention to processes of othering, the concepts used to define the Other, and the socio-political emergence of these concepts.

**Table 12. Evidence of strategies of deflection and challenge by research participants**

Deflection strategies*	Who used these strategies	Examples of the strategies used
Claiming incongruence between personal identity and ideal-type stereotypes	C8	Because stigma of diabetes, it is there, but it's very definitely individual, and it's a direct line to one type of diabetic; and the word I use is obese. That is the only place where you see stigma. (C8 – 6m post-group interview)
Claiming that the stigmatised condition features as a minor aspect of the totality of one's personal identity	C7, C8	Well, I never ever thought of myself as a diabetic, I knew I was, but it's like I've got a steel knee, but I don't think I've got a steel knee, I've just got a leg. (C8 – pre-group interview)
Defining the stigmatised condition in less serious terms	C6, C7, C8	When I first got diagnosed I felt as though I had to tell, I thought it was a real serious medical problem, but that relates to my father [with type 1 diabetes], you know, how it affected his life (C6 – pre-group interview)
Challenge strategies*		
Contradicting stereotype expectations	C1, C3	One of my good friends, her father is a diabetic and he's a recently diagnosed type 2 diabetic, and we were at her birthday, and we had cake obviously, it's her birthday cake, and I had a piece of it, and he was like – first he said, no I can't have that, you know I'm a diabetic, and she sort of looked at me because she knows I'm a diabetic, and I said, yeah, you know, I'm a diabetic, give me the cake, and he's like, "Are you going to eat that?" And I said, "Yeah, I might even eat two pieces." And he's like – he was really disapproving, and I said to him, you obviously don't understand your diabetes because you are allowed to have cake. Diabetes doesn't just eat too much sugar. I said you can have a piece of cake, it's not the end of the world. (C1 – 6m post-group interview)
Educating others about the nature of the stigmatised condition and its (medical) management	C1, C4, C7	
Confronting stigmatisers	C1	I went to Woolworths, and I went in, my husband was in the car, I come out and there was a guy, some scraggy looking guy, sitting in front of the shop having a smoke. As I walked past him, he said to me, "Fat fuck." He actually said that to me. Now, I think your study helped me a bit because six months ago I would've kept walking, but I didn't. I turned around and said to him, "What did you say?" He goes, "Oh, you're okay." I'm like, yeah, I'm okay, but you're not. And he went really red and looked away and I just walked off. It really – it did upset me but I thought to myself, no, no, I'm not putting up with that anymore. (C1 – 6m post-group interview)

\* Adapted from (Thoits 2011)

## Constraints to challenging stigmatisation: the struggle to identify a non-stigmatising alternative

Adopting characteristics of the focused autonomous reflexive, as interpreted by Scambler (2013b), the majority of participants in this research could be characterised as having an uncompromising commitment to diabetes self-care through acts of dietary self-restraint and weight reduction. As Scambler describes it, this standpoint emerged from 'a coherent set of vested interests – that brooks no alternative' (2013b, p. 150), what he refers to elsewhere as the TINA (There Is No Alternative) principle (Scambler 2018b, p. 160). Originally described in the context of *constraining* factors for the transformation of financial capitalism and drawing on Archer's use of the term with reference to structural-cultural constraints on human agency, Scambler suggests that the TINA principle functions to both make invisible taken-for-granted ideologies and makes it difficult to construct an alternative vision for the future. For Scambler (2018b, p. 160), this lack of a viable alternative creates 'frustrated citizens-cum-consumers [who] are clearer about what they oppose than they are about alternative and better futures'.

For participants in this research, it is clear that biomedicine and biomedical knowledge about the body has a pervasive effect on how the PWD see themselves and other PWD. As participants in this research assert, there exist very real consequences that might result from shortcoming in diabetes self-care, a point that is partly supported by observational clinical research (Adler et al. 2002; Sami et al. 2017; Selvin et al. 2004; UK Prospective Diabetes Study Group 1998; Zheng, Ley & Hu 2018). This assertion has likely contributed to an impasse where participants (particularly C1, C3, C7, and C8) were 'angered' or 'annoyed' by the medicalisation and moralisation of their lives as PWD yet remained bound to these ideas in order to preserve their own health. Similar findings have been observed amongst parents of children living with impairment/disability, who have been observed to creatively combine elements of medical and social models of disability as they 'grapple with their own internalized cultural values, goals of social justice, a desire for obtaining the best opportunities for their children, and the tedious tasks of everyday family life' (Manago, Davis & Goar 2017, p. 170). Despite value being placed on such social models of health as a reaction to the medicalisation of disability, in the context of the everyday management of disability it can simply be seen as easier to change the person rather than the social structure. This tension was evident in the following claim made by C3 in his post-group interview, who recognised the perils of blaming PWD for their conduct whilst recognising the harm that might result from shortcomings in diabetes self-care. What is apparent in this excerpt is the way that C3 evaluates co-participants against norms of self-care behaviour, constructing the irresponsible Other along the lines of what was discussed in Chapter 8. Of relevance to the discussion here, this Othering functioned to fortify the logic of (ir)responsibility and constrained his ability to pose a realistic alternative reality, or what Bhaskar and Archer refer to as a *concrete utopia*, reflecting the 'the real, but non-actualized possibilities' (Archer 2019, p. 240) for future configurations of culture and structure. This observation of C3 was also true of others in

group two, particularly C5, C6, and C8, and raises the question of what such an alternative reality might look like for PWD:

I realised that what I'm doing is probably the best course of action for me personally. A couple of those girls [in the group] – lovely girls - but, I've got diabetes but I'm still going to eat my ice cream and cakes and I go, "You've got diabetes. What are you doing?" To me – and I'm not going down the blame thing – but you already know – you now know what exacerbates it and you want to continue doing it. Therein lies a problem. And that comes back a little bit to the blame thing. And I saw that with a couple of them – I'm not going to change this, I'm not going to change that or I've cut down. Are you taking sweeteners as sugar in your coffee? No, no. I like sugar. But you've got diabetes. Now I'm not going down the blame path but what I'm seeing there is a lack of responsibility for self in some people. Do you understand what I'm saying? Once you've got it you have to help it. You can't pretend it's going to go away and you can't rely on modern medicine to fix it because at this stage we do not have a fix for it. The ultimate thing is you get your legs chopped off. (C3 – post-group interview)

Inspiration for answering this question comes from the social disability movement, where there has been a relatively effective challenge to the medicalisation of impairment. The social disability movement sought to promote a shift in representation of disability as personal tragedy towards a recognition of the way that disability is socially produced (Beaudry 2016). Echoing earlier findings about the importance of notions of injustice or unfairness in supporting a critical analysis of stigmatisation (Chapter 8), this desired shift in representation was motivated by the realisation that:

...the body which disabled people had received from institutions and professions – the 'handicapped body' – was socially created; it was a body created to their blueprint. Where there had been stasis born of a lack of hope and a sense of individual failing, derived from the received notion of having a malfunctioning body, the social model prompted new ways of thinking. The model introduced contingency. If the conditions of disablement were made socially, then they could be made differently. The social model was, however, more precise than this, because it positioned disability as oppression – in doing so, disability not only became contingent, it also became unjust. (Beckett & Campbell 2015, p. 278)

This challenge was made possible because of the articulation and political use of a social model of disability from the 1970s, which itself emerged as a 'community' of disabled persons began to 'identify its injuries and to articulate its grievances' (Hoy 2005, cited in Beckett & Campbell 2015, p. 271). These grievances were largely based on the idea that the dominant individualistic framing of disability acted to conceal the way that those living with *impairment* were *disabled* by societies that are unable to accommodate such impairment (Shakespeare 2013), but also that the medicalisation of disability had resulted in the 'oppression' of people with disabilities through medicine's claim to knowledge about and the objectification of the bodies of persons with disability (Hayes & Hannold 2007). The social model of disability thus acted as an 'oppositional device', whereby it provided a way of critiquing past practices, with the purpose of 'destabilising the present' and bringing 'the future into view' (Beckett & Campbell 2015, p. 272), contributing to a so-called 'collective disability consciousness'<sup>20</sup> (Oliver 2013, p. 1024). Relevant here is the observation that the medical framing of disability has tended to produce practices of stigma deflection, whereas use of the social model

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<sup>20</sup> It is recognised that the notion of a 'community' of disabled persons, as inferred here by Oliver, is disputed by other disability advocates. In particular, Shakespeare (2013) highlights problematic aspects of the 'disability' label and various levels of affinity between disabled persons and the social disability movement.

of disability as a discursive frame tends to lead to the greater use of challenge strategies (Manago, Davis & Goar 2017, p. 170). This observation suggests that an alternative set of concepts is required in order for individuals to engage in reflexive projects aimed at challenging stigmatisation. Although alternative concepts were drawn upon by certain participants to contest understandings of the body and fatness, as in the below interview excerpts, no comparable alternative concepts were drawn upon in relation to diabetes.

If you look at the Special K symbol, it's shaped like a red high heel, right? And they had all these ads with this very glamorous lady in her red – beautiful red dress, stepping out with her high heel shoes and she looks that good, because she eats Special K and she's got a Special K body. But now, it's about strength and it's how good Special K is for you when you exercise and you're a strong, powerful woman. But all those women are still thin and it's not about – I mean, I like to think that I'm quite a strong, powerful woman too. They wouldn't put me on their Special K box, because I don't look like I eat Special K. (C1 – post-group interview)

That's where I feel stigmatised, is I'm telling people how important it is to exercise and they're looking at my belly and it's like, don't look at my belly, look at my strong legs, look at my strong arms. (C7 – pre-group interview)

Interestingly, whereas a contest has occurred over the framing of fatness/obesity between fat activists and medical/public health authorities, unlike for the social disability movement this contest has seen fat activists being politically discredited by powerful voices within medicine (Saguy & Riley 2005). In this context, medical arguments about the risky nature of the obese body and the moralisation of self-care (via the prevention of weight gain or weight reduction) have been used to stymie the rights claims proposed by fat activists. Therefore, it would appear that representations of diabetes (and PWD) may have more in common with the fat acceptance movement than the social disability movement given a central concern with the medicalised risky body and personal responsibility for managing this risk. However, whereas the fat acceptance movement is motivated by representing fatness as a reflection of normal human diversity (Saguy & Riley 2005), in a similar way to the social disability movement, it is hard to imagine that PWD, diabetes advocates, or medical authorities would accept end-stage complications of diabetes as a comparable example of human diversity. Therefore, the likely focus for PWD is not to make diabetes-related complications more acceptable, but rather to de-couple notions of irresponsibility from the disgust and/or shame associated with the body disabled and disfigured by diabetes-related complications. Drawing on the distinction made by De Block and Cuypers (2011) between core disgust and sociocultural disgust<sup>21</sup>, this de-coupling might be achieved by challenging the way that moral concepts are used to solidify boundaries between 'us' (the healthy) and 'them' (the tragic-disabled) and the socio-political purposes served by these categorical boundaries.

The observation that such a social critique failed to emerge amongst participants in this research returns to the idea that the ways in which PWD think about themselves, including their rights as

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<sup>21</sup> Here, core disgust refers to co-opted disease-avoidance responses to potentially pathogenic objects, whereas sociocultural disgust refers to the way in which disgust is used to help resolve categorical ambiguity or fuzziness (De Block & Cuypers 2011, p. 476).

citizens, are highly biomedically mediated. As this chapter has shown, biomedical frames of reference function to constrain the ability of PWD to represent themselves in alternative ways and leads to a situation whereby PWD are individually tasked with avoiding or deflecting stigmatisation, doing little to raise awareness of or challenge the socio-political production of diabetes-related stigma. The following two chapters address this issue by identifying how the influence of medicalisation and bio-citizenship might be communicated to learners through articulation of a critical theory of diabetes-related stigma (Chapter 11) and how these ideologies might be challenged through democratic spaces within diabetes and other public health organisations (Chapter 12). It is through this last chapter that some inspiration is provided regarding possibilities for mounting effective challenges to diabetes-related stigma, overcoming some of the constraints to social action raised within this chapter.

## 11. CONSTRUCTING A CRITICAL THEORY OF DIABETES-RELATED STIGMA

By examining how participants represented PWD and stigmatising events, the previous chapters have offered insight into how these participants theorised the targets of and mechanisms underlying 'diabetes-related stigma'. In this chapter, I purposefully re-examine these accounts of stigmatisation through the lens of critical theory to construct a model of diabetes-related stigma that articulates the social and political processes that make stigmatisation possible. This chapter addresses a void within the extant diabetes-stigma literature, which although it has extensively described how PWD experience shame, guilt, and blame (Basinger, Farris & Delaney 2020; Browne et al. 2013; Hernandez et al. 2020; Himmelstein & Puhl 2020b) has had very little to say about the ideological and socio-political basis of these self-conscious emotions or whether these emotions are simply an unavoidable consequence of living with and caring for one's diabetes. By articulating these socio-political processes, it becomes possible to construct arguments regarding whether or not these processes are legitimate and to better focus stigma-reduction work, if that is warranted. In the absence of such knowledge, stigma-reduction work relevant to PWD runs the risk of creating the 'mixed bag' of interventions that has historically been found in stigma-reduction work relevant to persons living with HIV/AIDS (Deacon 2006).

In interpreting participant accounts, I recognise that interpreting participant accounts at face value, privileging epistemology over ontology, will lead to a situation where certain processes that constitute stigmatisation are obscured (such as demonstrated in the previous chapter) and where there is a need to adjudicate between competing accounts of stigmatisation. However, as outlined earlier in Chapter 5, this research assumes that there exist stigmatising mechanisms which operate independent of human knowledge of them (a realist ontology), and that knowledge of this reality is only ever partial and fallible (a relativist epistemology) (Danermark, Ekstrom & Jakobsen 2002). Given these ontological and epistemological assumptions, participant accounts can be used to make inferences about the structural basis of stigmatisation, something that is emphasised within the structural/critical paradigm within stigma research (Corrigan, Markowitz & Watson 2004; Hatzenbuehler 2016; Link & Phelan 2001; Scambler 2009, 2018b).

In this chapter, I draw upon Scambler's (2006a) critical realist jigsaw model of stigma as a best-fit interpretive framework for explaining how stigmatisation is produced. Using these insights, I identify how the medical and moral concepts that are drawn upon as resources for othering exist because of the way that biomedical knowledge and notions of neoliberal citizenship have been co-opted by governments and health authorities in order to govern risky bodies. In doing this, feelings of shame regarding the diseased and imperfect body are compounded by feelings of blame on the basis of failures of personal responsibility. These feelings then lead to forms of reified thinking where abstract notions of irresponsibility are seen to exist in real form within the enduring characters or personalities

of PWD. These findings are significant because they help organise the relationship between feelings of shame and blame/guilt observed within existing research, draw attention to the ideologically-framed concepts used to stigmatise, and identify structured practices that result in the widespread application of these concepts to PWD.

## **Relating feelings of shame and guilt**

Given the accounts of participants in this research, it is clear that an appropriate model must be able to accommodate processes contributing to: a) a potential deeply shameful experience of being very obese or possessing highly visible and disabling complications of diabetes, b) holding PWD personally responsible for inappropriate risk-reduction behaviours and by logical extension the onset of diabetes and its complications, and c) attributing inappropriate risk-reduction behaviours to personal character flaws. The question for this section is what theoretical model offers the best fit for explaining construction of these stigmatised sub-groups of PWD? Answering this requires an abductive model of inference where judgements are made about what extant theories, models, and frameworks of stigmatisation (examined in Chapter 2) provides the best fit for these data. Selection of an appropriate model then helps re-contextualise theoretical understandings of stigmatisation as it relates to diabetes. Through the lens of critical realist ontology, an appropriate model will provide insight into real mechanisms that drive diabetes-related stigma, regardless of whether these mechanisms are triggered or not. This theoretical perspective recognises that PWD, through the triggering of different mechanisms within different contexts, will have very different experiences (representing domains of the *actual* and *empirical*) of diabetes-related stigma. Evidence of differences in perceived stigma by body-mass-index, gender, HbA1c, and educational attainment (Liu et al. 2017) are evidence of the effect of interacting mechanisms on the experience of stigmatisation. Therefore, an appropriate model should also be able to accommodate variations in participant accounts, recognising that ‘people’s actions are never determined by a certain structure; they are merely conditioned’ (Danermark, Ekstrom & Jakobsen 2002, p. 56).

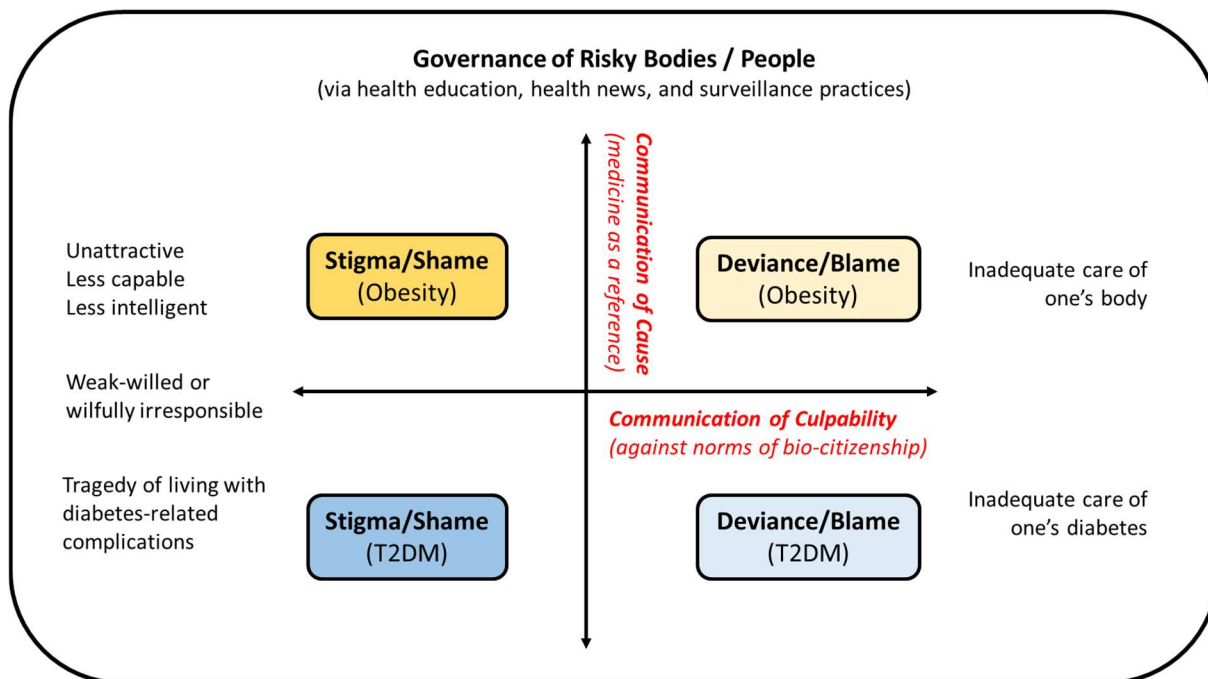
Graham Scambler’s critical realist approach to examining ‘stigmatisation’ is helpful here, which he has applied to the study of stigmatised groups that include persons with HIV, persons with epilepsy, persons with chronic and disabling conditions, sex workers, migrants/refugees, and the homeless (Scambler 2002, 2006a, 2006b, 2009, 2018a, 2018b, 2019; Scambler & Paoli 2008). Firstly, he makes the distinction between social relations of stigma/shame and deviance/blame. According to Scambler (2006b), stigma (producing feelings of shame) is taken to refer to an ontological deficit, whereas deviance is taken to infer a moral deficit, which results in the blaming of the stigmatised individual. As Scambler (2004, p. 36) puts it, ‘it remains important to distinguish socio-culturally between ‘doing wrong’ and ‘being wrong’, between immorality and imperfection’. The distinction here follows distinctions made between emotions of shame and guilt within a psychological literature, with studies suggesting they are experienced differently and lead to distinctly different outcomes (Price



Tangney & Dearing 2002). In these studies, shame is observed as a negative evaluation of the self and is regarded as being deeply painful because it affects the persons' core identity. Persons that experience shame tend to feel more closely watched by others and are concerned more with other's opinions of them than their own self-perceptions. Shame leads to the affected individual wanting to hide or disappear. On the other hand, guilt emerges from a focus on deviant behaviour. It is less painful because it doesn't tend to affect one's core identity or self-concept. The experience of guilt is more of regret or remorse, which prompts a response towards making things 'right'. What guilt and shame do have in common is an evaluation of blame, and that the attribution of blame may lead to different individuals experiencing a response of shame or guilt. Misheva (2019, p. 165) conceptualises this relationship slightly differently, recognising that shame and guilt remain interrelated, although there are cases where the experience of shame is dominant (described as 'shame-fused' guilt) or relatively absent ('shame-free' guilt).

However, one of the issues that confronts the diabetes-stigma literature is that the relationship between shame and blame/guilt has not been examined in detail. Ideas around culpability and blame have tended to dominate this literature, with qualitative interview research by Della, Ashlock and Basta (2016), Browne et al. (2013), Broom and Whittaker (2004), and Kato et al. (2016b) all highlighting the centrality of feeling blamed for one's diagnosis and/or for sub-optimal blood glucose management or diabetes self-care. Like in this research, feelings of shame (regarding bodily imperfections related to obesity or diabetes-related complications) become intertwined with the feeling of being blamed for these imperfections if one is said to have transgressed against norms of responsibility, which itself is seen to be evident because of the obese body or inappropriate self-care behaviours. As Chapter 8 has demonstrated, such evidence of irresponsibility is used to make inferences about irresponsible character as people act as 'intuitive virtue theorists' (Uhlmann, Pizarro & Diermeier 2015, p. 73). Therefore, irresponsible acts (which might infer guilt) are recast as being informative of an irresponsible self, thus eliciting feelings of shame-fused guilt. Scambler (2006a) approaches this issue by suggesting that blame and shame are related to one another under the logic of capital accumulation and economic class relations. According to Scambler, this political-economic logic has led to the introduction of a culture-ideology of consumerism that emphasises personal responsibility and places emphasis on culpability as individuals are expected to address their ontological deficits. The following section examines more closely how these processes play out in the context of diabetes-related stigma, providing a re-interpretation of Scambler's (2006a) jigsaw model of stigma.

## **Articulating a conceptual model of stigma-deviance relations for persons with diabetes**



**Figure 5. Conceptual model of stigma-deviance relations for persons with T2DM**

Scambler’s distinction between stigma and deviance was used to construct a model of the stigma-deviance (or shame-blame) relations for T2DM (Figure 5). The first point to note is that the stigma-deviance relation appears for both T2DM and obesity. This demarcation recognises that when PWD talk about diabetes-related stigma, they might potentially be drawing upon experiences of weight stigma that are unrelated to their diabetes, but nonetheless intersects with their experience of diabetes-specific stigma. This interaction explains why several participants referred so heavily to weight stigma and the status of fat persons throughout their participation in the research. Such an effect has also been observed within the workplace, with obesity rather than diabetes found to explain the experience of stigma and discrimination amongst workers with T2DM (Olesen, Cleal & Willaing 2020). In the obesity stigma-deviance dyad, the shame of being very overweight/obese (due to perceived ontological deficits of ugliness, incapability, and low intelligence) is layered with feelings of culpability resulting from a perceived deviance from norms of behaviour, namely a self-disciplined regime of diet and exercise. In turn, attributions of culpability add the character flaw of being weak-willed and/or wilfully irresponsible to existing ontological deficits that run afoul of norms of beauty, capability, and intelligence. Take the following excerpt for example:

But her [bariatric surgeon’s] whole attitude, it was like being back at school. You go in for your appointment and if you haven’t lost the five kilos you were meant to lose, it was like you were naughty. You can do better. You’re not trying. I feel like I am trying. I felt like, I don’t know, I just felt like she was, you know, typical fat person, doesn’t try. (C1 – pre-group interview)

For those living with T2DM, observations of fatness infers a character flaw and culpability for diabetes-related complications, independent of one’s true diet and exercise behaviours. Therefore, the stigma-deviance dyad for obesity is layered on top of the stigma-deviance dyad for T2DM,

brought about by oversimplification of the obesity-diabetes causal relationship (indicated by the vertical line in Figure 5) that medicalises and interprets fatness as a risk factor for diabetes development and progression. Findings from this research suggest that for OPWD, the experience of stigmatisation is not the additive effect of weight stigma and diabetes-specific stigma, but rather the multiplicative stigmatising effect of being an ‘obese diabetic’. This logic follows the line of reasoning in intersectionality studies of obesity, which suggests that multiple devalued social categories may create cumulative disadvantage, greater than the effects of each social category per se (Himmelstein, Puhl & Quinn 2017). The layering of weight stigma and diabetes-related stigma was apparent in the following interview excerpt from C4, which describes a seminal pre-diagnosis event that helped establish feelings towards her future diabetes:

We celebrated birthdays and we had cake, cake, cake and cake and we kept eating cake when it wasn't birthdays and someone else said to me, who I shared an office with a while down the track, he [an overweight person with T2DM] shouldn't be having that when he goes to get a piece of cake and she is a very critical person about weight and everything like that and so I knew, it must have been before I got diagnosed, yeah it was actually, I knew that I wouldn't be telling anybody apart from my manager, who had to know about having diabetes, the way they thought about him. (C2 – pre-group interview)

Whereas the shame of obesity focuses on the imperfect body and character of the obese person, the shame of diabetes partly emerges in response to ontological deficits regarding the decaying, diseased, and disabled body, symbolised by the ulcerated or amputated leg. Because of relatively uncontested beliefs about the S-B-C causal relationship and imperatives to ‘take control’ of one’s diabetes via activities of self-care (Diabetes NSW & ACT 2019; Edelman 2017), persons with diabetes are evaluated against norms of self-care by themselves and others. Running foul of these norms of self-care, evident through observations of obese bodies, inappropriate eating behaviours, and disabling diabetes-related complications, infer the existence of character flaws (being weak willed or wilfully irresponsible) as an ontological deficit. In other words, these stigma-deviance relations are used to make inferences about culpability of PWD for adverse diabetes outcomes (real or imagined), creating the stigmatised Other. This interactivity between stigma and deviance is indicated by the horizontal line in Figure 5, with the concept of culpability reflecting the way that ontological deficits associated with T2DM have to some extent been reconstituted as moral deficits through the lens of bio-citizenship. Interaction between stigma and deviance gives rise to different ideal types of stigma-deviance relations specific to T2DM (Table 13), adapted from Scambler’s (2018a) ideal types of shame and blame.

**Table 13. Ideal types of stigma-deviance relations for persons with T2DM (adapted from Scambler (2018a))**

	Deviance +	Deviance -
Stigma +	<p><i>Abjects</i></p> <p>‘Tragic-diseased <i>and</i> irresponsible diabetics’ who are deserving of disgust and separation</p>	<p><i>Rejects</i></p> <p>The biologically ‘out-of-control’, ‘authentic’, or ‘brittle’ ‘diabetics’ that are deserving of pity</p>

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	<i>Losers</i>	<i>Normals</i>
Stigma -	'Irresponsible (obese) diabetics' who are likely to suffer in the future and are deserving of contempt, correction, or control	The disciplined, relatively healthy, and well-managed 'achievers' that are deserving of praise

What is apparent from Table 13 is that not all PWD will be labelled with the stereotype of the 'diseased, obese, and irresponsible diabetic', which is a stereotype frequently evoked within qualitative studies of diabetes-related stigma (Basinger, Farris & Delaney 2020; Browne et al. 2013; de-Graft Aikins 2006). In fact, focusing on stereotypes as a package of beliefs about PWD fails to engage with the ways that concepts subsumed within these stereotypes are selectively applied and how the application of these concepts may be avoided in cases where PWD possess a 'normal' body weight, maintain outwards displays of dietary restraint and self-control, or do not possess visible diabetes-related complications. It is also important to note that participants in this research experienced a more lukewarm experience of stigmatisation than reflected in these ideal types, which meant that the effect of stigma-deviance relations were often misrecognised as considerate or helpful practices. Two notable examples included being exposed to well-intentioned practices regarding food choices, such as having others avoid offering certain foods or making PWD aware of inappropriate food choices (as a reaction to deviance) or being compared favourably to others who had experienced complications or ate poorly (as a reaction to stigma and deviance). These practices often produced what participants referred to as feelings of annoyance, which on further reflection were justified as a form of considerate action or rejected as a violation of personal liberties. Although such persons might not experience the same adverse psychological effects as reported in the diabetes-stigma literature (Gredig & Bartelsen-Raemy 2017; Kato et al. 2017), these experiences clearly illustrate how relations of stigma and deviance function to influence the experience of living with diabetes, even amongst 'normal' PWD. However, those that are very obese, deviate widely from norms of self-care, and possess more severe complications are likely to experience the effects of stigma and deviance most strongly.

## **Relating feelings of shame and blame to the governance of risky bodies**

How and why did the institutional order and symbolic framework emergent in modernity in nation-states like Britain come to incorporate cultural norms of identity or being that denounced and oppressed people with epilepsy as imperfect? To what extent were these norms the intended or unintended consequences of the system imperatives of the economy and state? Do they bear the taint of ideology? ... The posing of questions such as these provides a number of pointers towards a long overdue re-framing of stigma ... (Scambler 2004, p. 37)

The above excerpt was taken from an article in which Scambler re-visits his earlier hidden distress model of stigma (Scambler & Hopkins 1986), specifically raising questions about the ideological, economic, and political production of epilepsy stigma. This section follows this logic by examining

the ideological basis of feelings of shame or blame/guilt experienced by certain PWD. The assumption here is that certain ideologies inform 'representations of aspects of the world which can be shown to contribute to establishing, maintaining and changing social relations of power, domination and exploitation' (Fairclough 2003, p. 9). In relation to stigmatisation, ideologies represent the taken-for-granted beliefs that are drawn upon to legitimise the inferior status of stigmatised groups. Although the above quote refers to ideology as a 'taint', inferring a bad or polluting quality, this section adopts a more neutral understanding of ideology, recognising the material benefits that certain ideologies have brought PWD at the same time as contributing to the stigmatisation of certain groups. This stance reflects findings within the disability literature, which has identified how persons with disabilities, given the embodied reality of impairment, tend to partly benefit from medical understandings of disability rather than being out-and-out oppressed by these understandings (Manago, Davis & Goar 2017; Shakespeare 2013). To talk about ideology as a 'taint' in the context of diabetes prevention and care ignores the positive contributions of these knowledges to PWD and risks producing defensive and hostile reactions amongst those involved in diabetes prevention and care.

In this chapter and the previous findings chapters, it is apparent that medical understandings of the body and ideas about individual responsibility for the maintenance of health converge in the ideological form of the bio-citizen (Rose 2007) or patient-consumer (Briggs & Hallin 2007). Whereas medical understandings of the 'diabetic' body might give rise to the tragic and individual framing of diabetes-related complications and the vulnerable body, eliciting feeling of shame, it is the representation of PWD as freely-acting agents of disease management that functions to transfer responsibility for health onto PWD, allowing for blame to be cast on those that have not acted responsibly. Thus medico-scientific discourses, despite claims of neutrality, are observed to be infiltrated by alternative discourses that serve a specific social need (Salmon & Hall 2003, p. 1969). In the context of diabetes, this overarching need involves the prevention of diabetes-related complications, which is apparent in the way that threshold values for the diagnosis of T2DM have been established based on estimates of risk for the development of diabetes-related complications (American Diabetes Association 2014). A good example of the infiltration of cultural beliefs regarding the desired or appropriate role of PWD can be observed in the following interview excerpt, which provides an account of a general practitioner's response to C5's diagnosis and his disposition towards diabetes self-care. What is apparent from this excerpt is that scientific understandings of the relationship between self-care behaviours and blood glucose level (and presumably the relation of this to the risk of developing diabetes-related complications) are accompanied by a shift of responsibility towards the patient/PWD. This shift in responsibility is observed to occur in both negative (first incident in the excerpt) and positive (second incident) interactions with healthcare providers:

... 'you don't know you're diabetic!'. So, he went absolutely off his bloody trolley ... And I was heavily depressed, there was a lot of other problems and diabetes will cause that. He didn't ask. From then on, I was a complete idiot and every time I went to see him, I got blessed with the bloody idiot. So, that makes me angry and that makes it 10 times even worse ... Now, I've got a doctor, whenever I see him and he's a diabetic. He's got an interest in diabetes, okay? But he says ah, my boss is here. He says, "You're the only patient I have that doesn't look after yourself and all I do is listen to you and do what you tell me." Never had that in my life. (C5 – post-group interview)

For participants in this research, this ideology and the demand it places on PWD to assume responsibility for and 'take control' of their diabetes (Diabetes NSW & ACT 2019; Edelman 2017) was maintained through the professional surveillance of their (obese) bodies, blood glucose levels, and diet/exercise behaviours. Notably, participants recounted the way that surveillance was performed against rigid normalisations of the body and behaviour that included body-mass-index, cut-off values for acceptable glycaemic control, and dietary standards. This professional surveillance intruded into the private lives of participants as they maintained food and blood glucose diaries for later presentation to healthcare providers or continued to monitor their body weight at home. At the same time, close family members frequently drew on dietary standards in extending surveillance over dietary behaviours, albeit with beneficent intent. As was demonstrated in earlier chapters, participants (as PWD) also readily participated in the surveillance of the bodies and conduct of other PWD. The following interview excerpts demonstrate how the surveillance of bodies and behaviours of PWD, performed by healthcare providers, others, and PWD themselves, function to reinforce their role as responsible bio-citizens:

And they [endocrinologists'] say – no, you've got it worked out and it's working. And you've got proof in the pudding. It's in your books, in your record book. I record everything. It's working. Don't matter what we bloody say, it's working. We don't want to give you tablets. We don't want to give you insulin. But if you're keeping it down, so we don't need to, hey, we're as happy as pig in shit. Simple as that. (C5 – post-group interview)

I try really hard to make sure that one meal a day has plenty of veggies. It's a rule I made for myself so that a dietitian isn't going to go, "Oh no, you're doing that wrong". She'd probably tell me to add more. (C7 – 6m post-group interview)

If you have a cream cake because sometimes I take it and don't eat it, just make out I have it just to stir them up. I wouldn't do it if I had morning tea here [at the research venue] this morning and I didn't know anyone, I wouldn't be so stupid, yeah. They'd probably think big fool you. (C6 – 6m post-group interview)

Here, participants are seen to be exposed to value-laden medico-scientific knowledge containing 'specific ideas of what counts as biocommunicable success (accepting ascribed positions) or biocommunicable failure (failing to take up or challenging ascribed positions)' (Van Beveren et al. 2020, pp. 1363-4). Whereas participants in this research focused on the biocommunicable power of health education, health news, and structured diabetes education programs, other research has also identified how school health education (Leahy 2013), public health campaigns (Brookes & Harvey 2015; Lupton 2014), and chronic condition self-management practices (Kendall et al. 2011) contribute to the production of knowledge that establishes how PWD should view themselves as biological citizens. In this respect, health and media communications can be seen to co-produce

knowledge about the bio-citizen/patient-consumer (Briggs & Hallin 2016). Through exposure to these texts, PWD will come equipped with the cognitive resources, what Van Dijk (2006) refers to as *long-term memory* or Fairclough (2013) refers to as *member resources*, that generate expectations about how PWD should respond in healthcare contexts defined by surveillance of the body and behaviour. Following Fairclough's (2013) logic, these expectations function to produce styles of discourse that reproduces the status quo of knowledge about the nature of PWD and how they should behave. Such discursive styles are observed in the construction of the 'naughty' and child-like PWD, who need to 'learn new ways of being responsible for themselves' (Broom & Whittaker 2004, p. 2379). The discursive construction of the child-like PWD is clearly evident in the above excerpts and in the excerpt below:

I only went to a couple [structured diabetes group education sessions] and they talk about diet, and being overweight, and how it's important, and things you should always remember to check your blood sugars all the time, and always carry a – well, I still do from then carry a few jelly beans in the car so if you know you're feeling a bit – you don't wait until it happens to eat a jelly bean, preventative is better than waiting for it happen. But, I didn't find it – mostly I felt it was like they were talking down, putting me down, that I should do this, and I should do that, and I should that, well it's my life I do what I want my life to do... (C8 – pre-group interview)

As this last excerpt highlights, it is important to recognise a schism between participants in relation to their affinity to bio-citizen role. Certain participants (particularly C2, C3, C5, and C6) took-for-granted their role as bio-citizens as a natural consequence of having diabetes and being at-risk of developing diabetes-related complications. This highlights the embodied reality of living with diabetes, whereby 'no one else can manage it [diabetes] for me' (C1 – 6m post-group interview). A similar bind is observed amongst persons living with impairment/disability, who both resist the medicalisation of their bodies whilst also drawing benefit from medical services (Shakespeare 2013). Although retaining a belief in the importance of diabetes self-care, other participants (particularly C1, C7, and C8) communicated a broad concern with their lack of control over definition of their own illness. As C1 noted in session 4, 'I feel like everyone else gets to control my [relationship to my] diabetes except me.' This utterance relates to the relativist idea that there are multiple possibilities for interpreting illness, and that medico-scientific understandings are only one such possibility (Turner 1995), albeit bringing with it certain material benefits to the lives of PWD. What the latter group of participants reacted against was the way in which medical and moral understandings of illness took on a hegemonic quality, constraining their ability to represent their illness in different ways or on their own terms.

Although the discussion so far has focused on the operation of powerful knowledges and ideologies that constrain how PWD might imagine or represent their illness, a critical question relates to how such knowledge is maintained within a socio-political structure. Inspiration to answer this question comes from the following claim by Hannem (2012) in her attempt to relate interactionist and structural perspectives on stigma:

The issue of symbolic stigma becomes one of sociological concern when it is symptomatic of stigma at a structural level: when stigma is systematically applied by agencies, institutions and individuals to a particular group of people or population as a whole—moving beyond stigma as a perception of an *individual* attribute, to a wider, stereotypical concept of stigma that taints an entire group and pushes them to the margins of society. Increasingly we find that these structural-level identifications of stigmatic attributes are related to the notion of risk, and interventions are justified by the rhetoric of risk-management. (Hannem 2012, p. 23, emphasis in original)

For Hannem, structural stigma is intentional in that it emerges from an awareness of problematic attributes of members of the stigmatised group, who are perceived to be 'risky' or 'morally bereft' (Hannem 2012, p. 24). This means that the problem with stigma does not necessarily emerge from the stigmatised condition itself (reflected in notions of disease stigma (de-Graft Aikins 2006)), but from institutional responses to the condition. This idea is consistent with Lupton's (2013b, p. 37) claim that theorising about risk is united by the idea that risk has 'become a central cultural and political concept by which individuals, social groups and institutions are organised, monitored and regulated', whereby ideas about risk and its management come to shape human subjectivity. In relation to diabetes, the problem raised by participants involved the way that healthcare practices and health pedagogies represent PWD in certain ways or justify paternalistic treatment due to the generalised belief that they belong to a statistically risky group. Politically speaking then, stigmatisation can be observed to originate from institutional policies and practices that attempt to manage this risk, or more specifically transfer responsibility for this risk management onto PWD. For participants in this research, these policies and practices related to the performance of standardised diabetes health care plans (C1), standardised 'textbook' nutrition and diabetes management education programs (C1, C2, C3, C4, C5, and C8), standardised regimes of body (weight) and blood glucose surveillance and evaluation (C1, C2, C4, C5, C6, C7, and C8), and health news communicating the riskiness of PWD and the obese body (C1, C3, C4, C5, C7, and C8). As was observed in Chapter 8, the medicalisation of PWD and their framing as bio-citizens coalesced around notions of the risky body, producing stigmatised sub-groups (the tragic-disabled, irresponsible, and obese) based on those with particularly risky attributes. Participants also described the way that individuals within these sub-groups are subject to particularly intense and intrusive forms of risk management, particularly for those that are obese.

Although hinting at the relevance of surveillance to the experience of stigma amongst PWD (Kato, Yamauchi & Kadowaki 2020), the extant diabetes-stigma literature has avoided an analysis of how risk-management policies and practices, informed by medical knowledges and assumptions about bio-citizenship, facilitate feelings of shame and/or blame amongst stigmatised PWD. This chapter has developed a way of conceptualising this relationship, offering a roadmap for understanding the individual, ideological, and structural dimensions of diabetes-related stigma. However, a glaring issue here is that this analysis offers limited direction in challenging stigmatisation at a structural level. It is not appropriate to suggest that the status quo of risk-management practices should be fully abandoned given the health benefits such practices bring to PWD (van Bruggen et al. 2019).



What was apparent at this stage of the doctoral research was that structural challenges to diabetes-related stigma were unlikely to be easily sustained within such an environment given the general lack of appetite amongst PWD (and presumably those within healthcare systems) for opposing the status quo of diabetes prevention and care. This impasse led to the expansion of this doctoral research in an attempt to seek out alternative ways in which critical pedagogy might contribute to this structural challenge. This expansion involved taking the findings from this chapter and presenting these findings to a cross-section of staff and board members within a state-wide diabetes organisation, done with the purpose of identifying how diabetes organisations might best approach diabetes-related stigma and where might a critical pedagogy fit within this approach. The findings from this deliberative research are discussed in the following chapter.

## 12. LOCATING CRITICAL PEDAGOGY WITHIN EXISTING STIGMA-REDUCTION WORK

As the previous findings chapters have demonstrated, the ability of individual PWD to form projects of sufficient scope to begin to transform stigmatising processes is quite limited. It is limited because of the embodied reality of caring for one's diabetes, where it becomes easier to change oneself than a social structure that acts to stigmatise those who are obese or possess diabetes-related complications and those that fall short of obligations for self-care. To expect PWD to engage in such political projects unaided would just shift the blame from individuals (who self-stigmatise) to a collective of PWD, running the risk of labelling PWD as apathetic, selfish, or unenlightened for failing to challenge stigmatisation. Following Tarlau's (2014) critique that the academic practice of critical pedagogy (as a 'language of resistance') has created a disconnect between processes of education and social organisation, there is clearly a need to re-connect critical pedagogy with social movements or organisations that might create real opportunities for social change. This chapter specifically looks at how this re-connect might be achieved given the current policy and practice landscape in which stigma-reduction work occurs, relevant to an Australian state-wide diabetes organisation.

Diabetes organisations, which operate at international (e.g., the International Diabetes Federation), national (e.g. Diabetes Australia), and state (e.g. Diabetes South Australia) levels, are ideally positioned to support sustained action to address diabetes-related stigma. They are ideally positioned to support such action for at least three reasons. Firstly, reducing stigma and discrimination already exists as a policy priority for many of these organisations, evident within the International Diabetes Federation's (IDF) *Global Diabetes Plan 2011-2021* (International Diabetes Federation 2011a), the Diabetes UK position statement on *transforming the mental well-being for people with diabetes* (Wylie et al. 2019), and various position statements seeking to correct stigmatising language (Banasiak et al. 2020; Diabetes Australia 2016). Secondly, these organisations tend to assert that their actions are guided by values of person-centeredness and the protection of human rights, reflected in documents such as the IDF's *International Charter of Rights and Responsibilities of People with Diabetes* (International Diabetes Federation 2011b). This rhetoric suggests that diabetes organisations are more likely to uphold stigma-reduction efforts in the face of forms of ethical reasoning that might be used to legitimise stigmatisation, such as forms of utilitarianism and contractualism (Bayer 2008; Bayer & Stuber 2006; Courtwright 2013). Thirdly, diabetes organisations tend to possess the organisational infrastructure required for sustained social action, including infrastructure to facilitate member participation, access to human and financial resources, managerial structures, and links to important stakeholders (Laverack 2016).

However, there is currently limited knowledge about what interventions might be useful in reducing diabetes-related stigma and exactly where critical pedagogy might locate itself within stigma-

reduction work. In their review of diabetes-stigma research, Schabert and colleagues (2013, p. 7) were 'unable to identify any literature regarding strategies to reduce, or assist people to cope with, diabetes-related stigma'. More recently, this paucity of evidence has been recognised in the Diabetes UK position statement on *transforming the mental well-being for people with diabetes*, which declares a need to identify 'interventions designed to reduce stigma, learning from existing successful stigma reduction interventions for other stigmatised conditions' (Wylie et al. 2019, p. 3). Despite the lack of direction afforded by existing scientific literature, diabetes organisations are currently active in performing stigma-reduction work, albeit not necessarily directly referencing the stigma concept, having done so prior to the surge in diabetes-stigma research over the past decade (American Diabetes Association 2017; Hilliard et al. 2015). Diabetes organisations have approached stigma-reduction work by correcting 'myths' and 'misconceptions' about diabetes (Diabetes Australia 2015; International Diabetes Federation 2011a, p. 16), using high-profile individuals to communicate the needs and rights of people with diabetes (International Diabetes Federation 2011a), and through political lobbying to address issues raised by those with diabetes, including issues related to inequities in insurance coverage, access to pharmaceuticals, driver's license standards, and discrimination (Diabetes Australia 2015; Hilliard et al. 2015; International Diabetes Federation 2019). However, stigma-reduction work has so far avoided addressing issues that emerge from the medicalisation of PWD and their ideological framing as bio-citizens. As this doctoral research has shown, stigma-reduction work is not *simply* a matter of correcting inaccurate knowledge and beliefs (on medical terms) and preventing discrimination on the basis of one's diabetes-status – it also requires a re-evaluation of 'unstated or taken-for-granted assumptions about what is good or bad, right or wrong, required or not required' (Carter 2018, p. 190) when it comes to the conduct, bodies, and moral character of PWD. Such moral reflection becomes particularly complicated in cases where diabetes organisations perform both public health functions<sup>22</sup>, potentially justifying stigmatisation, and functions that give voice to and advocate for the needs of PWD who might reject stigmatisation given its unwelcome intrusion into their lives.

For the above reasons, it is timely to identify: 1) how diabetes organisations currently conceptualise the problem of diabetes-related stigma; 2) how these conceptual understandings are used to justify existing stigma-reduction work or envisage future approaches to stigma-reduction; and, 3) where critical pedagogy might fit within these approaches so to better support an engagement with the ideological and socio-political processes that structure stigmatisation. This chapter addresses these points by drawing on the findings from deliberative democratic groups performed with board members (BRD), healthcare services staff (HCS1 and HCS2), and communications and marketing staff (COM) from a single Australian state-wide diabetes organisation. In this chapter, the findings of the deliberative process are described, including an assessment of the quality of deliberation,

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<sup>22</sup> Such public health functions include primary, secondary, and tertiary disease-prevention activities (Bowman et al. 2003), as outlined earlier in this thesis.

followed by a discussion of the implications of these findings for future stigma-reduction work and how critical pedagogy might interface with organisational attempts at stigma-reduction.

## Assessing the quality of deliberation

The overarching purpose of deliberative methods is to ‘generate informed and considered opinion’ (De Vries et al. 2011, p. 3) about a particular issue. Therefore, it is important to identify to what extent the deliberative process in this research has achieved this aim, and consequently whether it is appropriate to trust that the themes presented in this findings section are based on a careful and thoughtful examination of the presented information and vignettes rather than drawing solely on pre-conceived ideas about diabetes-related stigma (De Vries et al. 2011). To evaluate the quality of deliberation, I drew from De Vries and colleagues’ (2011) *Framework for Assessing the Quality of Democratic Deliberation*, which has been previously developed to evaluate the quality of deliberative methods examining ethical and value-laden issues within healthcare contexts (De Vries et al. 2010; De Vries et al. 2011). Table 14 provides an overview of how this framework was used to assess the quality of deliberation in this research and what findings were produced from this quality assessment.

There are several points to note from this quality assessment. Firstly, the *process* of deliberation was relatively unproblematic. Although there was some evidence of inequalities in participation, in each of the groups both facilitators compensated for this by supporting contributions by quieter or less dominant members. The facilitators also demonstrated efforts to keep discussion on track by repeatedly encouraging participants to relate discussion to specific actions taken by the diabetes organisation and encouraging deliberants to reflect critically on group discussion by requesting clarifications, inviting critique and counter-arguments, and facilitating an analysis of pros and cons of certain actions. However, examining evidence of *participant engagement*, it was also apparent that the different groups deliberated in qualitatively different ways. The group comprising members of the board (BRD) tended to build dialogue around the ideas of others, expanding on ideas presented by others but also offering critique in a respectful manner. Alternatively, participants in the HCS groups were less likely to directly engage with or critique the reasoning of other members, but rather drew on shared frameworks (such as ‘social determinants of health’ or person-centred care) to move towards consensus of action. Different again, participants from the COMS group engaged in a respectful process of turn taking, which led to the articulation of individual perspectives with limited dialogical examination of these perspectives. Despite these differences in discursive style, likely reflecting social practices bound up with organisational and professional roles, these differences did not appear to exert much influence on the forms of *reasoning* used by participants across the four groups.

**Table 14. Assessing the quality of deliberation**

Domains of quality	Quality considerations	How quality was assessed	Appraisal of deliberative quality
Process	Facilitation	Qualitative evidence of facilitators keeping participants on task, encouraging participation and eliciting viewpoints from all participants, and avoiding inserting their own opinions in the discussion	Evidence of: facilitator identifying neglected aspects of discussion (BRD/COM); refocusing discussion on the role of the diabetes organisation (all groups); prompting participants to identify current actions taken by diabetes organisations (all groups); facilitating contributions by quieter participants (all groups); facilitating the introduction of novel perspectives (BRD/COM/HCS1); facilitating others to critique the reasoning used to justify stigma-reduction actions (BRD/COM/HCS1); keeping discussion on track (BRD); seeking clarification on points made (all groups); and summarising the content of deliberation (HCS1/2).
	Equality of participation	This relates to the fairness of the deliberative process. Notes about the equality of participation were taken from field notes completed by the facilitators	<i>BRD</i> – Reasonably equal participation was maintained within the group. <i>COM</i> – There were two dominant participants within the group, with one expressing strong opinions about the importance of personal responsibility for diabetes self-management, and the other focusing strongly on the role of providing PWD (and to a lesser extent others) with information about diabetes symptoms, risk, and management. <i>HCS1</i> - As a senior manager within the organisation, one participant took a more dominant position within the discussion. Other participants contributed less content within the group, although expressed their own point on several occasions following prompting by the facilitator. One participant was very quiet, and with the exception of the last group contribution, did not volunteer information unless prompted by the facilitator. <i>HCS2</i> – One participant was prominent within group discussion – frequently evaluating ideas or other content raised within the group.
	Participant engagement	Qualitative evidence of participants questioning and building on each others ideas	Evidence of: agreement and expansion on points made - towards a more detailed or comprehensive understanding of the issue (BRD/COM/HCS2); expanding on points made by identifying how the organisation has addressed a particular issue (BRD/HCS1/HCS2); identifying overlooked issues (BRD/COM/HCS2); matching issues with interventions (COM/HCS1/HCS2); offering counter-argument (all groups); requesting clarification on points made (BRD/COM); and validating discussion contributed by other participants (BRD/COM/HCS1).
	Respect	Qualitative evidence of positive group dynamics and amicability	The BRD group more frequently engaged in explicitly respectful behaviour (5 instances), than the other groups (2 instances for the COM group and 1 instance for the HCS1 group). Respectful behaviour included recognising the contributions made by others and apologies for breaking deliberative conventions (e.g. interrupting).
Information	Use of on-site experts	Qualitative evidence of using on-site experts to fill gaps in knowledge	The HCS1 group drew on the expertise of a participant regarding how the organisation is currently approaching the strategy of service co-design.

Domains of quality	Quality considerations	How quality was assessed	Appraisal of deliberative quality
	Use of incorrect information	Qualitative evidence of incorrect information going unchallenged and what affect this had on deliberation	The use of stigmatising and blaming assumptions by one participant within the COM group went unchallenged by other participants.
	Learning new information	Qualitative evidence of explicit remarks indicating that learning has occurred or new knowledge has been acquired	No evidence of this.
	Understanding and application of information	Qualitative evidence of understanding of information (e.g. through correcting incorrect information or offering clarifications to other participants) and its application	Evidence of the COM group relating information regarding stigma-blame relations to challenges in recruiting persons with T2DM to share their stories in public fora.
	Impact of information on opinions	Qualitative evidence of the explicit relationship between information introduced via deliberation and changes in perspective	No evidence of this.
Reasoning	Justification of opinion	Qualitative evidence for how participants <i>explicitly</i> justified their positions on the issues discussed	Discussed in detail within the remainder of this chapter.
	Openness to complexity	Qualitative evidence of recognition of complexity of issues involved vs. the oversimplification of complex issues	Evidence of a recognition of: the complexity of the diabetes-weight stigma relationship (COM); challenges in communicating complex issues for public audiences (BRD/COM); incongruence between organisational policy and stigma-reduction goals (COM); the interrelationship between structure and agency (HCS1/HCS2/COM); and PWD as both potential stigmatised targets and stigmatisers (HCS2/COM).
	Adoption of a societal perspective	Qualitative evidence for participant's acting for the 'common good' (cf. self-interest)	Evidence of values regarding the importance of: a communitarian perspective on diabetes care (HCS1/COM); compassion towards others (HCS1); identifying and advocating for the needs and rights of PWD (BRD/COM/HCS1); addressing issues that emerge outside of the diabetes organisation (all groups); and 'empowering' PWD (all groups).

More problematic was the limited explicit reference to the information provided prior to conduct of the deliberative discussion. One of the purported benefits of deliberative methods is that the outcomes of discussion are likely to be more trustworthy given the involvement of an informed public (Fishkin, Luskin & Jowell 2000). This consideration is particularly important for this research given the intent of facilitating a deliberative process where deliberants might consider diabetes-related stigma in a different light. Keeping in mind that the use of recorded group discussion offers only limited insight into the discursive effects of the presented information, there was limited evidence that the presented information was contributing to novel interpretations of the presented vignettes. Rather, participants tended to draw upon on pre-existing experiences and understandings of stigmatisation, which at times allowed for the (what appeared to be unintentional) reproduction of stigmatising or blaming discourse, such as contained in the utterance made by one participant:

But I would just like to share a story where a friend of mine was in a rehabilitation hospital recovering from a very major stroke which nearly killed her, and she had to learn to walk and talk and write and dress herself and do everyday functions all over again, and she's got to the point now where she's nearly probably 90% back to what she was, but she'll never get fully back. But all that was through sheer determination and hard work; she would never have achieved what she has without sheer determination and hard work. She was in hospital at that time with a lady that had had a foot amputated because of diabetes and this lady basically had chocolates delivered to her and was up all night; you could hear them rattling, eating all the chocolates and then saying to the nurse in the morning, "Oh, I don't know why my sugar level would be so high," when she was tested. Wouldn't get up and do anything except lay in bed and whinge. So people can only do so much to assist; at the end of the day it is up to you to do it, so I'm in a bit of two minds about this one. Yeah, none of their business – well the government spends millions and probably billions of dollars on diabetes to assist people and to help themselves manage, so that's a bit of a probably a selfish attitude I think. (COM)

Limited reference to the presented findings was potentially a consequence of the use of vignettes to initiate deliberation, where vignettes function to support participants to interpret the fictional characters' actions by inserting their own self (i.e. beliefs, motivations, and learned behaviours) into the fictional character. That is, 'by putting themselves in the character's place, participants assume that the protagonist is exposed to the same group norms as themselves and so explicate those norms in their responses to the vignettes.' (Jenkins et al. 2010, pp. 180-1).

The following sections provide an overview of the findings of the deliberative discussion, that is, what stigma-reduction interventions (past, present, and future) were described by participants and the types of reasoning drawn upon to justify, reject, or qualify these interventions. These interventions are organised according to their target of action, including whether they focus on removing the stigmatised attribute by addressing the *health problem*, assist individuals to *manage the emotional impact of stigmatisation*, change the knowledge, beliefs, or attitudes of *stigmatisers*, or influence *social and health policy* through activities of advocacy, lobbying, and legislation (Weiss, Ramakrishna & Somma 2006). By examining this interventional landscape, it becomes possible to identify spaces where there is potential for coherence between stigma-reduction work and critical understandings of diabetes-related stigma. However, as the following presentation of results highlights, these suitable spaces are located within a broader landscape of interventions that either

individualise the stigma concept or unintentionally reproduce the concepts used to stigmatise in the first place.

## **How diabetes organisations might address diabetes-related stigma**

### **Addressing the health problem**

A prominent narrative that featured within each group was the organisational imperative to ‘empower’ PWD to better manage their diabetes, addressed through the organisation’s existing suite of individual and group education services. Although the term ‘empowerment’ is an unremarkable feature within diabetes self-management discourse, generally referring to the ability of PWD to efficaciously perform self-management tasks and develop a positive disposition towards one’s diabetes and its care requirements (Asimakopoulou et al. 2012), in the context of stigma-reduction work, the notion of empowerment related to the confidence that might be obtained by knowing that one’s self-management regime is appropriate. This then reduces culpability for adverse outcomes and contributes to a reduced risk of or delay in the onset of shame-inducing complications.

P1: So does education help eradicate that or does it empower people to try and not put so much emphasis on and not worry about that? Because that’s ultimately - if we can try and just - - -

P2: Allay them.

P1: Yeah. Give people the confidence to - - -

P2: Empowerment.

P1: Empower. I like that word.

P2: Empowerment. The confidence. It’s about that confidence.

P1: To then be like, well, you can judge all you like but I’m doing this because I know I’m doing the right thing. Do you know what I mean? Because you’re never going to stop judgement.

P2: Especially with diabetes, they’ve got the confidence to say well, no, I’m managing it and this is what I feel is the best thing for me. (HCS 2)

Although the notion of ‘empowerment’ was widely accepted by participants as a universally desirable activity, one participant (HCS1) offered a critique of the empowerment-concept (as used by other deliberants) by suggesting that it conceals the way in which personal agency, assumed to operate freely within the notion of empowerment, is constrained by what she referred to as ‘social determinants’, making generic reference to a social determinants of health framework (Clark & Utz 2014). In offering this counter-point, she inferred that empowerment-based approaches might fail to reduce stigma in an equitable manner given that certain individuals will be less able to ‘empower’ themselves through acts of self-management because of social and cultural constraints on dispositions and behaviours. This point stimulated further discussion amongst the group (HCS1), recognising interactivity between behaviour, socioeconomic status, and food environments, which



led to the assertion that the asymmetrical focus on behaviour change interventions (emphasised within diabetes organisations) versus socio-ecological interventions (de-emphasised) might conceal problematic assumptions about personal agency and responsibility for health. Underlying this point was the assertion that a greater emphasis on socio-ecological interventions for diabetes prevention might function to reform or redirect (tacit) understandings of the problematic individual towards understandings of a problematic environment in which diabetes prevention and management occurs.

I just focussed as well on, "The decision and responsibility is solely mine," and I think collectively as a community, we all have a responsibility ... But I kind of reflected on okay, so smoking campaigns and those sorts of things. We put the responsibility back on to that person with lots of [messages about] why you shouldn't be smoking and relationship with lung cancer. Not everyone who gets lung cancer is a smoker. But maybe we have a responsibility in somehow influencing government to shift reliance on packaged or processed foods and trying to shift it to supporting processed whole foods, healthy foods, whether it's in I guess, the more disadvantaged SES [socio-economically disadvantaged areas] and maybe, the disadvantaged and remote communities as well... This person's saying it's their decision and responsibility is theirs, however for some people, the choices they make are based financially or lack of education. (HCS1)

Although each group in this study gave rise to un-prompted discussion regarding ways in which diabetes organisations might support weight reduction at individual and population levels, the relationship of obesity to the stigma concept was not a prominent feature within the deliberative discussion. One exception was amongst dietitians from the HCS1 group, who drew from the Health At Every Size (HAES®) approach as a strategy for improving desirable health-related behaviours whilst reducing implicit weight biases within their practice (Robison 2005). However, these actions focused on therapeutic approaches taken by individual healthcare providers and less on the role of diabetes organisations in addressing implicit weight bias within organisational practices and discourses. Overall, the role of diabetes organisations was to continue to support individuals (both with diabetes and those at risk of developing T2DM) to reduce weight given the potential health benefit of weight reduction, with no discussion of the role of weight-reduction actions in reducing feelings of weight-related shame or fending off attributions of blame for a diabetes diagnosis or sub-optimal diabetes management.

### **Reducing the adverse emotional impact of stigmatisation**

Although no group identified existing actions to specifically reduce the adverse emotional effects of stigmatisation, the HCS1/2 and COM groups suggested that a potentially useful approach would be to provide education to PWD to allow individuals to better cope with stigmatisation. This claim was premised according to two lines of reasoning. Firstly, it was argued that for those experiencing stigmatisation, the internalisation of stigmatising beliefs must be disrupted with information that: a) stimulates a self-awareness of these internalised beliefs, where relevant, and b) brackets off cultural beliefs that are either not-personally relevant or are otherwise unhelpful to the central task of diabetes self-management. Secondly, a focus on education as a stigma-reduction strategy was premised on the belief that dominant stereotypes about PWD are relatively stable within society, and that educational interventions act to emphasise personal agency in a context that functions to

constrain it – both because of the effects of stigmatisation and because of broader paternalistic practices affecting PWD. Although not named as such, this approach to education appears to closely resemble a psycho-education approach for the reduction of self-stigma, similar to what is observed in (self) stigma-reduction work relevant to persons living with mental illness (Mittal et al. 2012). Notably, the educational approach described by participants is consistent with what Mittal et al. (2012, p. 979) categorise as interventions that support stigmatised persons to ‘accept the existence of stigmatizing stereotypes without challenging them and that enhance stigma coping skills through improvements in self-esteem, empowerment, and help-seeking behavior’. The following excerpt, again drawing on the notion of empowerment, illustrates how knowledge about the relationship between self-care and diabetes-related complications is thought to enable PWD to better cope with shameful emotions regarding the potential future disabled self, offering a cognitive strategy for deflecting a felt stigma.

If you have awareness campaign about preventing complications then you will actually learn that even when someone tells you it's really bad, you will know, well actually I have that knowledge, the powerful knowledge that I know that it's preventing complications that I have the power, I feel empowered to actually deal with the condition as it is. (COM)

### **Actions to influence stigmatisers**

This group of interventions involved actions used to modify the beliefs, attitudes, and practices of those who either currently stigmatise PWD, or those that might do so given the opportunity. These interventions represented a dominant category of actions within this deliberative research, drawing on the assumption that there exists commonly held inaccurate stereotypes about PWD (or sub-groups of PWD) on which negative attitudes are built, and which are then communicated (and experienced) via a stigmatising medical and moral discourse. For participants in this study, this logic led to tasks of correcting inaccurate beliefs about features of diabetes and its management and developing positive feelings towards PWD and their efforts towards self-management. Details regarding the specific interventions used to achieve this broad aim are described below.

One group of actions, already occurring in a limited way via existing channels of communication, include attempts to communicate *factual* information about diabetes or correcting inaccurate information. The need to communicate accurate information was largely premised on the claim that news media has historically and continues to portray PWD in inaccurate ways, attributed to the manipulation of information by journalists and editors within news organisations in order to appeal to their consumer market. In particular, participants described how news media has tended to draw on obsolete understandings of diabetes as a ‘death sentence’, has oversimplified diabetes aetiology in a way that portrays T2DM as a self-inflicted disease, and has established inaccurate ideas about the ‘diabetic diet’. For participants in this research (BRD/HCS1/2), diabetes organisations were seen to have a potential role of providing more accurate representations of (or factual truths about) diabetes in order to counter or ‘dilute’ inaccurate messages produced via news media. This activity was seen to be the role of diabetes organisations given that a change in reporting was considered unlikely to

occur spontaneously given a belief that media and public health organisations have a vested interest in manipulating information about diabetes given financial business drivers of news sales and reducing healthcare expenditure.

Participants proposed that a more accurate communication of information about diabetes could potentially be achieved through mass communication efforts, involving media liaisons or ambassadors, conducted independent of (i.e. initiated and performed by the diabetes organisation) or in collaboration with existing news-media organisations (i.e. collaborative work initiated by and maintained by the diabetes organisation, but performed by media organisations). Central to this proposal was the role of PWD themselves in representing diabetes and PWD. Member stories were seen (BRD/HCS/COM) as a powerful means of obtaining audience attention and communicating 'factual' medico-scientific information about diabetes whilst generating positive attitudes towards PWD and their efforts towards self-management. Although limited detail was provided regarding the desired content of these stories (BRD/COM), it was clear that appropriate ambassadors should have positive stories to tell about their illness experience and positive dispositions towards diabetes self-care. This idea about the ideal-type candidate is reflective of the observation that 'socially sanctioned illness narratives [should] dwell not on loss and failure but on the overcoming of loss and failure' (Diedrich 2007, p. 54), thus painting a 'particular configuration of a 'public patient' (Roney, 2009), who has not only survived, but thrived through, illness' (Lucherini 2019, p. 11).

I think if you go down the media path and you have a media personality that might be about profile. But you really need a person that actually understands diabetes. And that's not just a health professional; they are people living with diabetes. So the approach that I'd like to see is that you actually have ambassadors that actually have diabetes across the types of diabetes, that are trained, are able to – and most people – you saw it in our TV commercials that we developed for our campaigns last year – we picked certain people, board included, that could actually talk about their personal experiences of living with diabetes. (BRD)

However, the assertion that diabetes organisations must provide factual and unembellished information about diabetes from a standpoint of neutrality was met with the counter-argument that a neutral stance is difficult to achieve given the public health functions of the organisation. For example, several participants suggested that communicating obesity as a modifiable risk factor for T2DM development is important in order for individuals to promptly identify and manage risks associated with diabetes development or progression (BRD). Reflecting a similar but more formally expressed logic, one participant in the HCS1 group claimed that risk communication efforts need to be sufficiently 'strong' in order to promote behaviour change, justified using the theoretical logic of the Health Belief Model (Champion & Skinner 2008). Taking an explicitly neutral stance on communicating 'facts' about diabetes also was challenged on the basis that stereotypes and prejudice often draw heavily on moral concepts about the PWD. Therefore, a distinction was drawn between scientific beliefs about diabetes per se and moral beliefs about PWD. This distinction is evident in the following excerpt, which emerged in response to claims regarding the need to communicate more scientific-factual information about diabetes and its management.

My initial reaction was it's a focus on diabetes from the standpoint of lifestyle exclusively, and in a way I think it's creating its own stigma with that kind of reporting and that kind of message rather than the cross section of all those people affected by diabetes. I think it creates a stigma of people don't look after themselves, don't manage their condition and that people that have diabetes are lose/wins [losers or winners], which, as I say, is not in all cases, but it creates this, I guess, stigma for me also, these people, why should they be helped, because they're creating a problem for themselves. (COM)

The idea of adopting a neutral communicative stance was also countered by the need to strategically portray life with diabetes in positive terms. For members of the board, the status quo is for diabetes to be framed in a way that is obstructive to living a good life, drawing on notions of suffering, and that the positive framing or normalisation of diabetes provides a means of counteracting unhelpful portrayals of life with diabetes (BRD). However, attempts to de-emphasise the suffering associated with diabetes might also have the undesirable consequence of communicating a reduced need for research or support services for PWD (BRD) and might also fail to adequately recognise the challenges of diabetes self-management, potentially running afoul of the organisation's goal of maintaining an empathetic relationship with members (HCS1/2). Following a similar logic to the HCS groups, board members also deliberated on the benefits of communicating the capabilities of PWD in an assets-based manner (to offset the frequent problematisation of PWD) versus the risk that an assets-based approach may further contribute to the blaming of those that have 'failed' to effectively manage their diabetes, particularly in contexts where diabetes incidence and management is structured by social issues such as poverty.

Implying that they themselves assume the role of the stigmatiser at times, several participants (COM/HCS1/2) argued for the need to reflect on one's own practices and identify how these practices might unintentionally contribute to the stigmatisation of PWD. This need was justified given past observations of other diabetes organisations employing fear-based tactics for purposes of fundraising (COM), and recognition of the way that the training of healthcare professionals has led to the uncritical adoption of assumptions about overweight persons and persons with chronic illness (HCS1/2). For the HCS1 group, several participants recognised the unequal power that tends to exist between healthcare providers and PWD, which means that the onus placed on healthcare providers to reflect on their use of language as it relates to stigmatisation.

### **Policy and advocacy**

As an organisational work-in-progress and a broad aspirational statement, all groups within this deliberative research sought to establish their organisation as a highly visible, credible, and authoritative voice in representing diabetes and PWD. In relation to stigma-reduction work, the desire to do so was founded on the logic that:

1. their organisation was accountable to the needs and interests of members given the organisation's mission of supporting members to 'live well' (BRD/COM) with diabetes;

2. that stigmatisation is antithetical to the goal of living well with diabetes, at least for a certain proportion of its members; and,
3. that powerful financial business drivers of news media organisations and healthcare systems, which act to maintain stigmatisation, mean that changes in stigmatising practices and discourses are unlikely to occur spontaneously.

In developing a credible and authoritative voice, members of one group (HCS1) discussed the central role of co-design policy<sup>23</sup>, which was in early stages of development within the organisation. In relation to stigma-reduction work, co-design was described in a way that assumes that PWD are inherently capable of identifying and correcting stigmatising practices contained within the activities and communications performed by the diabetes organisation, and in doing so can reduce the exposure of PWD to distressing content produced by the organisation. However, this assumption was also problematised within the group, based on observations of PWD contributing to a stigmatising discourse by labelling themselves as 'diabetics'. The idea of co-design was also problematised with reference to behaviour-change interventions (particularly those informed by the Health Belief Model) that require a certain level of (paternalistic) manipulation of cognitive and affective processes in order to motivate desirable behaviour. Therefore, there were limits placed on both the ability of PWD to identify stigmatising practices and the organisation's ability to avoid these practices (if identified) given limits on autonomy in the face of a preventative health agenda. This discussion reflects a broader literature examining the limits placed on public/patient autonomy within democratic approaches to healthcare planning and delivery (Munthe, Sandman & Cutas 2012).

P1: We are really sensitive and careful when we're developing content about, for example, any services or program in the future and it's a challenge for us to balance between raising awareness and in the meantime, protecting participants' mental health, in terms of not creating distress or a negative emotion as is it also our message, because message needs to be strong, because we know from the health belief model that we have to communicate and the more they are aware or they are concerned about the consequences of disease, the more they think with intent to change their behaviour. So that's for us, a challenge how to include in the design and delivery of services and programs.

P2: And that's where the co-design can certainly come into it. (HCS1)

Although co-design was described with reference to actions taken internal to the organisation, there was further discussion about how the organisation might support healthcare reforms towards a model of person-centred care (PCC). Reflecting typical components contained within PCC and related approaches (Munthe, Sandman & Cutas 2012), PCC was described by participants as a model of healthcare that allows for and is responsive to patient narratives and supports collaborative decision-making between the patient and their care provider, which is performed with the purpose of allowing the PWD to care for their diabetes in a more autonomous way. Across the deliberative

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<sup>23</sup> Co-design, as described by participants in this research, represents a participatory approach to healthcare service delivery that purposely seeks to reshape relationships of power between patients/consumers/citizens and healthcare services (Donetto et al. 2015).

groups, PCC was described as an approach that might mitigate stigmatisation via several mechanisms:

- Person-centred care functions to draw attention to non-behavioural factors which contribute to difficulties with diabetes self-management, contribute to weight gain, or inhibit weight reduction, thus avoiding the imposition of assumptions about the PWD being weak-willed or irresponsible and having the effect of limiting attributions of personal blame (HCS2).
- Person-centred care functions to support recognition of the diversity of aetiology and needs amongst PWD, which is useful in overcoming over-generalisations about PWD (COM).
- There exists a power-gap between healthcare providers and PWD, which allows for the reproduction of stigmatising and blaming practices and discourses. PCC provides a mechanism for the disruption of unequal modes of interaction (HCS1).

According to participants in this study, mainstream healthcare services were considered likely to forego PCC because of the inability of these services (prioritising efficient service delivery) to accommodate the additional time requirements for PCC. These business drivers, rooted in national healthcare financing arrangements, were seen to be intractable from the standpoint of a diabetes organisation. Therefore, a possible solution to this problem was to establish referral pathways to care providers, such as those healthcare providers employed by diabetes organisations, who are more likely to practice PCC and who understand the complexity of issues involved in diabetes self-management (BRD/HCS). This point led to discussion of informal cultures within their diabetes organisation that supported the adoption and enactment of certain person-centred virtues. Reflecting their *client services charter*, participants within both HCS groups described an organisational culture that promotes an ethics of care for PWD. These participants emphasised the inherent human value of PWD and discussed how principles of honesty and empathy acted as guiding principles for interactions with PWD. The below excerpt, involving one participant reflecting on the research vignette, illustrates the way in which empathy functions to support an inter-subjective understanding of the way that the medicalisation and moralisation of diabetes functions to create a shameful experience for certain PWD.

I just felt quite sad that they're viewing themselves as defective. I think as humans, we need to show compassion and empathy towards others. And just because we have a particular condition, doesn't mean you're broken. You hear that all the time with chronic conditions that you know, I've either got a gene that's caused this or my diet, my lack of exercise has caused this. I'm the one that's at fault here. (HCS1)

## Discussion of Findings

In interpreting these findings, it is apparent that participants drew from a complex assemblage of ideas about PWD and stigmatisation. Unsurprisingly, many of the discursive practices observed with group deliberation reflected those produced by participants in earlier parts of this doctoral research. This included discourses related to the medicalisation of PWD, the pervasive effects of ideas around

bio-citizenship and consumerism in healthcare, the role of public health pedagogies, and the individualisation of the stigma concept. This observation warrants further consideration about how diabetes-related stigma was conceptualised by participants and how this conceptualisation influenced their choice of stigma-reduction strategies. As the following discussion demonstrates, stigma-reduction interventions are intimately tied to the concepts used to understand stigmatisation, with certain concept-intervention configurations being more congruent with a critical theory of diabetes-related stigma.

### **Conceptualising diabetes-related stigma and stigma-reduction work**

When deliberants spoke about stigma, they often referred to *diabetes* being stigmatised per se, reflected in utterances claiming a 'stigma of diabetes' or that 'diabetes is stigmatised'. In this way, there was a tendency to conceptualise stigma as a collection of negative beliefs regarding the disease and disease process itself. The focus on diabetes itself is consistent with the notion of disease stigma, representing the 'negative social "baggage" associated with a disease that is not justified by the medical effects of disease on the human body' (Deacon et al. 2005, cited in de-Graft Aikins 2006, p. 428). A focus on features of diabetes appeared to contribute to a set of actions designed to address this social baggage, either by correcting myths about diabetes (via mass education) or re-appraising the personal relevance of certain beliefs about one's diabetes (via psycho-education). For participants in this deliberative research, addressing 'disease stigma' formed a relatively simple logic, best addressed through educational interventions purposed with communicating factual or medico-scientific 'truths' regarding diabetes. However, this logic is somewhat naïve in that it assumes that medical knowledge exists as a value-free and 'bounded scientific system separate from wider influences' (Salmon & Hall 2003, p. 1969). As this doctoral research has found, medical knowledge of the body is buttressed by notions of biological citizenship, which are drawn upon as mental resources to construct the stigmatised Other. This interaction between medical and moral knowledges recognises that 'although scientific understanding of the person influences medical practice, the needs of doctors [or public health practitioners] should also be expected to shape the way that medical science describes the person' (Salmon & Hall 2003, p. 1969). Therefore, correcting 'misinformation' about diabetes with medico-scientific 'facts' may simply deflect blame away from those 'normal' PWD who experience a courtesy or associative stigma (Corrigan, Watson & Miller 2006; Goffman 1963; Phillips et al. 2012), whilst doing little to challenge the production of stigmatised sub-groups who are defined by their tragic-disabled bodies and 'irresponsible characters'.

But despite frequent use of the phrase 'stigma of diabetes', participants often made reference to appraisals of the conduct and character of the *PWD*. Here, the focus was on language and the way that it functioned in a performative way to represent PWD as (im)moral agents, leading participants in this research to assert that changes in a moral language required changes in the way that PWD are represented through public communications produced through diabetes, public health, and news

media organisations. This claim led to suggestions that media ambassadors (as PWD) and models of person-centred care and service co-design might contribute to shifts in representations of PWD. Specifically, participants in this research sought to represent PWD as socially embedded agents (Auduly, Asplund & Norbergh 2010; Goldberg 2017). Although participants wanted to preserve the agential properties of PWD, particularly given the focus on personal 'empowerment', they also wanted to do so in a way that acknowledges the way in which individual dispositions and choices are constrained by economic, social, and cultural resources (Weaver et al. 2014). Acknowledgement of these constraints were seen to challenge the underlying assumptions of moral responsibility and culpability for a diabetes diagnosis or the onset of diabetes-related complications (Persson 2013). However, because the business drivers of media organisations and public health/healthcare services were considered unlikely to support such representational change by themselves, participants suggested that diabetes organisations would need to take an active role in transforming representations of PWD through policy and advocacy approaches. Such intervention would apply to policy activities internal to the diabetes organisation, such as with the adoption of co-design principles to guide service delivery and public communications, and advocacy work external to the organisation, such as that involving media organisations.

Whereas reducing 'disease stigma' was discussed as a task that could be performed by medico-scientific experts, addressing the moral basis of stigma (what de-Graft Aikins (2006) and Deacon (2006) refer to as symbolic stigma) was a task that should be performed by PWD themselves. At an individual level, actions to deflect stigmatisation were contained within interventions designed to 'empower' PWD to better manage their diabetes or better cope with stigmatisation. Use of the term 'empowerment' in the context of stigma-reduction work is interesting given observations that empowerment (as a cognitive construct) is a mediator of *self-stigma* for those living with mental illness (Corrigan, Larson & Rüsck 2009). Empowerment and self-efficacy both work to ensure that the individual is able to pursue and achieve desirable (self-management and other) goals in the face of stigmatisation (Corrigan, Larson & Rüsck 2009; Mittal et al. 2012). This has led to claims that 'self-esteem and empowerment could be independently targeted to reduce self-stigma' (Mittal et al. 2012, p. 979). However, a likely unintended consequence of use of the empowerment concept by participants in this research is that it locates the problem of stigma in the cognitions, emotions, and behaviours of individuals, rather than in 'societal-level conditions, cultural norms, and institutional policies' that are problematised within structural forms of stigma (Hatzenbuehler and Link 2014, 2). In this way, the empowerment concept functions to remove 'the ambiguity in the biopsychosocial model as to the primacy of the person over the disease' (Salmon & Hall 2003, p. 1974), reinforcing notions of personal responsibility and control.

Actions to challenge the moral basis of stigmatisation at a more structural level were apparent in references to person-centred care (PCC), service co-design, and media advocacy work, following broader policy drivers towards public and patient involvement (PPI) or 'consumer engagement' in



healthcare and the democratisation of healthcare planning, implementation, and evaluation (Mittler et al. 2013; Mitton et al. 2009). However, within these broader reforms, stigma-reduction work was envisaged to focus on specific aspects of public/patient involvement. Such aspects of public/patient involvement included enabling communication of the patient narrative within healthcare encounters so to acknowledge the tension between behavioural self-control and the socially-embedded nature of diabetes self-care (de Wit et al. 2020), or using co-design principles to identify and correct inappropriate representations of PWD within public communications performed by diabetes organisations, public health communicators, and news media organisations. These findings suggest that rather than requiring a new suite of strategies for stigma-reduction, many existing activities within the policy landscape of diabetes organisations may be able to accommodate stigma-reduction work with some modification.

### Locating critical pedagogy within stigma-reduction work

Like that observed in stigma-reduction work relevant to persons living with HIV-AIDS (Deacon 2006), this deliberative research has produced a mixed bag of possible stigma-reduction interventions (Table 15). Each of these interventions can be seen to emerge from implicit understandings about the nature of diabetes-related stigma. In relation to *addressing the health problem* and *addressing the emotional impact of stigmatisation*, it is apparent that stigmatisation is simply being avoided or deflected through individual acts of self-care or coping. The logic and legitimacy of stigmatisation remains intact within these approaches, albeit with benefits for those that are able to comply with obligations of self-care and are better able to cope with their illness. In *addressing the stigmatisers*, stigmatisation is assumed to occur because of erroneous beliefs about features of diabetes and/or its management. Here, medical understandings of diabetes care are assumed to represent a body of neutral or value-free ‘facts’ that can be drawn upon to correct these erroneous beliefs. In doing so however, there is no defence for those PWD that are evaluated against such ‘facts’ and who are deemed to be ‘irresponsible’ and/or tragically disabled. However, the last group of actions, highlighted in red in Table 15, imply that the conceptual knowledge used to evaluate PWD lies at the root of stigmatisation and should be subject to critique and revision. This last group of actions is where a critical pedagogy is required.

**Table 15. Suggested interventions for stigma-reduction work relevant to persons with T2DM**

Stigma focus	Specific targets for action	Potential actions (internal to diabetes organisations)	Potential actions (external to diabetes organisations)
Addressing the health problem	Support PWD to efficaciously perform self-management tasks and develop a positive disposition towards one’s diabetes and its care requirements	Provision of individual healthcare services	Support engagement of PWD with individual healthcare services

	Support individual weight-reduction	Provision of individual healthcare services	Support engagement of PWD with individual healthcare services
Addressing the emotional impact of stigmatisation	Enhance ability of PWD to cope with disease stigma	Psycho-education (stand-alone or integrated into existing counselling and disease self-management interventions)	Encourage help-seeking behaviour in support of individual counselling
Addressing the stigmatisers	Promoting a <i>factual</i> understanding of the aetiological complexity of diabetes	Organisational communications	Changing media representations of diabetes and PWD in proactive/anticipatory and reactionary ways
	Clearly communicating the current status of knowledge regarding norms of self-management for PWD	Organisational communications	Changing media representations of diabetes and PWD in proactive/anticipatory and reactionary ways
	<b>Raising visibility of practices and discourses contributing to feelings of shame and/or guilt</b>	<b>Co-design</b>	<b>Breaking silence through social justice-oriented movements</b>
Policy and advocacy work	<b>Transformation of the way that PWD are represented – towards the socially-embedded but capable agent</b>	<b>Co-design</b> <b>Provision of individual healthcare services guided by principles of person-centred care</b> <b>Increased emphasis on and communication of interventions that seek to address risky/unhealthy environments</b>	<b>Advocacy for person-centred care</b>

This last group of actions, particularly actions of service co-design and the provision of and advocacy for PCC, appear to reflect a desire to make diabetes healthcare services more *democratic*. This desired outcome is relevant to critical pedagogy, which is broadly concerned with developing the literacies to support individuals to become competent democratic citizens (Wisniewski 2015) and for marginalised voices to be articulated and included within democratic processes where dominant groups and forms of knowledge tend to dominate decision-making processes (Steinberg & Kincheloe 2010). For Giroux (2004), a desirable outcome of critical pedagogy is for learners to understand the relationship between knowledge, values, social relations and power and to make visible alternative forms of democracy. For Giroux, learners must first make problematic their representation of certain issues through a process of deconstruction, which is then used to create alternative discourses. Such a post-structuralist inspired approach to critical pedagogy offers a way of overcoming the limitations of existing work seeking to democratise healthcare services and policy. A key problem

with healthcare democracy is that involving 'patients', 'publics', or 'consumers' in decision-making fora often fails to enable the production and consumption of new voices. Drawing from Foucault, patient voices are likely to represent *subjugated knowledges* that when held up against medico-scientific understandings of, and evidence for, disease prevention are likely to be discredited as being naïve or inferior (Lancaster et al., 2017). Of relevance to this research however, such subjugated knowledge can be seen to 'provide points of rupture' (Bacchi 2009, p. 36) that offers opportunities to critique and challenge powerful forms of knowledge. This is not to say that challenging medical and consumerist ideologies should result in PWD rejecting these forms of knowledge outright, but rather recognising how these forms of knowledge are bound up with the exercise of power designed to control the conduct and bodies of PWD and in doing so lay the foundation for stigmatisation.

For certain participants in this deliberative research, this subjugated knowledge took the form of a social model of diabetes that sought to represent PWD as socially-embedded agents. Use of this social model of diabetes can be seen as a form of resistance to the dominant framing of PWD as free-acting and responsible health citizens functioning as an oppositional device that might destabilise the present and bring 'the future into view' (Beckett & Campbell 2015, p. 272). Whereas the social disability movement sought to use the social model of disability as a political instrument to make visible a disabling environment and recognise impairment as a form of human diversity (Oliver 2013), participants in this research used a SDH framework to recognise how diabetes is produced via a risky environment, thus challenging notions of irresponsibility. From this perspective, the use of fear of complications as a pedagogical or motivational tool becomes illegitimate as it violates a core assumption about the PWD – as they cannot be assumed to act in a free or unconstrained way. For certain participants in this research, an increased emphasis on interventions that address risky or unhealthy environments offered a symbolic strategy for communicating assumptions about the social embeddedness of diabetes prevention and care.

However, this is not to say that such subjugated knowledge might be easily expressed or even considered valid by PWD. One troubling observation is that persons without diabetes (i.e., healthcare services staff) rather than PWD (i.e., the majority of participants in the earlier case study research) were generally better able to communicate alternative representations of PWD. Previous research has observed how the contributions of illicit drug users (as a stigmatised group) acting in 'consumer' advisory roles can be distorted by discursive-material practices that constrain how they might participate (Lancaster et al. 2017). Such discursive-material practices include the way that drug users come to see themselves as 'irrational and illegitimate political subjects' (Lancaster et al. 2017, p. 66), how they draw upon dominant medical discourses in attempt to enhance the legitimacy of their contributions, and how they are inappropriately constructed as being representative of the collective of drug users. Likewise, for participants in the earlier case study research, the expression of potential subjugated knowledges were highly constrained by medical and moral reasoning applied

to understanding the self and Other. Furthermore, the expression of alternative forms of knowledge about PWD is likely to be constrained by the dependence of PWD on medical services, in which PWD derive direct material benefit. Like that observed amongst parents of children with impairment/disability, the desire to represent disability in social terms is tempered by the embodied reality of managing impairment and the material benefits that medical involvement brings (Manago, Davis & Goar 2017). In relation to diabetes-related stigma, this observation would seem to suggest that critical pedagogy would be best served by using a social model of diabetes as a vantage point from which to think differently about the statuses of PWD, without discounting the value of medicalised understandings of the body.

In summary, this chapter has demonstrated that amongst a mixed bag of stigma-reduction interventions, democratic spaces within diabetes organisations and healthcare systems offer a potential site where marginalised subjectivities can be expressed and used to re-interpret stigmatising practices. This idea follows the claim by Lancaster (2017, p. 66) that 'to overcome what we see as being problematic subjectification effects, finding modes of engagement which allow for multiple possibilities and emerging political subjectivities would appear to be an essential endeavour'. For such engagement to occur however, a critical pedagogy is likely required to initiate a process of critique and support PWD to actively question the truths and obligations handed to them and begin to create alternative representations of PWD. The following section provides an overview of how this engagement might practically occur, bringing together the findings from the chapters in this section.

## Section Four: Research Discussion

In this doctoral thesis, I originally posed the question: *what understandings of diabetes-related stigma are produced through participation in an educational intervention informed by a critical pedagogy and what pedagogical and non-pedagogical processes contribute to these understandings?* Within this section, I provide an answer to this question by synthesising the findings presented in Section Three of this thesis. The purpose of this synthesis is to make explicit how knowledge produced from this analysis has advanced current understandings of diabetes-related stigma and the role of critical pedagogy in stigma-reduction work (relating to the literature reviews within Section One of this thesis), why these findings should be trusted (relating to the research methodology presented in Section Two), and what implications this knowledge has for future stigma-reduction work.

In short, I present the argument that the ability of PWD to engage in a critical analysis of diabetes-related stigma is heavily constrained by discourses of risk and risk management, which obstruct attempts to 'conceptualize and enact new ways of being human' (Kincheloe 2004, cited in Horn 2011, pp. 81-2). These risk discourses, drawing on medical and moral concepts, provide individuals with the resources that function to promote forms of identity thinking that seek to classify PWD along lines of (physical) health and moral status. Despite the pervasiveness of this stigmatising logic, there was some evidence of participants engaging in a nascent critical analysis of and challenge to stigmatisation. This evidence meant that it was possible to identify several features of learning that appear to play a role in a critical analysis of diabetes-related stigma. These features of learning included a process of *specifying the precise target of stigmatisation, evaluating the fairness of stigmatisation, using certain texts to facilitate an analysis of how dominant forms of knowledge are used to stigmatise, and being able to articulate an alternative non-stigmatising reality*. Based on a deliberation of these findings with staff from an Australian state-wide diabetes organisation, it appears that a critical pedagogy project relevant to stigma-reduction work would be best located within broader practices seeking to democratise public health and healthcare delivery. These conclusions are discussed in detail within this section, along with a critique of the research methodology used to produce them and a discussion of their likely implications for future public health research and practice.

## **13. DISCUSSION OF THE RESEARCH AND ITS IMPLICATIONS FOR PUBLIC HEALTH RESEARCH AND PRACTICE**

In providing a discussion of research findings, this chapter is structured into three main parts. The first part provides an overview and interpretation of key findings against the research aims and a broader literature, describing how these findings have advanced knowledge in these areas. The second part presents an argument for why these findings should be trusted, whilst also describing some of the limitations of this doctoral research and how these limitations might be addressed in future research. The third part then offers an interpretation of the role of critical methods of education within stigma-reduction work and the implications of this role for future public health research and practice. Throughout these parts, I offer a critique of the assumptions contained within this research, specifically how these assumptions relate to the definition of the problem of diabetes-related stigma, public responses to research recruitment activities, design of the research and educational program, and the analysis and interpretation of findings. I then conclude this thesis by pulling together what knowledge this doctoral research has produced, in what ways this contribution has advanced existing knowledge, and the implications of this knowledge for public health research and practice.

### **An overview and interpretation of key findings**

In examining a critical pedagogy for understanding diabetes-related stigma, this doctoral research has entered uncharted conceptual space in two main ways. Firstly, literature examining diabetes-related stigma (Chapter 2) has largely focused on the content of culturally derived beliefs and attitudes towards PWD (or diabetes per se) and the individual response of PWD to these things, particularly in relation to feelings of shame and blame/guilt (Basinger, Farris & Delaney 2020; Browne et al. 2013; Hernandez et al. 2020). With some exceptions (Bock 2012; Brookes & Harvey 2015; Whittle et al. 2017), it was demonstrated that this literature has yet to engage with broader criticisms of stigma research as being too individual-focused and avoidant of issues of power and social inequality (Hatzenbuehler & Link 2014; Parker & Aggleton 2003; Scambler 2019; Tyler & Slater 2018). A comprehensive critical theory of diabetes-related stigma is notably absent from this literature.

This thesis has addressed the first gap by identifying how diabetes-related stigma emerges from the way that societies attempt to govern the risky bodies and dispositions of PWD, which shapes the way that PWD derive meaning from their illness and its management. This governing of risk has allowed biomedical understandings of the body to flourish, offering an opportunity for PWD to develop literacies in risk management and a potential way out from a natural history of disease progression. This governing of risk also produces a series of concepts used to understand the body, which forms the basis for feelings of shame regarding one's fat body and present or future tragic-disabled self. What gives diabetes-related stigma its potency is the coupling of biomedical ideas

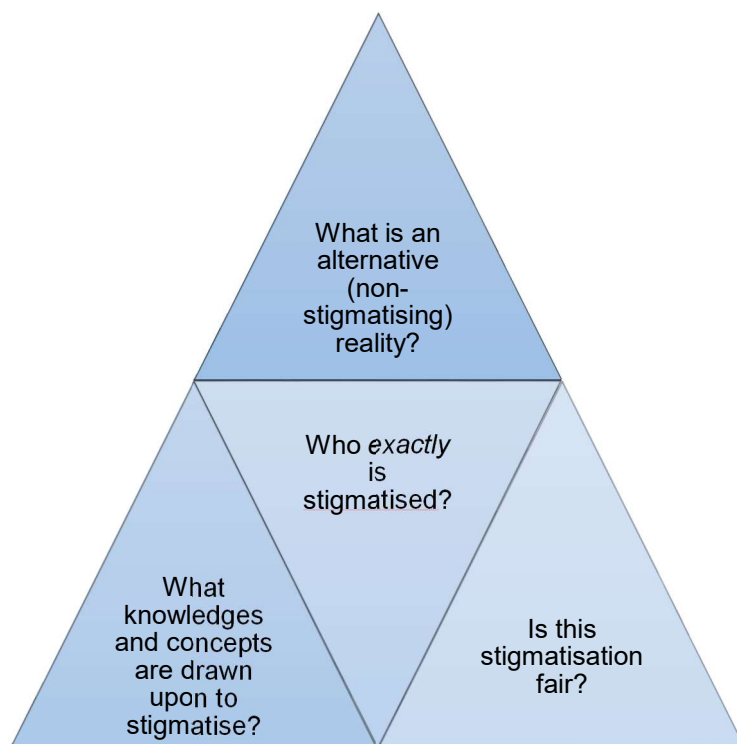
about the body and self with an ideology of responsible citizenship, creating the ideological bio-citizen. Concepts related to personal responsibility, including the primacy of personal agency and moral obligations for self-care, are then drawn upon as a resource for othering, separating the 'normal' (i.e., responsible, resilient, and strong-willed) self with the stigmatised (tragic-diseased, irresponsible, and obese) Other. This othering has the effect of heaping blame on shame, whereby the shameful experience of being fat (or obese) or possessing diabetes-related complications also infers blame due to deficits in moral character. This process appeared to be supported by the pedagogical function of health news and health education, transmitting ideas around risk and (individual) responsibility, and by surveillance practices leading to professional, public, and/or self-administered disciplinary measures that are justified by a paternalistic logic. Whilst this interpretation of diabetes-related stigma reflects existing theorising about stigma/othering as a product of the way that societies govern risky, dangerous, and disgusting (obese) bodies, ideas which converge within the work of Lupton (1995, 1998, 2003, 2012a, 2013a, 2013b, 2013c), Scambler (2002, 2006a, 2006b, 2009, 2018a, 2018b, 2019), Douglas (1966), and Rose (2007) for example, this doctoral research has provided a re-interpretation and revision of these ideas in relation to type 2 diabetes. This re-interpretation offers a novel framework for thinking about diabetes-related stigma in a more critical way, bringing to attention neglected considerations of othering, ideology, and the governing of risky bodies. These findings also strengthen the claim that critical pedagogy is appropriate for examining diabetes-related stigma given the ideological role that public health pedagogies play in transmitting the values of the state and shaping the subjectivities of PWD.

Despite the promising role of critical pedagogy, there is no quality evidence that critical pedagogy has been used to guide stigma-reduction work in relation to diabetes or other stigmatised conditions, as established in Chapter 4 of this thesis. This forms the second void in knowledge that this doctoral research has addressed. To some extent, this observation partly ignores the implicit educative function of advocacy work<sup>24</sup> that has been observed to occur amongst persons living with HIV (Gillett 2003), mental illness (Holland 2018), fatness (Saguy & Riley 2005), and disability (Beaudry 2016). However, critical pedagogy can be differentiated from these approaches in that it 'does not determine how we see the world nor does it provide a blueprint for particular actions' but rather 'helps us devise questions and strategies for exploring them' (Steinberg & Kincheloe 2010, p. 143). The focus therefore, is on helping learners to engage in a critique of social identity rather than offering a vision of what alternative forms of identity might look like. Consistent with this former approach, this doctoral research has contributed an understanding of what questions and strategies might facilitate an understanding of diabetes-related stigma, as depicted in Figure 6. The nature of these questions

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<sup>24</sup> This reflects the dialectical relationship between education and advocacy, reflected in questions of whether 'organizing educates' or whether 'education makes organizing possible' (Horton & Freire 1990, cited in Tarlau 2014, pp. 382-3).

and strategies is discussed below, followed by a discussion of the constraints to engaging in such questioning.



**Democratic spaces for PWD**

**Figure 6. Processes involved in learning about diabetes-related stigma**

### **Questions and strategies for learning about diabetes-related stigma**

#### ***Who exactly is stigmatised?***

Determining who is stigmatised is a task that is located at the centre of the pyramid structure in Figure 6, as all other learning processes are dependent on clarifying who is the precise target of stigmatisation. What is apparent from the findings presented in Chapter 8 is that participation in the educational program functioned to support participants to distinguish between the 'normal' self and the stigmatised Other, with the latter defined by their tragic-disabled and obese bodies and/or irresponsible characters. By getting to the core of who *exactly* is stigmatised, it is possible to move beyond an analysis of more superficial concerns about disease stereotypes (e.g. the imprecise conflation of obesity and diabetes, which would largely impact on 'normal' or 'non-obese' PWD), and towards a more fundamental analysis of how moral concepts related to personal (ir)responsibility are used to stigmatise. The importance of specifying exactly who is stigmatised extends beyond the analysis of diabetes-related stigma. Amongst persons living with HIV for example, within-group stigmatisation is used as a strategy for re-directing stigmatisation towards immoral sub-groups (Ranjbar, McKinlay & McVittie 2016). Although social identity theories would suggest that such an



act of inter-group denigration is used to preserve a positive sense of self (McVittie & McKinlay 2017), the act of within-group stigmatisation also offers a glimpse of the forms of taken-for-granted knowledge that are used to fuel this inter-group process. Therefore, clarifying exactly who is stigmatised offers a strategy for bringing into sharp focus the moral or symbolic basis of stigma, something that is central to diabetes-related stigma (Broom & Whittaker 2004; de-Graft Aikins 2006; Della, Ashlock & Basta 2016) and the operation of health-related stigma more broadly (Deacon 2006; Scambler 2019).

For participants in this research, this process of identifying the precise target for stigmatisation occurred spontaneously in the form of othering (including self-othering). As Lupton (2013b) suggests, this process of othering is an expected outcome in contexts of health-related risks and where there is a crossing of culturally-defined bodily boundaries, such as is the case with diabetes, obesity, and amputation. Therefore, the process of othering provides a convenient resource that may be drawn upon by learners and educators to draw attention to the target(s) of stigmatisation. Consistent with postmodern perspectives within critical pedagogy (Giroux 2004; Healy 1999; Kaufmann 2010; Lane 1999; Lather 1998), this observation supports the claim that dialogue functions both to (re)create identity whilst also being shaped by other aspects of one's identity. For participants in this doctoral research, it was clear that dialogue functioned to construct oneself as a responsible bio-citizen, frequently in reference to the reformation of one's disposition towards self-care. This fluidity of identity, enabled by the potential for personal reform, meant that a collective 'diabetes identity' held little relevance for participants. With the exception of persons with advanced diabetes-related complications, one could always (presumably) dodge the moral concepts used to stigmatise.

Despite its role in clarifying the precise targets of stigmatisation, this process of othering continued to exert destructive effects on learning as participants continued to amass evidence for why the stigmatised Other was deserving of their inferior status. In reference to the synthesised framework of critical consciousness development described in Chapter 3, these participants were stuck in an introspective loop whereby new information (particularly that generated by co-participants) continued to be interpreted against a resilient and enduring set of beliefs about personal responsibility for diabetes self-care. Therefore, this process of othering functioned to perpetuate reasoning used to 'justify or rationalize the status quo in society' (Dovidio, Major & Crocker 2000, p. 8). In this research, it was a sense that the application of stigmatising or identifying concepts was in some way unjust or unfair that brought these concepts into disrepute and offered an exit from this confirmatory process of introspection. The influence of feelings of unfairness and injustice is examined in more detail under the next heading.

### ***Is stigmatisation fair?***

The question of deciding *whether stigmatisation is fair* is positioned at the base of the pyramid in Figure 6, given how the task of envisaging an alternative non-stigmatising reality becomes logically unnecessary if the current reality is judged to be fair and just. In this research, only two participants (C1 and C7) raised a concern with the unfair or unjust nature of stigmatisation, with their concern limited to a sub-group of obese PWD. Although public health understandings of fairness or justice tend to focus on evaluating whether or not there exists equal opportunity for the pursuit of health (Braveman et al. 2011; Ruger 2004), this was not the case for participants in this research. Whereas a public health interpretation might rightly suggest that stigmatisation is unfair because of the socially structured nature of diabetes presentation and care (Weaver et al. 2014), thus contributing to victim-blaming, participants in this research were more concerned with the way in which alternative understandings of their fat bodies were discounted or marginalised.. Exposure to alternative framings of the fat body and self, in the form of online bloggers inspired by fat acceptance and feminist perspectives, appeared to 'provide points of rupture' (Bacchi 2009, p. 36) that offered opportunities to challenge powerful forms of knowledge about the obese self. However, the inability of participants to articulate alternative framings of the PWD may explain why a sense of unfairness was created in relation to obesity but not for diabetes. In this way, it would appear that the ability to articulate a vision for a non-stigmatising reality is dialectically related to the ability to engage in an evaluation of fairness. By having an alternative vision for how PWD should be represented, a different set of concepts for understanding the PWD is created against which stigmatising representations might be critiqued. An alternative vision was evident in the deliberative research in Chapter 12, with healthcare services staff drawing on a social determinants of health framework to imagine PWD as socially-embedded agents.

The emotional response to unfairness (at least in relation to OPWD) in this research reflected a moral outrage. This observation is relevant to the point raised in Chapter 3, which queried the precise role of emotion within critical forms of learning. In wider literature, moral outrage can be distinguished from other forms of anger in that it specifically attributes blame to a third party (typically a system of inequality or government authority) based on the perceived violation of a moral standard of fairness or justice (Thomas, McGarty & Mavor 2009, p. 324). This finding is important given the way that the experience of moral outrage has been related to prosocial political behaviour and increased solidarity between group members (Thomas, McGarty & Mavor 2009), which are desirable outcomes for socially critical education work. Furthermore, moral outrage can function to politicise identity, potentially bringing together disparate groups of people on the basis of shared grievances and recognition of a shared 'enemy' (Simon & Klandermans 2001). This politicisation of identity has been clearly observed within the social disability movement, who have challenged the medicalisation of impairment and rallied around the social model of disability to produce a 'collective disability consciousness' (Oliver 2013, p. 1024). However, the issue for participants in this doctoral research was that it was particularly difficult to identify shared grievances or identify this 'enemy'. For these participants, the fairness of the stigmatisation of PWD was maintained because there was no viable

alternative to their framing as biological citizens, with failures of citizenship associated with the development of diabetes-related complications. This meant that the 'enemy' took the form of 'internally imposed' risks to health (Lupton 1995, p. 77), producing feelings of anger towards those that fail to act on obligations for diabetes self-care. This observation raises the question of whether alternative representations of PWD (such as with the socially embedded agent) might function to redirect a sense of outrage away from 'irresponsible' PWD, who fail in their obligations for self-care, and towards unfair practices involved in managing or governing the risky bodies and characters of PWD.

In this research however, the sense of moral outrage exhibited by C1 and C7 failed to result in the identification of a specific third-party to attribute blame. This finding resonates with Beddoe and Keddells' (2016, p. 150) assertion that educators need to purposefully 'guide students in a planned manner from the initial 'outrage' they may experience, towards a more 'informed outrage''. For these social work educators, this initial outrage can be channelled into a more productive cognitive-rational analysis of stigmatisation, for example through a deconstruction of media texts. Beyond this literature however, the role of moral outrage or anger in stigma-reduction work has received minimal attention. Rather, the focus has been on how emotional responses to members of stigmatised groups might be manipulated through strategies of 'contact' (Herek 2007). Given an extensive literature examining the relationship between emotions, identity, and socio-political action (Thomas, McGarty & Mavor 2009), it would seem appropriate for critically-oriented stigma-reduction work to more closely examine the antecedents and effects of moral outrage amongst members of stigmatised and non-stigmatised groups. At current, this doctoral research suggests that exposure to alternative representations of stigmatised groups might be an important antecedent to this sense of outrage, whilst recognising that the individualisation of diabetes-related stigma tends to encourage individual acts of reformation. This tendency towards the individualisation of the stigma concept means that educators must be intentional in their selection of texts towards those that might attribute blame towards a third party, a point that is discussed in the next section.

### ***What knowledges and concepts are drawn upon to stigmatise?***

It is clear from these findings that there exists a strong tendency to locate the problem of diabetes-related stigma primarily in the individual stigmatised person. This tendency is not unexpected given sustained academic efforts to stimulate an analytical engagement with socio-political processes that maintain stigmatisation (Deacon 2006; Hatzenbuehler & Link 2014; Parker & Aggleton 2003; Scambler 2004), with these efforts emerging as a reaction to dominant individualistic and interpersonal analyses of health-related stigma. Therefore, a critical pedagogy applied to health-related stigma can safely be assumed to be received by learners as a counter-intuitive approach to examining the issue of stigma. This realisation places considerable demands on the educator to construct learning activities and instructional supports that can overcome tendencies towards the individualisation of social phenomenon. What this doctoral thesis adds is that certain texts are better

suiting to support this counter-intuitive analysis of stigmatisation than others. Although existing stigma-reduction work has examined the value of different texts in facilitating stigma-reduction, mostly in the form of interpersonal contact and education (Gronholm et al. 2017; Morgan et al. 2018; Thornicroft et al. 2016), this work has focused on the modification of cognitions and emotions that contribute to stigmatisation. For critical pedagogy, texts should function to re-direct attention to the transmission of dominant knowledges via social and political systems.

Along these lines, this doctoral research has shown that pedagogical texts of health news and nutrition education offer a more transparent insight into the way that certain forms of knowledge inadvertently supply the concepts used to reinforce the tragedy and shameful nature of diabetes-related complications and the blameworthiness of irresponsible acts of self-care. Drawing from the analyses within chapters 9 and 11, these texts can be seen to be responsible for 'teaching' the public about the nature of diabetes-related risks and how they should respond to these risks. This idea is underpinned by social constructionist assumptions about power (Lupton 2012b), and specifically how public communications function to shape bodies and dispositions in certain ways in order to achieve certain social goals (Briggs & Hallin 2016). However, an issue was encountered within this research where participants appeared to draw attention to health news and nutrition education as modalities of power, but further analysis was truncated by a realisation that such education brought with it material benefits in relation to the prevention of diabetes-related complications. Following Foucault's concept of bio-power, power here is not seen to be repressive but rather life and health-enhancing (Crossley 2004). This idea is particularly relevant to diabetes, where PWD are indebted to medicine for the transformation of diabetes from a life-limiting to chronic illness (Feudtner 2003). This raises the issue of whether a critique of these stigmatising discursive practices can be sustained given the benefit that these practices offer PWD.

Furthermore, health news has been shown to play a powerful role in shaping public opinion about the causes and effects of diabetes via its educative, interpretative, and socialising functions (Gollust, Fowler & Niederdeppe 2019). Analyses of newspaper articles from Australia (Bednarek 2020; Bednarek & Carr 2020), New Zealand (Gounder & Ameer 2018), North America (Gollust & Lantz 2009; Rock 2005; Stefanik-Sidener 2013), and the United Kingdom (Foley, McNaughton & Ward 2020; Hellyer & Haddock-Fraser 2010) tend to draw similar conclusions that news media tends to *frame* diabetes in such a way that draws attention to the biomedical and behavioural basis of diabetes, at the expense of social determinants. For these studies, the effect of this framing is to individualise the causes of illness and attribute responsibility and blame to those with diabetes, leading to lower levels of sympathy towards PWD (Anderson-Lister & Treharne 2014) or willingness to contribute funding to diabetes research (Gollust, Lantz & Ubel 2010). Interestingly for this doctoral research, the way that participants framed diabetes reflected the frames deployed within health news media. Participants drew upon metaphors, exemplar cases (as episodic frames), and meta-narratives (as thematic frames) within their interviews in order to infer causal attribution, identify

consequences of actions, make moral judgements, and locate responsibility (Entman 1993). Their representation of PWD as bio-citizens reflected the dominant medical and behavioural frames observed in health news, which functioned to individualise the problem of stigmatisation. Reflecting the relationship between stigma and deviance discussed in Chapter 11 of this thesis, behavioural frames of reference have been shown to 'view health issues through the lens of behavioural deviance', where deviancy is interpreted through a logic of market justice (Gounder & Ameer 2018, pp. 95-6). Although, medical frames are thought to distance individuals from blame (Gounder & Ameer 2018), this doctoral research has identified the way that ontological deficits (inferred by a medical frame) are recast as moral deficits (inferred by a behavioural frame) given the way that selfhood is tied to their role as bio-citizens. However, by drawing on a social determinants frame, staff from the diabetes organisation examined in Chapter 12 evoked 'injustice frames' (Gollust & Lantz 2009, p. 1096) that sought to avoid the blaming of certain sub-groups of PWD by rejecting individualised assumptions about disease cause, effect, and moral responsibility. In this way, these individuals avoided engaging in a process of othering by locating blame within a third party, representing systems of social inequality.

Given the way that medical and behavioural frames within these health news texts appear to provide individuals with the resources to construct the stigmatised Other, the critique of health news and nutrition education is likely to benefit from a specific focus on how othering is discursively achieved via the use of framing and other discursive strategies within these texts. This idea follows Steinberg and Kincheloe's (2010, p. 143) claim that critical pedagogy should seek 'to uncover the winners and losers in particular social arrangements and the processes by which such power operates'. Critical discourse analysis is likely to be useful in facilitating this process given its application in analysing media texts (O'Keeffe 2006) and ability to illuminate the way that 'social power abuse, dominance, and inequality are enacted, reproduced, and resisted by text and talk in the social and political context' (Van Dijk 2001, p. 352). Whilst there is evidence that non-academic audiences do engage in discursive acts of resistance to stigmatising texts (Basinger, Farris & Delaney 2020; Holland 2018), these acts of resistance appear mostly to be used to deflect stigmatisation rather than challenge the way that stigmatisation is enacted and reproduced. What is needed is an approach that might support learners to develop 'competencies to interpret the multiple meanings and messages generated by media texts' and 'construct alternative media' (Kellner & Share 2005, p. 372), thus providing a more effective challenge to stigmatisation. Fortunately, this task has already been picked up by educators seeking to develop *critical media literacy* amongst school-aged learners (Bhatia 2019; De Abreu & Mihailidis 2014; Gainer 2010; Jeong, Cho & Hwang 2012; Kellner & Share 2005), recognising that students are being exposed to an increasingly complex and evolving media environment. Given the findings within this doctoral research, future stigma-reduction work involving stigmatised groups are likely to benefit from an engagement with ideas contained within this literature.

Unfortunately for this educational research however, the use of personal experiences of stigmatisation as the content of learning contributed to a personalisation of mechanisms of stigmatisation. Interestingly, similar findings have also been reported in cases studies examining critical approaches to community-based education (typically in relation to community development work) using experiential learning content (for example, Carlson, Engebretson & Chamberlain 2006; Foster-Fishman et al. 2005; Teti et al. 2013; Van Wijnendaele 2011). Participants in this doctoral research were observed to struggle in identifying a precise grievance with their experience of stigma, which also made it difficult to select an appropriate critical incident. The problem here is that the production of diabetes-related stigma is rather diffuse, emerging from 'common-sense' ideas about the (medicalised) body and responsible self/citizen, which is enacted through taken-for-granted and seemingly beneficent activities of self/professional surveillance and health education. Work involving other stigmatised conditions is likely to encounter similar issues given the symbolic function of stigma and its tendency to promote a 'felt-stigma' rather than acts of overt discrimination (Deacon 2006; Link & Phelan 2014). Therefore, the use of personal experiences of stigmatisation for supporting a critical examination of health-related stigma may struggle to clearly identify and describe bodies of knowledge from which the assemblage of stigmatising practices emerge.

The analysis of health news and nutrition education partly overcomes this limitation because of the way that the focus on language draws attention to the ideological basis of education (Kellner & Share 2005; O'Keeffe 2006). By taking the ideological function of language as a starting point, it becomes easier to identify how stigmatisation is achieved through everyday experiences of living with and caring for one's diabetes. This approach also strikes the core of critical pedagogy as it is imagined within formal education. Here, it is assumed that schooling is used to transmit the values of the state, particularly related to the development of 'human capital' to maintain individual competitiveness within the job market (Tarlau 2014, p. 387). Critical pedagogy therefore is a reaction against this instrumental rationality (Steinberg & Kincheloe 2010, p. 144), proposing an alternative model of education that uses educational tools to help students critique the way in which certain values are reproduced through school cultures and systems of knowledge production (Tarlau 2014). This means that a critical pedagogy for understanding health-related stigma must maintain a closer focus on health pedagogy itself, rather than on experiences of stigmatisation with the assumption and hope that learners might relate the two given sufficient learning support.

### ***What is an alternative (non-stigmatising) reality?***

In this doctoral research, the inability to form a mental image of a non-stigmatising reality was found to limit the ability of participants to contest the knowledges and concepts handed to them in understanding themselves as PWD. In Figure 6, this ability to envisage an alternative future reality is positioned as the peak of the pyramid structure given how the ability to form a mental picture of

an unknown non-stigmatising reality is logically dependent on being able to precisely identify: the target(s) of stigmatisation; the knowledges drawn upon to stigmatise; and the (un)fairness of stigmatisation. This process of learning is not necessarily linear, but rather appears to involve an iterative process of development. For example, certain participants drew on pre-existing alternative representations of fat persons in order to challenge the fairness of weight stigma, which then led to further revisions in how OPWD are represented. However, one of the glaring issues facing this doctoral research is that participants were unable to imagine alternative representations of PWD independent of matters of fatness. The ability to do so was limited because participants were immersed in the logic of the self-care – biomarker – complications causal relationship, which was maintained through a desire to preserve one's health. Thus, participants were generally unable to imagine their bodies and selves outside of pervasive discourses of medicine and bio-citizenship. This is one of the key issues facing critical forms of education applied to health-related stigma, recognising that stigmatisation tends to be legitimised by established knowledge systems that act to limit the ability of stigmatised persons to think outside of or challenge such hegemony (Parker & Aggleton 2003). This is a significant problem for critical pedagogy in public health contexts, whereby medical authority and ideas about responsible citizenship maintains ideological dominance (Yadavendu 2013).

Although the earlier case study research was useful in identifying the ideological and material barriers to envisaging an alternative non-stigmatising reality, it was unable to contribute knowledge about the ways that stigmatised persons construct this alternative reality. However, by drawing on the deliberative discussion within a diabetes organisation and interpreting this discussion against the political use of the social model of disability, it would appear that representing PWD as socially-embedded agents offers a broad frame of reference or standpoint from which to bring to attention stigmatising knowledges, representations, and practices. Although participants in the deliberative discussion drew on a generic social determinants of health framework in order to argue that PWD's capacity for self-care are socially mediated, thus proposing alternative concepts for understanding the (social vs medicalised) body and the moral status of individuals (socially-constrained vs autonomous) this is not to say that such a framework should be uncritically adopted without further examination.

An alternative 'social' understanding of PWD might, for example, draw on understandings of the *illness career*, an idea which has its origins in the stigma-related work of Goffman and is more closely related to the social construction of identity (Grue 2016). This understanding assumes that illness careers are simultaneously personal, socially structured, and subject to public regulation. Within this term, the word 'career' is used purposefully to bring together ideas about the relationship between 'internal and external aspects of identity formation' (Grue 2016, p. 402) and the temporal changes in meaning associated with the progression of illness. This way of understanding chronic illness recognises that the selfhood of PWD and the standards used to understand and evaluate themselves

are profoundly shaped by institutions that they are exposed to, and that the meaning associated with their diabetes is likely to change with illness progression (culminating in the onset of diabetes-related complications). If stigma-reduction work is ultimately concerned with manipulating the social construction of identity, then the latter theoretical perspective may be more useful because it makes explicit (rather than assuming) how health-related stigma operates at the intersection between identity, illness, and society. This discussion implies that more work needs to be done to specify exactly what is meant by the 'socially-embedded agent'. But in the meantime, the general idea that PWD are not fully autonomous or unconstrained in the way that they relate to or care for their diabetes, a broad idea that is inferred by the term 'socially-embedded', may function to assist learners to challenge taken-for-granted assumptions about the agency of PWD (and therefore fairness of stigmatisation) and allow for the refinement of ideas about what an alternative non-stigmatising reality might look like. As Lucherini (2019, p. 16) hints at within the following excerpt, this refinement of ideas is likely to form an ongoing project where, according to Giroux (2004, p. 34) 'power is not transcended, but reworked, replayed, and restaged in productive ways':

... as Diedrich and Frank [autobiographical authors and persons living with T1DM] argue we cannot escape the entanglements of power in which our stories are inevitably caught. The chaos autobiographies are caught in this entanglement; unable to express their feelings in everyday encounters but able to do so in writing. Publically available testimony, such as the autobiographies discussed here, needs to be considered critically to understand what it is they do for people. Do they assist in providing relatable accounts of living with illness, or do they create idealistic public patients that embody a narrow model of what it is like to live with illness and disability? Even so, writing is still limited, as Roney's reflections reveal: stable diabetic subjectivity remains out of reach. (Lucherini 2019, p. 16)

### **Locating critical pedagogy within public health practice: the role of democratic spaces**

In reviewing how critical pedagogy has been deployed within public health contexts (Chapter 4), it became apparent that much of this education work presents a poor fit with the organisational demands of public health practice towards efficiency and the quantification of intervention outcomes (Parkhurst 2017). While these demands are useful given the way that they promote a judicious use of scarce public resources, they also inadvertently function to marginalise constructivist approaches to education that require extensive facilitation and involve loosely defined or process-oriented learning outcomes (Narayan et al. 2013). Furthermore, socially critical forms of education are likely to bring foundational public health ideologies and practices into disrepute, even to the extent that public health authorities and the state are implicated in the reproduction of stigmatisation, a point that some public health researchers and ethicists are cognisant of (Bayer 2008; Bell et al. 2010; Brookes & Harvey 2015; Courtwright 2013; Lupton 2014). Therefore, it would appear that the mainstream disease-prevention-oriented environment of public health practice, with its own privileged forms of pedagogy, is a poor location for the future practice of critical pedagogy.

However, within public health and healthcare organisations there is also a discernible movement towards involving the recipients of care or intervention (i.e., publics, consumers, or patients) into decision-making processes at various levels (Greenhalgh 2009; Li et al. 2015; Mitton et al. 2009;



Thompson 2007). This movement opens up a space within the public health policy and practice landscape that might readily accommodate critical pedagogy. In relation to chronic illness, Greenhalgh (2009) has conceptualised public/patient involvement according to approaches of self-management, illness coping, social ecological approaches, and critical public health, with each approach seeking different outcomes and affording the patient/public a different status and role within decision-making processes. Importantly, the framing of 'involvement' has important implications for the participatory role given the way that discursive constructions of the 'consumer' can constrain the expression of subjugated knowledges (Lancaster et al. 2017; Martin 2008). It is the critical public health approach that provides a suitable environment for critical forms of education to flourish because of the way that it seeks to reduce health inequalities through social and political change, supported by democratic processes involving 'engaged' citizens that challenge 'prevailing norms and values' (Greenhalgh 2009, p. 629). This approach is suitable precisely because of its democratic ideals, which follows the purpose of critical pedagogy to enable the articulation and inclusion of marginalised voices within political processes as an ongoing democratic project (Giroux 2004; Steinberg & Kincheloe 2010). But for critical pedagogues such as Giroux (2011), the meaning of 'democracy' itself is subject to political manipulation. This assumption means that democratic spaces within health systems cannot be automatically assumed to provide fora where publics/patients can freely voice their opinions free of the coercive effects of ideology (Hammond 2018; Rostbøll 2008), a point that has been observed within policy-making work involving illicit drug users (Lancaster et al. 2017).

To date, stigma-reduction literature has made no mention of the role of critical democratic spaces within health systems as a site for stigma-reduction work. Rather, the focus has been on the articulation of alternative representations of stigmatised groups outside of formal political systems, such as occurred with the UK-based Union of the Physically Impaired Against Segregation (UPIAS) or academic discipline of disability studies (Beaudry 2016). These alternative representations have then been used politically to challenge stigmatising beliefs, policies, and practices, captured within stigma-reduction strategies of *advocacy* and *protest* (Heijnders & Van Der Meij 2006; Weiss, Ramakrishna & Somma 2006). However, there are a number of potential advantages in locating critical pedagogy within democratic spaces in healthcare and public health systems. Practically speaking, it brings the practice of critical pedagogy within the reach and remit of public health practitioners. By drawing from policy imperatives for patient, public, or consumer involvement in healthcare and public health policy (Government of South Australia 2013; NHS Public Participation Team 2017), the public health practitioner is better able to secure organisational commitment to and resources in support of education work designed to enhance the ability of individuals to participate in decision-making processes (Kovacs Burns et al. 2014). It might be argued that because diabetes-related stigma emerges from the way that governments and health systems manage risky bodies, locating critical pedagogy within these systems provides more direct access to decision-making processes involved in establishing and maintaining stigmatising practices. In Australia for example,

involvement with healthcare systems might invite access to activities that include diabetes and obesity prevention campaigns, mandated requirements for Medicare-funded diabetes prevention and management activities in primary care settings, policy development within nationally-funded Primary Health Networks (PHNs), or the delivery of public hospital and health services for PWD and those at risk of developing diabetes. However, one issue facing the implementation of critical education within healthcare and public health systems is that critical forms of education are likely to present a poor ideological fit with the perceived roles of 'consumers' within decision-making processes (Joseph-Williams, Elwyn & Edwards 2014; Martin 2008), and may provoke politically undesirable critiques of medical power and ideas about responsible citizenship.

Although similar issues were also encountered in relation to the diabetes organisation examined in this doctoral research, the organisation's emphasis on the needs of its members (most of which are PWD and their supporters) made challenges to stigmatisation more viable. The values and virtues endorsed by staff and board members, including those related to empowerment, advocacy, compassion, and empathy, appeared to offer defence against a utilitarian logic in support of stigmatisation (Bayer 2008; Bayer & Stuber 2006). Although their ability to directly influence stigmatising practices might be small compared to public health systems, it appears that the organisation is politically less constrained in their ability to support the practice of critical pedagogy. However, given various theoretical orientations from which to view co-design (Litchfield et al. 2018; Martin 2008), person-centeredness and empowerment (Aujoulat, d'Hoore & Deccache 2007; Kitson et al. 2013), and media advocacy (Holland 2018), the development of *critical* democratic spaces is not a given. Rather, these approaches may run the risk of conforming to the status quo of consumerism in public/patient involvement in healthcare (Newman & Vidler 2006). Furthermore, the challenge for these organisations will involve issues of representativeness, which is a key consideration within democratic approaches to policy development (Degeling et al. 2017; Martin 2008). As this doctoral research suggests, accessing only 'normal' PWD will do little to incorporate the perspectives of highly stigmatised groups, including those that are obese, struggle with diabetes self-care, or possess diabetes-related complications. Therefore, diabetes organisations will also need to actively ensure participation from these marginalised groups, which means that representativeness should be assessed according to the inclusion of marginalised perspectives rather than criteria solely related to external validity (Abelson et al. 2003).

## **Appraising the strengths and limitations of this research**

Earlier in this chapter, I noted how this doctoral research had entered uncharted and uncertain conceptual space given limited theorising about diabetes-related stigma from a critical/structural perspective and this research's novel use of critical pedagogy for understanding health-related stigma. In light of this uncertainty, it is important to determine how well this research was able to anticipate and effectively manage challenges to research quality, thus demonstrating that the

findings should be trusted, but also where unexpected challenges detracted from the trustworthiness of these findings and contributed to certain blind spots. The major strengths of this research related to features of the study design and analytical strategy, which were design elements developed in response to the limitations of existing research and literature presented in Section One of this doctoral thesis. Alternatively, major limitations emerged in relation to pervasive discourses of risk and othering, adversely affecting the ability of participants to engage in a critique of diabetes-related stigma. This stunted critique meant that there were several blind spots within the research data, most notably in relation to how critical pedagogy might contribute to critically-oriented projects of stigma-reduction given sizeable constraints to learning. It was partly a recognition of these blind spots that led to the expansion of this doctoral research to involve the deliberative democratic methodology, done with the intention of addressing some of these weaknesses. To help order a discussion of these research strengths and limitations and the effect they had on the ability to answer the research questions and on the quality of findings, I will first discuss the strengths of the doctoral research in relation to some of the anticipated methodological challenges.

In performing a systematic literature review of the outcomes of critical pedagogy within public health contexts (Chapter 4), it was found that the majority of this research had used cross-sectional qualitative case studies to examine learning outcomes. Although a case study methodology is appropriate for examining learning in relation to critical pedagogy given the methodology's potential to facilitate an analysis of discursive, socially-constructed, and contextually-bound processes of education and learning (Daley 2010; Hamilton & Corbett-Whittier 2013), a number of methodological and reporting limitations dampened these research findings. Specifically, these limitations included the absence of longitudinal and cross-case data collection and analysis, and difficulties in identifying precisely how learning was being assessed. With the presentation and discussion of findings sometimes shrouded in universalising and modernist narratives of enlightenment, it became difficult to identify exactly what learning had occurred, how this learning might be explained, and how learning might have differed between individual participants.

This doctoral research has addressed these limitations in several ways. Firstly, it has drawn upon the meta-theory of critical realism to support forms of reasoning that could identify relevant processes of learning operating with complex and interactive learning environments. This theoretical approach made it possible to make theoretical generalisations about educational and non-educational processes that influence learning, which is a key strength of the study given how forming a scientific basis for the generalisation of research findings forms a central issue confronting case study research (Bassegy 1999). Secondly, the longitudinal and comparative design of the case study enabled insight into the dynamics of learning over time and allowed the intervention to be scrutinised for its ability to produce similar results or to predict different results for theoretically predictable reasons, thus further supporting theoretical generalisation (Yin 2014) and providing insight into the temporal dimensions of a critical praxis. Thirdly, this research provided a structured analytical

strategy, drawing on a broader literature examining processes of critically oriented learning and the critical analysis of discourse, to identify and explain relevant learning outcomes in a systematic, rigorous, and transparent way. Although still an interpretative process, the use of the synthesised framework of critical consciousness development (developed in Chapter 3) and Fairclough's (2003) approach to critical discourse analysis provided an analytic strategy that offered a defence against criticism directed at critical educational research where researchers are accused of reading their critical social theory into the text (Rogers et al. 2005). Furthermore, the use of discursive representations of PWD and stigmatisation offered insight into how participants make sense of their world and how these representations might be manipulated to represent alternative possibilities for the 'material', 'mental', and 'social' world, reflecting personal projects for change (Fairclough 2003, p. 124). A focus on representation directly engages with the aims of critical pedagogy, whereby learners are supported to problematise their representation of certain issues and use this problematisation as the basis for creating alternative discourses (Giroux 2004).

Despite this methodological potential, there were a number of issues that emerged during the course of the research that impacted on the ability to make rigorous inferences about the relationship between education and learning. A key issue related to the design of the education program, which drew on the *Model of Critical Reflection for Professional Practice* (Fook & Gardner 2007). At the time, this method was considered particularly useful because of the relative simplicity of its aim, that is, to 'unsettle' assumptions made about PWD and to use this unsettling to create different ways of thinking about PWD and stigmatisation. However, because the logic of stigmatisation is bound up with powerful knowledges and logic of biomedicine and bio-citizenship, a logic in which participants were deeply immersed, assumptions about deservingness for poor health tended to be validated by participants rather than unsettled. In this context, the use of personal experiences of diabetes-related stigma generally failed to unsettle assumptions about PWD. While this outcome provided useful data for identifying constraints on learning, there was much less data that could be used to make generalisations about the learning processes contributing to a critical consciousness of diabetes-related stigma. Difficulties in facilitating a critique of stigmatised identities meant that evidence of learning tended to draw on data from a limited number of cases, with certain participants engaging with certain aspects of critical learning but not other aspects. Therefore, it was not possible to identify 'ideal' case participants who engaged in a comprehensive or fully fledged critical analysis of diabetes-related stigma (as per Figure 6), but rather cases who offered fragmented accounts of learning, borrowing both from stigmatising-hegemonic and counter-hegemonic ideas about PWD. The continued operation of stigmatising discourses contributed to a bleak outcome, where participants tended to legitimise stigmatisation because of an inability to identify a viable alternative. This limitation was partially addressed through the later deliberative democratic research, which was able to identify potential ways in which viable alternatives could be developed.

Low participant numbers in the case study research likely also contributed to this bleak outcome. Although educational case studies are rarely interested in sample size as it relates to the external validity of research findings, a small sample might adversely affect the ability of the research to support theoretical generalisations. As Schofield (2009, p. 76) suggests, sampling within case study research tends to be guided by two questions: 'to what do we want to generalize?' and 'how can we design qualitative studies in a way that maximizes their generalizability?' In Chapter 6 of this thesis, it was stated that the aim of generalisation within this research is to make inferences about underlying mechanisms and structures of learning and of diabetes-related stigma (see p.62-63). At the outset of this research however, there was only limited understanding of the variables that might shape the experience of diabetes-related stigma and engagement with a critical pedagogy. In designing the research so to maximise generalisability, it was originally hoped that three groups of 6-8 participants would provide sufficient variation to identify important variables or processes impacting on the experience of diabetes-related stigma and processes of learning. In practice, only four participants were recruited to each of two groups. This smaller number of participants meant that group dialogue was vulnerable to the effects of challenging behaviour (as was the case for group two) and offered participants limited exposure to stigma-related texts. Although lower-than-anticipated participant numbers were acceptable given the extensive collection of data from multiple sources and time points, use of a detailed analytical strategy involving within and cross-case analysis, and a focus on theoretical (cf., statistical) generalisation, these lower numbers made case comparison and theoretical generalisation difficult where particular phenomena were observed in only a limited (one or two) number of cases.

There was also a lack of representation amongst PWD receiving insulin therapy, PWD with advanced diabetes-related complications, and persons with early onset T2DM. These omissions are important given how these groups may experience the effects of bodily disruption and medicalisation in more powerful ways, potentially creating a context where processes of stigmatisation become more available to critique. Additionally, ethnic minority groups and Indigenous peoples were not represented within this research. Inclusion of these groups may have helped the research to examine how stigmatisation might operate when individualistic and biomedical understandings of health and responsibility come into conflict with alternative models of health. It may also help examine how intersectionality operates in relation to diabetes-related stigma, expanding on research examining intersections of race and ethnicity in relation to diabetes and weight-stigma (Himmelstein & Puhl ; Himmelstein & Puhl 2020b). Furthermore, for Indigenous peoples it is possible that historical and contemporary exposure to racism and colonial processes, along with potential exposure to socially critical discourses (Cross-Townsend 2011), may function to create novel responses to a critical pedagogy for understanding diabetes-related stigma. Therefore, involvement of these groups in future critical pedagogical research may provide a stronger base from which to facilitate and observe learning.

Despite an extensive recruitment process involving multiple recruitment strategies (pp.72-74) conducted over a period of one year, there was limited interest from potential participants. Field notes maintained throughout the doctoral research highlight how critical approaches to education were resisted or opposed by both healthcare professionals and PWD themselves. Throughout the research, I was confronted with healthcare professionals, members of the public, and persons with diabetes (including those with type 2, type 1, and gestational diabetes) who readily engaged in a discourse of othering, yet vehemently denied the existence of 'diabetes-related stigma'. Furthermore, many PWD responded to the educative purpose of this research by asking questions along the lines of 'are you going to tell me what to eat?' Interestingly, similar experiences have been reported by Warin and Gunson (2013) in their ethnographic study of women's experiences of food, bodies, and weight. Here, overweight women positioned themselves as problems that research sought to fix, drawing from taken-for-granted and tacit knowledges about obese persons. Likewise for diabetes, in examining the yearly program for the 'expert speaker' education series provided by the state-wide diabetes organisation examined in this doctoral research, it was apparent that education for PWD is squarely founded on a deficit model, what Freire refers to as banking education (Roberts 2000). In this environment, constructivist approaches to education, such as that assumed within critical pedagogy, may be seen as both irrelevant to the task of self-care and inferior to forms of expert knowledge that enable such self-care. This logic appeared to contribute to the slow uptake of participants in this research, with many potential participants explicitly wanting to participate in research projects that might supplement existing projects of self-care.

Further work is still required in order to bring together the fractured accounts of learning observed within this research into a more unified understanding of how individuals and organisations might form and participate in critically-informed projects of stigma-reduction. Further evaluative studies are required to empirically identify what understandings of PWD are produced when the educational practices described in this chapter are brought together and implemented in a more refined form. In overcoming the limitations encountered within this doctoral research, a key consideration for future research should be on the appropriate selections of texts as the content of learning. Specifically, there needs to be further consideration of what genre or features (linguistic, semantic, or visual) of texts contribute most to stigmatisation and the precise mechanisms by which stigmatisation occurs. Furthermore, although the ideological construction of certain texts have been critiqued by public health researchers in relation to diabetes (Brookes & Harvey 2015; Lupton 2014), it is uncertain as to how these texts are *received* (Fairclough 2013) by the public or PWD and how they might be critically analysed. There is potential here to draw on approaches used to develop critical media literacies (Kellner & Share 2005). In addressing a blind spot within this doctoral research, it will also be important to focus on the interaction between stigma and other forms of marginalisation and disadvantage, reflecting an emerging literature examining how the experience of diabetes-related stigma is shaped by intersecting identities (Himmelstein & Puhl ; Himmelstein & Puhl 2020b). A closer examination of the role of intersectionality is relevant because of the way that multiple forms

of disadvantage tend to coalesce amongst those that are obese or experience poorer diabetes-related outcomes (Bissell et al. 2016; Hill, Ward & Gleadle 2019; Hill et al. 2017; Keramat et al. 2020) and the way that stigmatisation functions to maintain social inequalities in health (Hatzenbuehler, Phelan & Link 2013).

## **Implications of these findings for future critically-oriented stigma-reduction work**

The findings from this doctoral research have potential implications for the practices of several audiences. Described in Table 16, key audiences for this research include practitioners tasked with stigma-reduction work, policy officers tasked with diabetes prevention work and/or advocating for the needs and rights of PWD, and stigma researchers who are seeking to better understand diabetes-related stigma or develop stigma-reduction interventions. Table 16 offers an overview of what findings from this doctoral thesis are likely to be relevant for each audience, what implications these findings have for future practice, and what questions remain or emerged from this research. The latter point is important because it raises the visibility of issues that will need to be accommodated or addressed within future work, for example through program evaluation, further research, or adopting methods and ideas from other relevant literature. These considerations recognise the way that public health practitioners and researchers are required to operate in contexts of complexity and interventional ambiguity (Connelly 2007; Petticrew 2011), making visible places where such issues of complexity and ambiguity are likely to arise.

**Table 16. Implications of research findings for future research and practice**

Key research findings	Implications for future practice		
	Practitioners tasked with stigma-reduction work	Practitioners and policy officers tasked with disease-prevention work	Stigma researchers and public health evaluators (outstanding questions)
A critical pedagogy for examining diabetes-related stigma (and likely health-related stigma) must respond to questions about who exactly is stigmatised, whether stigmatisation is fair, how is stigmatisation produced, and what alternatives to the current arrangements of stigmatisation exist?	These findings may be used to structure learning outcomes and learning activities in order to facilitate a more critical analysis of diabetes-related stigma	Questions may be used to facilitate a reflexive analysis of the ethics of diabetes-prevention work	When incorporated into a revised education program, what effect do these questions have on understandings of stigmatisation?  How useful are these questions in facilitating a critical analysis of health-related stigma more broadly?
Stigmatisation is likely to fall on sub-groups of PWD considered to be particularly risky or disgusting, specifically those with advanced diabetes-related complications, those who are obese, and those deemed to be irresponsible carers for their diabetes. This othering is made possible because of hegemonic understandings of the self as a responsible bio-citizen.	Stigma-reduction work should focus on the process of othering, rather than on the stigmatisation of PWD as a unified group	The use of risky or disgusting attributes (obesity and diabetes-related complications) or behaviours (deviant eating or exercise behaviours) to promote behaviour-change should be subject to ethical critique given its contribution to stigmatisation	How do understandings of stigmatisation differ between 'normal' and highly stigmatised sub-groups? Does this effect the learning occurring within critical approaches to education?
Stigmatisation is considered to be unfair where marginal subjectivities are perceived to be suppressed	Potential role of exposing members of stigmatised groups to these alternative representations of members of the stigmatised group	Incorporate alternative (less-stigmatising) representations of PWD within disease-prevention work?	What are alternative (less-stigmatising) representations of PWD and how might they be used within stigma-reduction or disease-prevention work?
An analysis of pedagogical texts of health news and nutrition education offer better insight into the ideological basis of stigmatisation than interpersonal experiences of stigmatisation	A critical pedagogy for understanding stigmatisation should focus on the analysis of pedagogical texts over personal experiences of stigmatisation	Health communicators should be cognisant of the ideological nature of educational texts, including the stigmatising potential of these texts	What educational supports (e.g. critical media literacy) are required in order to capitalise on the analytical insights available via these texts?
A critical pedagogy for understanding stigma requires development of an alternative non-	Potential to use this alternative representation of PWD as a	Analysing existing disease-prevention practices from this	Further research is required to articulate exactly what is meant by



Key research findings	Implications for future practice		
	Practitioners tasked with stigma-reduction work	Practitioners and policy officers tasked with disease-prevention work	Stigma researchers and public health evaluators (outstanding questions)
stigmatising reality, which may be initiated by representing PWD as socially embedded agents	standpoint from which to examine existing knowledges of and practices affecting PWD	standpoint may offer a critique of potentially stigmatising assumptions contained with existing work	being 'socially embedded', the grievances raised by adopting this representation, and how this idea is used politically?
Critical pedagogy can be located within democratic organisational spaces in addressing diabetes-related stigma, with potential application to health-related stigma more broadly	Practitioners can use policy imperatives for public, patient, and consumer involvement in healthcare to locate and resource critical pedagogy within healthcare and public health systems. However, public involvement should explicitly orient itself with a critical approach	Facilitate establishment of processes and policy for involving publics, patients, and consumers in the delivery and planning of disease-prevention activities	How might publics function within democratic spaces in the critical tradition versus the liberal tradition How might knowledge created through these spaces inform policy and practice?
Diabetes-related stigma is structured by policies and practices that attempt to govern risky bodies/individuals	Together, these processes offer a way of relating the structural basis of stigma to the personal experience of stigmatisation. This allows stigma-reduction work to be conceptualised at various levels and enables practitioners to look beyond matters of self or felt-stigma	Disease-prevention work is implicated in contributing to the experience of stigmatisation amongst PWD	How might diabetes and disease prevention operate in a way that maintains its effectiveness whilst limiting its othering effect?
Diabetes-related stigma, and possibly stigma affecting persons with other manageable chronic illnesses, draws upon and is legitimised via ideologies that construct the self as a (medicalised) bio-citizen			
Diabetes-related stigma is experienced through a process of othering, whereby deviant behaviour is recast as an ontological deficit, which is then layered onto the ontological deficit of the diseased and disabled body			

The audience for whom this research is most relevant is likely to be practitioners involved in stigma-reduction work. A reading of stigma-reduction literature (Gronholm et al. 2017; Heijnders & Van Der Meij 2006; Mittal et al. 2012; Thornicroft et al. 2016) offers limited clarity about exactly how practitioners might go about this work, particularly when addressing issues of structural stigma or discrimination (Faulkner 2017). In addressing this issue, this doctoral research suggests that practitioners should firstly locate critically-informed stigma-reduction work within available democratic spaces, where stigmatisation is a pressing concern. In the case of diabetes and other non-communicable diseases, there is a mass of research and policy support for both stigma-reduction work and greater public/patient involvement in healthcare and health research (Faulkner 2017; Harris et al. 2019; Herrick 2020; Wylie et al. 2019). In the case of diabetes, this doctoral research has suggested that stigmatisation emerges from the orthodoxy of knowledge and practices within news media, healthcare, and public health organisations. Therefore, relevant democratic spaces also include those primarily designed to inform disease-prevention work, what Greenhalgh (2009) refers to as self-management, coping, and socio-ecological approaches to public/patient involvement, rather than those spaces dedicated to stigma-reduction work per se.

Once practitioners have identified a suitable location for their stigma-reduction work, the questions and considerations contained within Figure 6 can be used to structure learning objectives and educational activities to facilitate a more critical analysis of diabetes-related stigma. Additionally, there are certain actions that educators might take to support a more critical engagement with these questions. Firstly, this research suggests that critical pedagogy within stigma-reduction work should focus on the process of othering, rather than on the stigmatisation of PWD as a unified group. In doing so, the conceptually complex and contested stigma concept may need to be set-aside for an alternative terminology that offers a more concise and intuitive label for the processes involved in the marginalisation of certain groups of PWD. Use of the term 'stigma' within this educational research appeared to constrain the possibilities for imagining stigma-related processes, similar to observations described by Deacon (2006) and Basinger, Farris and Delaney (2020) in relation to HIV and diabetes-related stigma, respectively. Focusing on production of the Other offers an opportunity to bring to attention to moral and symbolic dimensions of stigmatisation. Secondly, the educator has role in exposing members of stigmatised groups to alternative representations of members of the stigmatised group. Here there is potential to use framings of PWD as socially-embedded agents as a standpoint from which to examine existing knowledges of and practices affecting PWD. Thirdly, educators should focus on the analysis of pedagogical texts over personal experiences of stigmatisation, which the former being more likely to provide more accessible insights into the content and reproduction of forms of knowledge used to stigmatise. In addition to there being examples of such texts within academic literature (Brookes & Harvey 2015; Foley, McNaughton & Ward 2020; Lupton 2014), an abundance of suitable texts can also be found within communications produced by diabetes organisations. Take for example the below excerpt from an online newsletter provided by the diabetes organisation featured in this doctoral research, offering insight into how

expert knowledges function to define notions of risk and responsibility in relation to the development of diabetes-related complications.

Blinded By Sugar tells the story of Neil Hansell, a man who woke one morning *blind in both eyes due to neglect of his diabetes*. In this confronting 20-minute keynote presentation, Dr Muecke [2020 Australian of the Year] discusses why type 2 diabetes is a *growing worldwide epidemic* and explores a number of *strategies to curb the toxic impact of sugar on our health* and on our world. (anonymous source, emphasis added)

One of the issues confronting this research, reflecting wider issues in public health practice, is that efforts to critique or reduce diabetes-related stigma offers limited benefit to the individual, but potentially large benefit to the broader population (Hunt & Emslie 2001). As participants in this research and elsewhere (Manago, Davis & Goar 2017) have demonstrated, it is often preferable to adopt strategies to cope with or avoid stigmatisation. Although public health practitioners have previously responded to this problem by appealing to communitarian values (Ataguba & Mooney 2011; Taylor et al. 2013), the hyper-individualism and rampant othering observed within this research appeared to limit the development of sense of solidarity and shared concern amongst PWD. However, within the diabetes organisation examined in this research, there were also actors that challenged these individualistic notions of education, particularly amongst board members (many with diabetes themselves) and healthcare professionals that drew on interpretative frameworks of social determinants of health, person-centred care, and critical dietetics/nursing. In fact, the advantage of performing deliberative democratic methods with staff and board members within this diabetes organisation was that it is explicitly appealed to communitarian values through its aim to extend 'the thinking of participants beyond their own interests to think about public goods and the collective needs of the community' (Degeling et al. 2017, p. 166). Therefore, going forward it would seem that critical methods of education would be best located within broader movement towards the democratisation of public health and healthcare systems, rather than as a stand-alone educational intervention. This approach may help overcome some of the issues with participant recruitment that were encountered in this doctoral research.

Findings from this research also have implications for practitioners and policy officers tasked with diabetes/disease-prevention work, particularly given the way it implicates their work in the production of diabetes-related stigma. Although there is a considerable body of literature that offers strategies for the ethical critique of disease-prevention work (Lee 2012; ten Have et al. 2012; Upshur 2013), there is no specific guidance for the ethical critique of stigmatisation in the context of diabetes prevention activities. Despite this doctoral research not being targeted towards the needs of this audience, these findings are likely to be useful in supporting a reflexive analysis of the ideological basis of health education and how the use of risky or disgusting attributes (obesity and diabetes-related complications) or behaviours (in relation to diet and exercise) inadvertently provides individuals with the resources required to identify the stigmatised Other. While this broad idea is not new within public health, at least in relation to obesity (Lupton 2014), the questions contained in Figure 6 offers a

specific strategy for seeing the reality of diabetes-prevention work in a different light. Those involved in diabetes prevention work may play a role in establishing processes for involving publics, patients, and consumers in the planning of disease-prevention activities, with the intention of incorporating less-stigmatising representations of PWD within disease-prevention work. These points are also true of health communicators from other sectors, including those within news media organisations, whose work is likely to also perform educational functions (Briggs & Hallin 2016).

For researchers examining diabetes-related stigma, findings from this research presents a dilemma. If diabetes-related stigma is assumed to be the iatrogenic consequence of the way that societies and health systems govern risky bodies, then research seeking to further understand the structural basis of stigma or seeking to engage in stigma-reduction work at a structural level will result in challenges to foundational knowledge that informs diabetes-prevention work. This raises the broad question of how diabetes prevention work might operate so to maintain its effectiveness whilst also reducing its tendency to stigmatise certain sub-groups of PWD. Given that this question reflects a tight interweaving of technical and normative considerations, it would seem appropriate for further deliberative democratic research to be performed in order to clarify an appropriate strategy for disease-prevention (Degeling, Carter & Rychetnik 2015). But as this doctoral research has demonstrated, a critical democratic approach is likely to be required because of the coercive effects of ideology relating to responsible bio-citizenship (Hammond 2018; Rostbøll 2008).

In broadening the relevance of this research, it will also be important to identify what understandings of stigmatisation are produced when applied to other stigmatised populations. A good place to start within the field of public health would be other major non-communicable diseases<sup>25</sup> given common experiences of stigmatisation and the way that their categorisation is derived from shared modifiable aetiological behaviours of unhealthy diet, physical inactivity, tobacco use, and harmful use of alcohol (Herrick 2020). However, further research would still benefit from a continued focus on diabetes and PWD given the emphasis on individual acts of self-care for preventing diabetes and diabetes-related complications. Diabetes provides an ideal context for learning about how political-economic imperatives for healthy populations might shape the illness experience.

## Conclusion

This research emerged from a recognition of the way that the illness experience and selfhood for persons living with type 2 diabetes is profoundly shaped by the socio-political construction of illness, which implies that the experience of stigmatisation also possesses ideological and socio-political dimensions. However, one of the limitations facing existing diabetes-stigma research and stigma-reduction efforts is that these dimensions have largely been overlooked in favour of more

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<sup>25</sup> Major non-communicable diseases, as defined by the WHO (2013), include diabetes, cardiovascular diseases, cancers, and chronic respiratory diseases.

phenomenological understandings of experiences of shame and blame. This limitation raised the question of how learners might be supported to look beyond a (social) psychology of diabetes-related stigma and begin to think about stigma in more socially critically ways, along the lines of critical theories of health-related stigma. This doctoral research approached this issue by turning to critical pedagogy. A socially critical approach to education was considered useful because of its potential to help learners develop the literacies required to problematise existing representations of stigmatised persons and processes of stigmatisation, and in doing so create alternative discourses that might guide projects of stigma-reduction. Given that the use of critical pedagogy presents a novel approach for understanding health-related stigma, this doctoral research sought to identify what understandings of stigmatisation are produced through participation in an educational intervention informed by a critical pedagogy and what pedagogical and non-pedagogical processes contributed to these understandings.

As originally envisaged, this research involved conducting a five-week education program, adapted from Fook and Gardner's (2007) *Model of Critical Reflection for Professional Practice*, with two groups of PWD (n = 8) who experienced a perceived or self-stigma in relation to their diabetes. Using a qualitative case study methodology, longitudinal interviews with research participants were analysed to identify changes in representations of persons with diabetes and stigmatising events following their participation in the research. These methods of data collection offered insight into how discursive regimes were used by participants to construct, legitimise, resist, or transform stigmatised social identities, and provided insight into the way that participants implicated certain processes or structures in the production of diabetes-related stigma. By way of case comparison, it was then possible to identify processes of learning that contributed to these discursive changes, drawing upon data collected through participant observation and participant-generated reflective journals. During the early stages of data analysis, it became apparent that the risk discourse that structured participant narratives was limiting the ability of participants to think about diabetes-related stigma in more critical ways. This observation led to the development of further research that aimed to identify how a critical education project might function within a diabetes organisation responsible for performing both disease prevention activities (informed by risk discourses) and advocating for the felt needs of PWD (potentially challenging these risk discourses). This second research component involved a facilitated deliberation on earlier research findings with staff and board members (n = 25) from a state-wide Australian diabetes organisation. The purpose of this research was to locate critical pedagogy within a current landscape of public health, patient advocacy, and stigma-reduction work, with the intention of providing guidance on how to bring this pedagogical approach from the margins into the mainstream of public health practice.

From the initial case study research, it was possible to identify several features of learning that appeared to contribute to a more critical analysis of diabetes-related stigma. Firstly, the ability to think about diabetes-related stigma in more critical ways depended on clarifying precisely who is

stigmatised. The ability to clarify the target of stigmatisation is important as it brings attention to the medical and moral concepts used to identify the stigmatised Other. Secondly, the ability of participants to draw upon alternative subjectivities as a counter-hegemonic frame of reference facilitated appraisals of unfairness and feelings of moral outrage in relation to the production of the stigmatised (fat/obese) Other. In the absence of these alternative frames of reference, blame continued to be located within the stigmatised person, thus legitimising stigmatisation. Thirdly, texts with an educative purpose tended to function best in drawing attention to the way in which certain dominant knowledges, providing the conceptual resources that are drawn upon to stigmatise, are communicated and maintained. Alternatively, the experiential-interpersonal content of learning privileged within this doctoral research tended to promote an individualisation of the stigma concept, locating the problem of diabetes-related stigma in the dysfunctional thoughts, emotions, or behaviours of stigmatisers or stigmatised persons.

Importantly, these processes of learning were stifled by hegemonic understandings of the risky and vulnerable body coupled with obligations for PWD to manage these risks through acts of self-care. It was in this context of risk that participants justified stigmatisation of the diseased-disabled and irresponsible Other and struggled to identify an alternative reality where this othering would not occur. For this research, the inability to identify an alternative reality meant that rather than thinking more critically about diabetes-related stigma, participants tended to legitimise and individualise stigmatisation given a close and deliberate examination. In this way, medical and moral understandings of the body/self was perceived to be a productive force, where seeing oneself as a medicalised subject and object offered a potential escape from a natural disease history of organ failure and premature death. This logic largely emerged from medical understandings of the self-care – biomarker – complications relationship, which sets diabetes (both type 1 and type 2) apart from other chronic illnesses where the self-care - disease outcome relationship is less pronounced. In developing a critical theory of diabetes-related stigma, it was apparent that one's experience of diabetes self-care, itself experienced as an intimately personal activity performed for reasons of self-preservation, was colonised by ideologies drawn upon to support the government of risky bodies. This is likely why certain pedagogical texts, which offer insights into how the public is taught about matters of risk and responsibility, may offer a clearer insight into processes of stigmatisation.

These findings also have implications for how future educators might frame their critical pedagogical practice. In light of hegemonic understandings of the risky and vulnerable body and imperatives for self-care, the hypothesis that learners might engage in a grounded critique of diabetes-related stigma if given the cognitive-reflective method to do so was not supported by this research. Rather, a high degree of coaching and modelling was required on behalf of the educator to encourage a more critical analysis of diabetes-related stigma, with limited demonstrable effect on encouraging independent learning. In relation to diabetes-related stigma, it would seem that a more bold facilitative stance is required than that offered by this research. Consistent with existing literature

examining facilitation within critical pedagogy (Fitzpatrick 2013; Fitzpatrick & Allen 2019; Tinning 2020), it would seem that a critical pedagogy for diabetes-related stigma may benefit from an approach where the educator is willing to take a more directive role in bringing attention to critical topics (particularly in relation to the representation of PWD within educational texts) and overtly challenging the function of medical and moral knowledges in relation to these topics. Early in the candidature, a key question raised by the doctoral candidate was *how directive should the education program be in relation to its engagement with critical theories of diabetes-related stigma?* At the conclusion of the research, it appears that not much is gained through a more tentative engagement; suggesting that a much closer theoretical engagement is required. The conceptual model of diabetes-related stigma developed through this doctoral research offers a framework from which future educators might adopt a bolder and more directive stance in examining the stigma concept.

The doctoral research also demonstrated that learning environments characterised by high levels of interpersonal conflict and poorly managed contests of illness representation make it difficult for the educator to maintain a focus on critical topics or adopt a more playful facilitative style. Such high levels of conflict required greater attention to the creation of a safe environment for critique, which detracted from the facilitator's ability to engage more closely with critical topics and theory. Such conflict should be anticipated by future educators given the fierce contests of representation observed within this doctoral research. Furthermore, the observation that these contests of representation are occurring suggests that PWD are already engaging in some form of lay critique of identity. It may be that such conflict can be productively used to steer contests of representation towards a more critical direction.

Although the educational case study offered valuable insights into relevant processes of learning and how this learning is constrained, participants did not demonstrate a wholesale movement towards a more critical understanding of diabetes-related stigma. This is not to say that a critical pedagogy has nothing to offer stigma-reduction education, but rather that the findings from this doctoral research may be used to further refine and develop future educational methods. A key aspect of this development is the role that critical pedagogy might play in facilitating more critical forms of deliberation within existing projects (observed in the second research component) to democratise healthcare services, health systems, and news media. By adopting explicitly critical forms of democracy, these democratic spaces are likely to be conducive to the critique of taken-for-granted beliefs and practices, the inclusion of marginalised voices within democratic processes, and the creation of alternative discourses, which are valued activities within critical pedagogy.

Far from providing a conclusive account of how educators might proceed with a critical pedagogy for understanding diabetes-related stigma, these findings have described important considerations in further developing a critical project for education-based stigma-reduction work. This is an acceptable outcome given the way that this doctoral research has placed critical pedagogy within a novel context

of public health-oriented stigma-reduction work, applying this educational methodology to a field with limited engagement with critical theories of stigmatisation. Therefore, further research is required to identify the discursive and behavioural effects of educational methods derived from findings of this doctoral research, how such methods might be used within democratic spaces relating to public/patient involvement in healthcare and news media organisations, and what implications this has for the representation of PWD and diabetes/disease-prevention practices. As observed in response to counter-hegemonic challenges by the fat acceptance movement, efforts to do so will likely come under intense scrutiny and attack from medical experts and governments who assert that current knowledges and practices exist for the public good. In recognition of the material benefits produced by existing practices affecting PWD, a deliberative research agenda seeking to establish a productive dialect between technical and value-laden aspects of diabetes/disease prevention may be more productive than a counter-hegemonic project built upon ideas of PWD as an oppressed group. In the meantime however, practitioners involved in stigma-reduction work may use the findings of this research as a guide for conceptualising and developing critical methods of education. Specifically, practitioners can use these findings to develop useful learning objectives and identifying activities that might support this learning and use the synthesised framework of critical consciousness developed earlier in this thesis to guide the assessment of learning.

Despite these outstanding questions, this doctoral research has advanced knowledge regarding the use of critical pedagogy for stigma-reduction work and about diabetes-related stigma in several important ways. In relation to stigma concept, it has offered an explanation of how self-conscious feelings of shame and guilt/blame, as frequently reported in the diabetes-stigma literature, are related and produced. In particular, this thesis suggests that stigmatisation occurs where ontological deficits of diabetes and diabetes-related complications are recast as moral deficits, drawing from ideological notions of the medicalised self and bio-citizenship that emerge in response to attempts to govern the risky bodies of PWD and those at risk of developing diabetes. This finding is important, as it offers a framework for identifying grievances directed towards a third party, offering an alternative to the blaming of stigmatised or stigmatising persons. Being able to frame stigmatisation in this way will help direct actions that can be taken to address the more diffuse experiences of felt stigma that are typically observed amongst PWD.

In relation to a critical pedagogy for stigma-reduction work, this doctoral research has articulated a related set of learning processes that appear to be drawn up in thinking more critically about stigmatisation, thus offering a pedagogical approach that responds to calls for researchers and practitioners to be cognisant of the ideological and socio-political basis of stigma. In this way, it has brought together diverse theory in relation to stigmatisation and othering, the role of moral outrage in social activism, the role of media texts in facilitating an analysis of power, and the role of novel frames of reference in facilitating social and political action. Given the broad relevance of this literature to other stigmatised populations, including persons with HIV-AIDS, mental illness,



fatness/obesity, and disability, it is likely that the findings of this doctoral thesis will have broad relevance beyond diabetes-related stigma. Importantly though, this research has demonstrated that the ability to engage in a critical analysis of stigmatisation is heavily constrained in contexts of health risks and where individuals assume primary responsibility for managing these risks. Therefore, what characterises a critical pedagogy for understanding diabetes-related stigma is the ability to critique and challenge existing discourses and practices used to produce and communicate knowledge about risky bodies and people. The pervasiveness of this knowledge and its profound effect on the identities of PWD demands that further attention be given to forming a critical democratic project that both seeks to prevent diabetes and its complications whilst avoiding stigmatising those that fall short of this public health imperative.

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# APPENDICES

## **Appendix 1. Published manuscript: Critical consciousness development: a systematic review of empirical studies**

Accepted manuscript from Pillen, H, McNaughton, D & Ward, PR 2020, 'Critical consciousness development: a systematic review of empirical studies', *Health Promotion International*, vol. 35, no. 6, pp. 1519–1530. <https://doi.org/10.1093/heapro/daz125>.

### **CRITICAL CONSCIOUSNESS DEVELOPMENT: A SYSTEMATIC REVIEW OF EMPIRICAL STUDIES**

#### **Abstract**

Developing an understanding of the social and political basis of marginalisation is an important educational task for health education guided by frameworks of social justice. With the intention of developing an evaluative framework for use in further research, the aim of this review article is to present a synthesised framework of critical consciousness development, developed from a systematic search and qualitative synthesis of empirical studies that have examined the processes by which individuals come to critically reflect upon and act on oppressive social relations. A systematic search was conducted examining English-language literature produced between January 1970 and May 2017 within databases of PsycINFO, SCOPUS, and ProQuest. A total of 20 articles were selected following a two-stage screening process and an assessment of methodological quality. Thematic analysis of findings from these texts produced a framework of critical consciousness development consisting of six qualitative processes and the relationships between them, including the priming of critical reflection, information creating disequilibrium, introspection, revising frames of reference, developing agency for change, and acting against oppression. This synthesised framework of critical consciousness development is presented as a useful tool for assessing learning within critical pedagogies, albeit requiring some modification to suit specific cultural contexts and epistemologies.

#### **Introduction**

In the context of disease prevention and management, health education has traditionally tasked itself with ensuring that individuals might avoid or minimise the effects of illness by adhering to certain health-related beliefs, values, and practices (Miller, 2011; Fitzpatrick, 2014). Although this functionalist approach to health education has been demonstrated to improve health status amongst healthy (The HEALTHY Study Group, 2010), at risk (Lindström et al., 2006) and chronically ill populations (Steinsbekk et al., 2012), it has also been criticised as contributing to inequitable outcomes due to its effect of upholding the interests of dominant population groups,

thus reinforcing a social hierarchy of health and illness through the exercise of symbolic power (Korp, 2008), and the privileging of individualistic, behavioural, and biomedical approaches to care (Kendall et al., 2011). For these reasons, a functionalist approach to education has been criticised by those espousing action on health inequities (Nutbeam, 2000).

An alternative approach to health education exists within a critical perspective, drawing inspiration from social conflict theories. These approaches focus on assisting learners to better understand and challenge social relations of domination and power so to enable them to achieve greater control over forces that constrain personal agency. Assumed within critical social theory is a relationship between social groups whereby one group, enabled by historical and social processes, may act to diminish the status of other social groups (Kincheloe, 2004). Members of a society may then willingly adopt the ideologies of the dominant group, for example through processes of governmentality (Leahy, 2013) or symbolic power (Korp, 2010). The problem with this arrangement is that it acts to conceal or naturalise differences in health, social, or educational outcomes (Fairclough, 2013).

There exists various theories and models of learning and development that attempt to explain how individuals might overcome the tendency to naturalise such outcomes. These include models of sociopolitical development (Watts et al., 2003) and critical consciousness development (Diemer et al., 2016), which attempt to explain how individuals might become aware of the sociostructural basis of marginalisation, and transformative learning theory (Taylor, 2007), which explains how individuals modify their frames of reference following a critical self-examination of personal assumptions and beliefs. These theories/models of learning make reference back to the early work of Freire, a Brazilian educator recognised for his method in developing a critical praxis with respect to oppressive class and social relations (Roberts, 2000). A Freirean approach to education has also inspired other critical approaches to education, including Critical Race Theory, Critical Feminist perspectives, and place and culture-specific critical Indigenous perspectives (Dei, 2011; Ledwith, 2016), which were developed in response to Feminist, Black, and Indigenous critiques of the Eurocentric and androcentric assumptions contained within earlier methods of critical education.

This paper provides a synthesis of the process of critical consciousness development, based upon a systematic review of frameworks, models, and theories of critical consciousness development and related constructs. Because a key challenge for the process-oriented constructivist and critical approaches to education involves determining what constitutes the attainment of meaningful knowledge or learning (Narayan et al., 2013), focusing on the learning process itself (i.e. development of a critical consciousness) offers a useful approach for assessing the effectiveness of education. The term critical consciousness development is defined here as the 'intentional

cultivation of self-awareness in context that attends to the dynamics of power in relationships and the structural environment invoking action toward social justice' (O'Neill, 2015, 626).

This review will provide an analytical framework that can be used by health promotion researchers and practitioners to evaluate the learning that has occurred in response to critical approaches to education, facilitating a more considered assessment of its cognitive, emotional, and behavioural effects and how these things might vary between learners. In the context of evidence-based practice and evidence-informed decision making in healthcare, this review is timely if researchers and policy makers invested in health education hope to appraise these methods alongside other approaches to health education for which causal logic and evidence of effectiveness is readily available (Parkhurst, 2017).

## **Methods**

The aim of this review was to systematically locate literature describing the processes involved in critical consciousness development and to qualitatively synthesise these findings in order to identify key stages involved in this learning process. Although there exists a vast literature that theorises how this process might occur, for the purpose of this review we are only concerned with studies that have developed theories or models of critical consciousness development from empirical data. Given questions regarding the ability of certain approaches to critical education to achieve their educative goals (Sicilia-Camacho and Fernandez-Balboa, 2009; Tinning, 2002), it was considered more appropriate to focus on observed versus theorised learning processes and outcomes.

## ***Eligibility criteria***

The 'BeHEMoTh' strategy (Behaviour/Phenomenon of Interest, Health context, Exclusions, and Models or Theories) proposed by Carroll and colleagues (Carroll et al., 2013, 2) was used in forming the eligibility criteria used to identify relevant models and theories of critical consciousness development. Studies eligible for inclusion in this review must have contributed to the development or refinement of frameworks, models, or theories of critical consciousness development or related constructs using empirical methods. For the purpose of this review, related constructs included socio-political development (Watts et al., 2003), Mezirow's transformative learning theory (Taylor, 2007), and theories/models of learning developed within the context of critical pedagogies (Kincheloe, 2004), as identified through an earlier scoping review. Eligible studies must have examined the process through which individuals come to understand and act upon social relations of domination and power, and given that the process of critical consciousness development is considered to consist of elements of critical reflection and action within a critical praxis (Diemer and Rapa, 2016; Ledwith, 2016), eligible studies must also consider processes related to both reflection and action. Eligible study populations included those experiencing marginalisation (or



related terms of discrimination, powerlessness, prejudice, vulnerability, and disadvantage) on account of their social identity, persons working in a professional capacity with those experiencing marginalisation, and members of relatively advantaged social groups. These populations reflect those that are typically targeted within critical education programs (Pillen et al., 2019).

### ***Search strategy***

Searches were conducted within academic databases of PsycINFO, SCOPUS, and ProQuest using keywords of 'critical pedagog\*', 'critical consciousness', 'sociopolitical development', and 'transformative learning', which were then combined with keywords of 'framework\*', 'model\*', 'theor\*', and 'concept\*'. Searches were limited to English-language articles produced between January 1970 and May 2017, including both published and unpublished literature.

### ***Study selection process***

Following the removal of duplicate articles, the title and abstract of each article was examined against the review's eligibility criteria in a first round of screening and followed by a more thorough full-text assessment of potentially eligible articles. All stages of searching and study selection were performed by a single reviewer (HP). The reference lists of all eligible articles were scanned to identify additional articles not identified through the original search.

After this, two reviewers (HP, PW) independently assessed the quality of included articles using the Joanna Briggs Institute's critical appraisal tool for qualitative studies (Joanna Briggs Institute, 2017) and an additional tool for the critical appraisal of psychometric instruments (Jerosch-Herold, 2005). Following independent appraisal, the reviewers compared and discussed ratings until consensus agreement was obtained. Studies deemed to be of poor methodological quality were excluded from the synthesis.

### ***Synthesis of results***

An inductive qualitative thematic analysis was used to synthesis findings from the reviewed literature. While thematic analysis provides a structured method for generating insights from qualitative data with few imposed theoretical constraints (Braun and Clarke, 2006; Nowell et al., 2017), it can also be prone to producing untrustworthy findings due to a lack of theoretical coherence within and between constructed themes (Nowell et al., 2017). To address this limitation, we conceptualised critical consciousness development within a rational constructivist framework of adult development (Moshman, 2003). Therefore, the task of this analysis was to qualitatively identify and describe the key stages involved in understanding and challenging social relations of domination and to identify how these stages might be ordered in a progressive or developmental configuration.

Taking this into account, our research used Attride-Stirling's (2001) thematic networks approach as an analytical tool for identifying relevant themes (representing qualitative developmental stages) and interpreting patterns within our data (representing the developmental relationships between these themes). Using this approach, the authors (HP, DM) constructed a coding framework following analysis of five articles, which was then used to code text from the remaining articles using an iterative process of constant comparison. Following this, themes were constructed and refined by reviewing coded text, and then assembling text into basic, organising, and global themes. A visual network relating these themes was then constructed and used as a tool for further examining the text and generating analytical insights. All data was organised using the NVivo qualitative data analysis software (QSR International Pty Ltd. Version 11).

## **Results**

From the 1,849 articles identified via the initial search, 20 were included in the synthesis of frameworks, models, and theories of critical consciousness development. The process of study selection is described in the PRISMA flowchart presented in figure 1, with study characteristics provided in table 1.

Thematic analysis of these findings produced a framework of critical consciousness development consisting of six qualitative processes and the relationships between them. Although several studies used language suggestive of epochal developmental changes, such as 'a-ha' moments (Landreman et al., 2007), or born-again metaphors (Wallin-Ruschman, 2014), texts overwhelmingly acknowledged the incremental and cyclical nature of development.

### ***Priming of critical reflection***

This organising theme was developed because of an inability of the following theme to sufficiently explain the variation in individual responses to information functioning to trigger reflective processes. The concept of 'priming' was chosen to illustrate the way in which earlier events, incidents, or cognitive frameworks might influence a person's response to subsequent events, increasing the likelihood that subsequent exposure might provoke a deeper or more perseverant consideration of the event. Amongst the reviewed studies there were three identified phenomena that served a priming function, including the historical exposure to oppressive events or incidents, the adoption of belief systems cognisant of unjust social relations, and having unmet psychological needs. The following excerpts provide some illustration of how these factors functioned in a priming capacity.

For minority learners, an alternative type of dilemma, one based on racist or sexist experiences and the accumulated effects of a lifetime of discriminatory actions may also trigger the start of the transformative process. (Kairson, 2009, 138)

All three participants shared an interest in social justice and helping people that began during their formative years...this commitment was significant in fostering their openness to the transformational experience in later life. (Frank, 2005, 56)

The catalyst for the transformative process in the minority women was the search for something they felt was missing in their life. (Kairson, 2009, 137)

### ***Information creating disequilibrium***

This theme represents the way in which information (broadly defined to include both cognitive and affective experiences) received through discrete events might generate uncomfortable thoughts, feelings, or emotions. Implicitly, it makes reference to Mezirow's concept of a disorienting dilemma (relevant to perspective transformation in adults) (Taylor, 1997), which is concerned with how individuals can integrate information incompatible with existing schemata/frames of reference via the process of perspective transformation.

Within reviewed studies, there existed four sources of information that were noted to create a sense of disequilibrium, disorientation, or discomfort. All were alike in that they presented an alternative version of social reality that conflicted with previously accepted or unquestioned models. One source of information involved the witnessing of oppressive acts, either through personal acts (Saheli, 2003; Landreman et al., 2007), media representation (Osajima, 2007), or through the embodiment of social inequality in objects of separation and segregation (Saheli, 2003). Secondly, exposure to non-dominant perspectives provided a way in which individuals might question the validity of dominant understandings of social reality, such as was the case in the following study.

He questioned why he hadn't learned any of this before? Why was his experience absent from U.S. history courses? This process had led him to think more critically about the racism embedded in his educational experiences. (Osajima, 2007, 67)

Thirdly, the experience of disequilibrium was created through the identification of deviant cases contradicting group stereotypes, leading to questions regarding the validity of these stereotypes (Saheli, 2003). And lastly, a deep or immersive exposure to cultural difference provided sustained and contextualised sources of information that might contribute to a state of disequilibrium (Landreman et al., 2007).

### ***Introspection***

This is taken to refer to the individual's self-examination of thoughts and emotions in response to a state of disequilibrium. Within the reviewed studies, the objects of self-examination included personal beliefs, motivations, and identity, which were used to make sense of the disorienting

incident. For example, a disorienting incident may bring into focus the individual's belief system, and so it becomes possible to evaluate whether personal actions are congruent with these beliefs. The following excerpt illustrates how introspection occurs recursively throughout the process of critical consciousness development, with social action contributing to the receipt of new information that in turn facilitates further self-examination.

While traditional adult education classes focus on dialogue and discussion to create disequilibrium, social action is a blatant, obvious way to facilitate disorientation and disequilibrium. The action of working on an issue was significant enough to create disequilibrium in the assumptions, beliefs or self-interests of a person. (Scott, 1991, 217)

### ***Revising frames of reference***

The focus within this stage was on the cognitive models involved with analysing and explaining social relationships (i.e. frames of reference) and how these might change following a critical analysis of the assumptions underlying these relationships. Amongst reviewed studies, existing frames of reference were shown to be modified through interrelated processes involving the questioning of assumptions informing existing frames of reference and the reconstruction of beliefs used to explain social reality.

Amongst texts examined in this review, there appeared to be two assumptions about social reality that needed to be unsettled in order for a revision of frames of reference to occur. First was the assumption that the existing state of social relations represented a fair or just arrangement. Following this was the assumption that powerful groups (defined politically and economically) were responsive to the needs of marginalised groups. By questioning these assumptions, individuals come to learn that aspects of social organisation are unfair, and that they cannot trust those with the power to address such injustice to act accordingly.

Participants also demonstrated an understanding of how those in positions of power (e.g., those with wealth and in political leadership) do not often provide help or support to people from lower socioeconomic groups or those who are seen as having less influence such as young people. (Baker and Brookins, 2014, 1023)

For this unsettling of assumptions to occur, there had to be a questioning of the status or validity of knowledge. Amongst reviewed texts, critical consciousness development required a recognition that assumptions about social reality did not represent natural, universal, or fixed social facts, but rather were constructed in a way that represented the interests of dominant social groups (Goerd, 2011).

Following the unsettling of assumptions, individuals were observed to develop a frame of reference informed by sociostructural understandings, with individual experiences related to social structures that, to some extent, acted to pattern group experiences and behaviour.

The chance to talk to other Asians about their lives and experiences with discrimination had helped respondents to see that their individual experiences were not unique. As they had seen similarities and patterns, it was easier for them to see how broader forces, like racism, shaped their individual lives. (Osajima, 2007, 67)

In some cases, this revised frame of reference was structured around dualisms of the oppressed and oppressors (or the powerless and powerful). More common however was the recognition that marginalised groups may also participate in the reproduction of oppressive social relationships. Intersectionality was one strategy used to understand and locate oneself within unequal social relationships, drawing upon experiences related to a co-existing marginalised social identity as a framework for interpreting other unequal social relationships. For example, one study described how for some participants 'understanding their gay/lesbian identities served as a gateway to think about other oppression around them' (Landreman et al., 2007, 287).

Relevant to the previous point, the ability to locate oneself within a system of social relations required clarification of one's social identity or group membership. Within reviewed studies, the revision of social identity involved: a) a realisation that individual identities have a social as well as personal basis, b) that an individual possesses multiple social identities, and c) that aspects of one's identity is amenable to change. Take for example the following excerpt from a study examining critical consciousness development in higher education.

The findings presented here illustrate the intersectional and intersubjective nature of identity development, that who and what we "are" in any given moment is shaped by our interactions within ever changing institutional, cultural, and group experiences that influence how we create meaning from words, the structures of institutions, and our own individual agency. (Peet, 2006, 385)

### ***Developing agency for change***

Agency is regarded here as the ability of a person to successfully perform actions in response to insights generated through a revised frame of reference. Despite the existence of an extensive body of literature theorising human agency (Hitlin and Elder, 2007), literature examined within this study provided little indication about what frameworks were used or assumed in explaining the operation of personal and collective agency. Our interpretation of the reviewed literature is presented with this limitation in mind.

Findings from this review are broadly consistent with McWhirter and McWhirter's conceptualisation of 'critical agency' as consisting of both a commitment to change and perceived self-efficacy

(McWhirter and McWhirter, 2016). In relation to the former point, our analysis reframed 'commitment to change' as 'assuming responsibility for change', which reflected the way in which individuals drew motivation for change from their own implication in the reproduction of oppressive social relationships. And in relation to the latter point, group dialogue played an important role in assisting the learner to articulate and refine ideas and to validate new forms of knowledge and plans of action. Reflecting a critical praxis, personal agency was also found to be dependent on processes of action and reflection occurring within and outside of formal learning environments. Within this process, changed behaviour produces new experiences that may trigger further introspection and revision of existing frames of references. This has the effect of clarifying the nature of social relationships and ways in which personal influence might operate within these relationships. Through action, skills may also be developed which in turn may lead to more effective forms of action into the future.

### ***Acting against oppression***

Given the importance assigned to social action within this literature, it was surprising to see that social action was under-theorised and under-reported in texts featured within this review. It was possible to identify actions occurring at either an individual level, in which individuals had control over the terms and execution of the action, or at a group level, which required actions beyond the capacity of individuals to fully plan and execute. The focus of attention for individual action was the reproduction of oppressive social relationships through interpersonal encounters, where discursive strategies might be used to 'interrupt' oppressive discourses.

...learning about interruptions gave them [study respondents] a sense of efficacy—a feeling that they could do something to intervene in injustice. Many participants viewed this practice as a powerful force for personal and political change (Wallin-Ruschman, 2014, 206)

Less clear was how this action related to the content of reflection. Examining the study from which the above excerpt was taken, there appeared to be some disjuncture between the sociopolitical framework used to conceptualise oppressive group relations and the mode of social action chosen (i.e. 'interruptions'). It was also unclear in this example and others (Landreman et al., 2007) which discursive strategies were being used to interrupt oppressive discourses and in which contexts they were being used.

For group-level actions, the focus was on the process of group organisation and how this occurred in a way that might afford the group greater influence in addressing oppressive social relationships. However, what these features of group organisation were and how group organisation might be used to gain influence was not explored in any of the reviewed texts.

## Discussion

This review examined various frameworks of learning and development that might be used to explain how individuals learn about and attempt to ameliorate unjust social differences in health or social outcomes. In doing so, a synthesised framework of critical consciousness development was constructed with the intention that it might be used to support the evaluation of critical education programs. This synthesised framework appears to align most closely with transformative learning theory, most noticeably because of its reference to a disorienting event and the questioning and revision of cognitive frames of reference. This alignment is expected given that transformative learning theory, as its name suggests, is primarily concerned with the process of critical learning, consistent with this review's aims. Theories and models of critical consciousness development and sociopolitical development on the other hand tend to provide classifications of thought and behaviour that might be expected as individuals move from an acritical/magical consciousness through to a liberatory/critical consciousness (Ledwith, 2016; Watts et al., 1999).

However, given that all of these theories/models identify with the work of Freire in a direct or indirect way, there is considerable overlap in the processes involved. For example, our synthesised framework suggests that pre-existing experiential, social, and psychological processes (including past experiences, belief systems, and needs for self-actualisation) are required to bring into consciousness a disorienting event and provide motivation for its further examination. Within a model of sociopolitical development, this is similar to Watts and colleagues' (1999) claim that African American spirituality (as a belief system) has acted to facilitate the process of critical learning. Like Dirkx (2018), Watts et al. (1999) highlight the role of the 'soul', in addition to cognitive and affective processes, in facilitating learning. From an Indigenous perspective, past histories of marginalisation and the desire to reclaim an Indigenous identity might also provide the foundation for a more considered socio-political analysis of this marginalisation (Settee, 2011). Although the synthesised framework does incorporate both cognitive-rational and extra-rational modes of knowledge production, its closer alignment with transformative theory (at least with earlier cognitive-rational approaches (Taylor and Cranton, 2012)) does mean that the former is privileged over the latter, which could possibly be construed as also containing Eurocentric and androcentric biases (Cross-Townsend 2011, Ledwith 2016). Saying this, transformative learning theory has been adapted for use in critical Indigenous education programs, suggesting it is flexible enough to accommodate alternative epistemologies (Jackson et al., 2013).

The synthesised framework has also highlighted the learning processes involved in the revision of frames of reference and how interaction between reflection and social action may act to build the agency required to disrupt oppressive social relationships. Here, oppressive social relationships can be conceptualised in quite different ways, ranging from class-based power relations within a Western political economy, through to processes involved in colonisation (Dei, 2011). These

different conceptualisations of 'oppression' draw upon different epistemologies in developing anti-oppressive frames of reference, for example drawing from relevant Indigenous or Feminist epistemologies (Jackson et al., 2013; Ledwith, 2006; Settee, 2011; Smith, 2013). Unfortunately, the reviewed literature featured little theorising of the processes relating changes in frames of reference to agency/self/group-efficacy and social action, which leaves uncertainty regarding the process by which a critical praxis develops and sustains itself. However, reviewed studies did appear to represent agency and structure as two analytically distinct phenomena, similar to Archer's (2003) morphogenetic sequences, in which antecedent structures constrain or enable the action of agents, which in turn reproduces/modifies these structures. This process, according to Archer, is enabled by human reflexivity that involves an inner-dialogue about the relationship between personal concerns and social circumstances. Further engagement with theories of human reflexivity and agency may therefore help extend current understandings of critical consciousness development.

Emphasis within reviewed literature was also placed on the progressive movement of individuals towards a state of moral maturity, similar to that observed in stage models of moral development (Kohlberg and Hersh, 1977). This moralisation of learning was evident in the use of rebirth metaphors, both in reference to personal revelations and radical social change (for example, see Wallin-Ruschman, 2014). The metaphorical use of rebirth is not surprising given historical attachment of consciousness raising efforts to liberation theology, expressed through the works of educators Freire and Horton (Roberts, 2000; Thayer-Bacon, 2004), and also given more recent attention given to the role of spirituality within critical consciousness development (Dirkx, 2001; Roberts, 2009; Watts et al., 1999). This observation is important given critiques that critical approaches to education can act to position particular worldviews as being superior to others, with these worldviews being employed as dogmatic moral codes of practice (Sicilia-Camacho and Fernandez-Balboa 2009) and reducing the capacity for critical reflection (Wallin-Ruschman, 2014).

Despite these limitations, the findings from this analysis should prove useful in supporting an analysis of the effects of educational methods (i.e. critical pedagogies) that attempt to develop a critical consciousness of oppressive or inequitable social relationships. Because the key challenge for constructivist and critical approaches to learning involves determining what constitutes the attainment of meaningful knowledge (Narayan et al., 2013), focusing on the process of learning itself provides a useful framework for assessing the effectiveness of these critical pedagogies. Taking cultural considerations and epistemologies into account, this synthesised framework of critical consciousness development provides a useful analytical framework for health promotion practitioners and researchers seeking to qualitatively evaluate the effects on learning for those participating in critical education programs.



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**Table 1. Characteristics of included studies – frameworks, models, and theories of critical consciousness development**

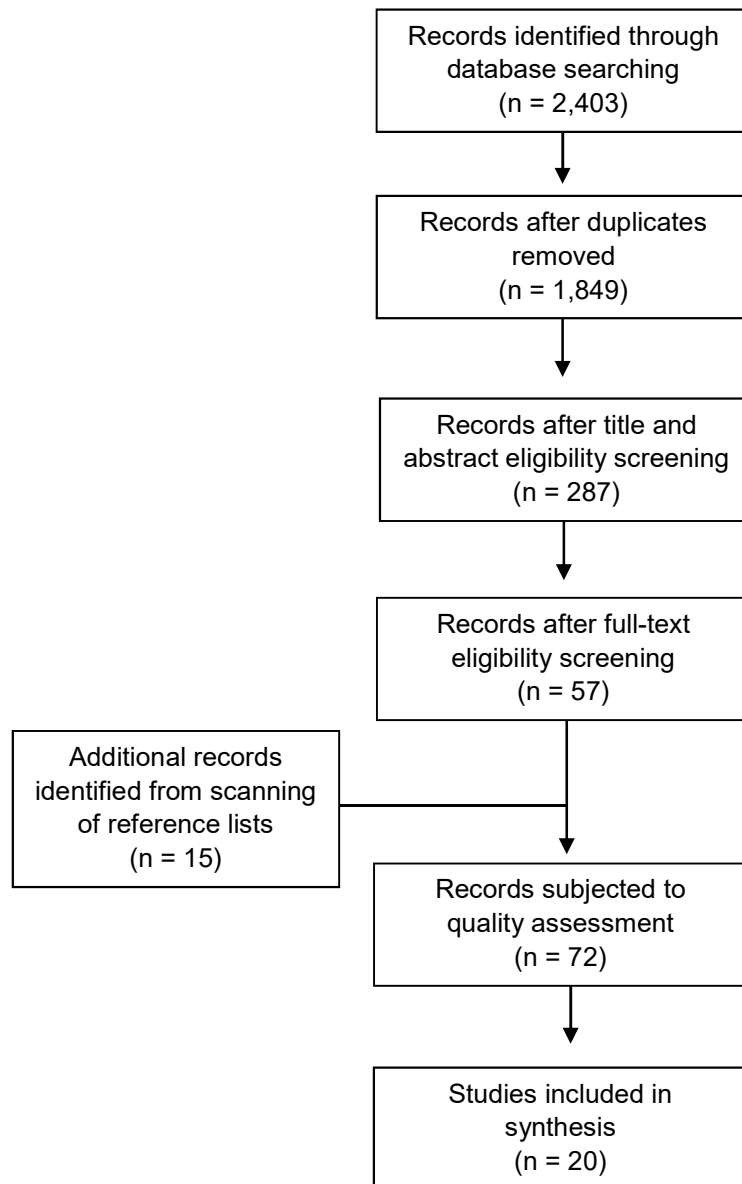
Study	Methodology	Setting for study	Population	Object of learning
Addleman et al. (2014)	Phenomenological interviews	Cultural immersion field trip within Austria and Ecuador	Students attending a Master of Arts in Teaching program at a private university within the USA (n =24)	Interaction between cultural difference and instruction within the classroom
Baker and Brookins (2014)	Mixed-methods	Rural village and high schools within El Salvador	Adolescents from a rural village (n = 11) and students attending high school (n = 682) within El Salvador	Sociopolitical development
Barlas (2000)	Qualitative case study	Private not-for-profit university within the USA	Students who identified themselves as being transformed through their participation in a doctoral program (n = 20)	Perspective transformation following participation in a transformative learning doctoral program
Carlson et al. (2006)	Photovoice	A poor neighbourhood located within a large urban centre within the USA	Self-selected community members residing within the study area (n=45)	Community-wide health concerns relevant to the selected neighbourhood
Diemer and Rapa (2016)	Cross-sectional survey	Sample drawn from amongst the 150 schools who participated in the 1999 US Civic Education Study (CIVED)	Ninth graders sampled from populations of poor or working class African American and Latino/Latina adolescents (n = 2811)	Racialised social inequalities
Diemer et al. (2017)	Cross-sectional survey	Sample drawn from across five urban high schools plus one African American high school student association within the USA	High schools students, with the majority self-identifying as African American (63% of sample) or as multiracial (24.6% of sample) (n = 326)	Racialised, gendered, or socioeconomic inequalities
Frank (2005)	Qualitative interviews	Care providers working in disability support organisations within the USA	Disability support workers who were identified as experiencing perspective transformation (n = 3)	Marginalisation of persons with disability
Furumoto (2001)	Qualitative case study	Two elementary schools in southern California	Working class Mexican women volunteering as school-based parent leaders (n =8)	Economic, racialised, and gendered oppression
Goerdts (2011)	Qualitative case study	Social work students from the United States and Germany who participated in an intercultural exchange via video/teleconference	13 German and 4 US social work students (n = 17)	National social welfare systems

Study	Methodology	Setting for study	Population	Object of learning
Kairson (2009)	Qualitative case study	Women enrolled in a collaborative leadership development program offered by a labour union within a large private university within the USA	14 women, drawn from a population of 228 women who were enrolled in the leadership development program between 2000 and 2007	Racial and gendered factors involved in transformative learning
Landreman et al. (2007)	Phenomenological interviews	Two large US universities with histories of institutional commitment to multiculturalism	University educators varying by ethnicity, gender, and sexual orientation (n = 20)	Development of social justice beliefs
McWhirter and McWhirter (2016)	Cross-sectional survey	Sample drawn from a 2012 Latina/Latino youth leadership conference within the USA, attended by approximately 1,100 high school students	Samples of 476 Latina/Latino students from across 65 high schools (study I) and 870 Latina/Latino students from across 74 high schools (study II)	Racism
Mustakova-Possardt (1996)	Qualitative case studies	Sample drawn from participants of the Midlife Development in the United States (MIDUS) survey (Boston area). The Bulgarian sample was drawn from across a large capital city and a small rural town.	20 US and 8 Bulgarian adults, aged between 35 and 60 years (n = 28)	Moral development
Osajima (2007)	Narrative interviews	Sample drawn from a population of Asian American college students involved in Asian American Studies at a large university within the USA	Asian American college students who described themselves as having a strong pan-Asian American identity (n = 12) and Asian American activists identified through snowball sampling (n = 18)	Racialised social inequalities
Peet (2006)	Qualitative case study	Sample drawn from a cohort of graduate-level social work students from a large university within the USA	Social work students that had participated in curriculum oriented towards developing a social justice orientation (n = 111)	Development of a social justice orientation within social work
Saheli (2003)	Participatory inquiry	Members of a 'churches of Christ' community within the San Francisco Bay Area (USA)	African American men and women aged 55 years or older (n = 6)	Racial labelling
Scott (1991)	Grounded Theory	Sample drawn from members of the Lincoln Alliance, a multi-issue organisation that existed in	Five past presidents, two past vice presidents, and three organisers from the Lincoln Alliance (n = 10)	Beliefs about the relationship between self and society

Study	Methodology	Setting for study	Population	Object of learning
		Nebraska (USA) from 1974 - 1982		
Shin et al. (2016)	Cross-sectional survey	Paid online survey	In the first study, the average age of the sample was 33.9 years and consisted of predominantly female (64.8%), Caucasian/European American (68.1%), heterosexual (83.3%), and middle-class (41.9%) respondents (n = 210). In the second study, the average age of the sample was 33.7 years and consisted of predominantly female (53.8%), Caucasian/European American (71.2%), heterosexual (85.0%), and middle-class (49.8%) respondents (n = 406)	Classism, racism, and heterosexism
Thomas et al. (2014)	Cross-sectional survey	First year students from across two universities within the USA	The mean age of participants was 18.98 years, with a majority of female (67.5%) and African America (40.0%) and White (32.2%) students comprising the sample (n = 206)	Development of social justice beliefs
Wallin-Ruschman (2014)	Qualitative case study	Students participating in the Girl Power Senior Capstone, which is taught at an urban public university within the USA	Mostly female college students of varying ethnic backgrounds and sexual orientation (n=17)	Social gender relations



Figure. 1. PRISMA flowchart for a systematic search of frameworks, models, and theories of critical consciousness development



## **Appendix 2. Published manuscript: A review of critical pedagogies in health and social care: findings from a ‘best fit’ framework synthesis’**

Accepted manuscript from Pillen, H, McNaughton, D & Ward, PR 2019, 'A review of critical pedagogies in health and social care: findings from a ‘best fit’ framework synthesis', *Critical Public Health*, vol. 30, no. 4, pp. 468-486. <https://doi.org/10.1080/09581596.2019.1591613>.

### **A review of critical pedagogies in health and social care: findings from a ‘best fit’ framework synthesis**

#### **Abstract**

Although recent research has highlighted the importance of understanding the structural social processes through which stigma is produced and maintained, educational approaches to stigma-reduction have not yet engaged with this concept. Recognising that critical pedagogies have been used in other contexts to help learners better understand and challenge structural social processes of marginalisation, we conducted a review of educational interventions that were informed by critical pedagogies and delivered within settings of health and social care. A systematic search was performed to identify all published and unpublished English-language literature published between January 1970 to May 17 2017 reporting on the learning outcomes of educational interventions informed by frameworks of critical consciousness development. Articles were selected following a two-stage screening process and an assessment of methodological quality. Of the 9,674 articles identified from the systematic search, 33 were found to satisfy the inclusion criteria and were of sufficient quality to be considered within this review. Two major findings emerged from the analysis of interventional studies. Firstly, it was found that learners consistently articulated a sociostructural understanding of oppressive social relations and their position within it, based upon an understanding of their own group identity. Secondly, and despite the sociostructural content of reflection, individual actions tended to focus on the modification of interpersonal interactions. Although educational interventions informed by a critical pedagogy appear to support a structural analysis of social marginalisation or disadvantage, there is limited evidence to suggest how these structural processes might be challenged following this analysis.

**Keywords:** critical pedagogy; marginalization; inequalities

## Introduction

Education has long been used as a stigma-reduction strategy within public health interventions (Thornicroft et al., 2016), often used alongside strategies of 'contact' (Herek, 2007), and political advocacy (Heijnders & Van Der Meij, 2006). Many of these educational approaches have assumed that inaccurate beliefs, in the form of negative stereotypes, are responsible for the reproduction of stigma and that by replacing these stereotypes with more accurate beliefs (via education) at a population level stigmatisation can be interrupted (Heijnders & Van Der Meij, 2006; Parker & Aggleton, 2003). However, researchers examining processes of stigmatisation are increasingly recognising the importance of understanding the macro-structural social processes through which stigma is produced and maintained (Hatzenbuehler & Link, 2014; Monaghan, 2017; Scambler, 2006). The term 'structural stigma' has been increasingly used to represent this perspective, bringing into focus the 'societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatised' (Hatzenbuehler & Link, 2014, p. 2). Seeing that stigmatisation acts to reinforce inequalities in health and social status and may act to mediate the effectiveness of certain public health interventions (Hatzenbuehler, Phelan & Link, 2013), it is of public health interest to examine new approaches to education that can assist members of stigmatised groups better understand and challenge social structural processes involved in stigmatisation.

With this in mind, a useful approach to education might exist within a critical perspective. This perspective has developed from the early work of Freire in low and middle-income countries (Roberts, 2000), the critical pedagogies of North American educational scholars (Evans, 2008; Kincheloe, 2004), and the social psychology of perspective transformation (Taylor, 2007) and critical consciousness of oppressive race and gender relations (Diemer, McWhirter, Ozer, & Rapa, 2015; Watts, Williams, & Jagers, 2003). Put broadly, these approaches focus on assisting learners to better understand and challenge social relations of domination and power so to enable them to achieve greater control over forces that constrain personal agency (Kincheloe, 2004).

Despite calls for greater use of critical methods in health education (Martos, 2016; Nutbeam, 2000), a comprehensive review and synthesis of the effects of interventions informed by such methods is notably absent within academic literature. To bridge this gap, we conducted a literature review, based on a systematic search of published and unpublished literature, to identify learning outcomes resulting from participation in educational interventions informed by critical pedagogies and delivered within contexts of health and social care. Specifically, the purpose of this review was to identify changes in thinking and behaviour occurring in response to participation in these educational interventions, and to identify how these cognitive and behavioural changes interact with one another and constitute a praxis relating self-reflection with social action and social change

(Shapiro, 1999). This is important given our ultimate interest in how individuals might transform social processes that maintain stigmatising social relationships.

Rather than focusing more narrowly on stigma-reduction interventions, which would have produced limited findings, we expanded the scope of the review to include educational interventions within settings of health and social care that employed critical pedagogies to examine and address issues relating to social inequalities affecting marginalised population groups. This comparison is reasonable within a structural stigma framework given assumptions about how certain social groups possess the 'social, economic, and political power' to establish 'differentness' and enact discriminatory behaviour (Link & Phelan, 2001, p. 367), and how this functions to maintain existing social inequalities (Hatzenbuehler, Phelan, & Link, 2013).

## **Methods**

The protocol for this review was published prospectively on the PROSPERO database of systematic reviews and meta-analyses (<https://www.crd.york.ac.uk/PROSPERO/>) under registration number CRD42017067777. This review follows the refined "best fit" framework synthesis' approach described by Carroll and colleagues (Carroll, Booth, Leaviss, & Rick, 2013). This approach uses a systematic literature search and thematic analysis of relevant theories, models, and frameworks to construct a conceptual framework for the phenomenon of interest, with this 'best fit' framework then used to analyse the findings of primary research studies identified via a second systematic literature search.

Because a key challenge for the process-oriented constructivist and critical approaches to learning involves determining what constitutes the attainment of meaningful knowledge (Narayan, Rodriguez, Araujo, Shaqliah, & Moss, 2013), focusing on the learning process itself provides a useful approach for assessing the effectiveness of education. For this reason, we grounded our understanding of learning within a framework of *critical consciousness development*, which we define here as the 'intentional cultivation of self-awareness in context that attends to the dynamics of power in relationships and the structural environment invoking action toward social justice' (O'Neill, 2015, p. 626).

## ***Study eligibility criteria***

Although interventions could relate to any health or social issue, accommodating the breadth of issues examined within socioecological approaches to health education (Fitzpatrick, 2014), the intervention must include an analysis of underlying issues of social power relations or social inequalities. The theoretical framework used within each study must have been explicitly stated and there should be evidence that this framework had informed intervention development and

assessment/evaluation. Interventions delivered as part of the primary or secondary schooling curriculum or within school settings were excluded from this review.

Eligible study populations includes those experiencing marginalisation (or related terms of discrimination, powerlessness, prejudice, vulnerability, and disadvantage) on account of their social identity, and persons working in a professional capacity with those categorised as being socially marginalised.

Outcomes were considered against a framework of critical consciousness development, which had previously been constructed through a systematic search and thematic analysis of frameworks, theories, and models of critical consciousness development, transformative learning, and sociopolitical development (Pillen, McNaughton, & Ward, 2018, manuscript in preparation). This synthesised framework describes how critical consciousness development occurs when information received through certain events generates uncomfortable thoughts, feelings, or emotions, which in turn can lead to a self-examination of thoughts and emotions and prompt the revision of frames of reference for understanding oppressive social relations. An overview of this framework is available as an online supplement (supplement 1).

### ***Search strategy***

Searches were conducted within academic and grey literature databases of PsycINFO, MEDLINE, SCOPUS, ProQuest, Web of Science, Trials Register of Promoting Health Interventions, Database of promoting health effectiveness reviews (DoPHER), Campbell Collaboration, CDC Database of Interventions, EPPI-Centre Database of Education Research, NHS Evidence in Health and Social Care, UNESDOC: UNESCO Documents and Publications, Google Advanced, and WorldCat. Searches were limited to English-language articles published between January 1970 and May 2017, regardless of publication status. The search string was developed in PsycINFO (supplement 2) and translated into the syntax required for the other databases.

### ***Study selection process***

Following the removal of duplicate articles, the title and abstract of each article was examined against the review's eligibility criteria in a first round of screening and followed by a more thorough full-text assessment of potentially eligible articles. All stages of searching and study selection were performed by a single reviewer (HP). The reference lists of all eligible articles were scanned to identify additional articles not identified through the original search.

After this, two reviewers (HP, PW) independently assessed the quality of included articles using the Joanna Briggs Institute's critical appraisal tool for qualitative studies, which uses a 10-item checklist used to assess methodological rigour, analytical transparency, and ethical conduct within qualitative research (Lockwood, Munn, & Porritt, 2015). Following independent appraisal, the

reviewers compared and discussed ratings until consensus agreement was obtained. Studies deemed to be of poor methodological quality were excluded from the synthesis.

### ***Synthesis of results***

Data was extracted from eligible articles by a single reviewer (HP) using a template that collected information regarding: the study design; population characteristics; intervention purpose, context, and characteristics; intervention fidelity; research methodology; outcomes assessed; and research findings. Using the synthesised framework of critical consciousness development, the findings of primary interventional studies were coded deductively by a single analyst (HP) with cross-checking and discussion with a second reviewer (DM). A thematic analysis of findings not captured by the *a priori* framework was then conducted by a single reviewer (HP). NVivo qualitative data analysis software (QSR International Pty Ltd. Version 11) was used to support organisation and analysis of the extracted data.

### **Findings**

Of the 9,674 articles identified from this search, 33 were found to satisfy the inclusion criteria and were of sufficient quality to be considered within this review (see supplement 3). Characteristics of the 33 included studies are provided in table 1. Findings from the analysis are presented according to stages contained within the synthesized framework of critical consciousness development. An additional theme of 'adverse effects' was created to capture adverse learning outcomes.

### ***Revision of frames of reference***

Of interest within this section are the cognitive frameworks (frames of reference) that individuals use to interpret their observations of events and the assumptions that these frameworks rest upon. Within the reviewed literature, emphasis was placed on describing the content of revised beliefs about social reality, with less detailed reporting on the processes by which learners questioned assumptions and constructed knowledge within the educational setting. This emphasis is problematic, as it acted to obscure the process through which these revised beliefs and assumptions were formed, and whether these changes reflect a constructivist approach to learning or the adoption of a preformed account of social reality.

Moving beyond description and examining changes in an individual's frames of reference at a more abstract level, a consistent theme within reviewed studies was the development of a socio-structural understanding of oppression/social inequality. This revised frame of reference could be characterised by a) a recognition of a systematic organisation of social relationships, b) the placement of individuals within this system according to certain personal characteristics such as gender, race, ethnicity, age, wealth, education, and disability status, c) the ability to attribute personal experiences to the effects of social organisation, and d) the positioning of oneself within

unequal social structures. In reviewed studies, this involved the individual naming their own social identity, and in some cases, acknowledgement of the co-existence or intersection of identities of relative advantage or disadvantage.

An important question here is what role did the questioning of assumptions play in this change in the individual's frame of reference? The questioning of assumptions is positioned as an antecedent to the revision of frames of reference, assuming that such revision can only occur when existing assumptions are delegitimised or unsettled (Fook & Gardner, 2007). However, the questioning of assumptions was not prominently reported within the reviewed studies. Of the 11 studies that did report on this, two outcomes were frequently cited. The first was a recognition that personally-held assumptions used to explain a given event do not represent an objective and universally valid truth, but rather are produced via social and cultural processes.

The second outcome related to a questioning of assumptions about social equality. This involved learners challenging the assumption that individuals might have equal access to social goods (housing, employment, wealth, quality food) regardless of their social position. This provided individual learners with opportunities for recognising how health and social status might be unfairly distributed within society (see for example Hess et al. (31)).

### ***Perceptions of agency***

Agency is regarded here as the ability of a person to successfully perform actions in response to insights generated through a revised frame of reference. In the absence of longitudinal observation, perceived self-efficacy or intention to change were used as proxies for action following conclusion of educational interventions. In several studies, reference was made to learners 'willingness' to enact some form of change in working towards socially just goals. The term 'willingness' was frequently used yet poorly defined or conceptualised within the reviewed literature (see for example Brown, 2004, p. 31). Related to a willingness to change were learners accounts of their perceived ability to enact change. However, these statements of self-efficacy did not refer to particular targets for action, thus it was not possible to identify particular activities or contexts within which self-efficacy relates.

An important learning outcome observed within certain interventions was the way in which the group functioned to refine and validate newly constructed ideas. The concept of 'voice' used in some studies is helpful here (Brown, 2006; Jeanetta, 2006). Although not explicitly described within these studies, voice implied the ability of learners to give structure or form to experiences related to oppression/social inequality, to refine the content and expression of ideas, and validate the worth of these ideas amongst their peers.

### ***Acting against oppression and inequality***

Individual-level action represented a dominant action-oriented outcome within this review.

Individual-level action could be further separated into actions that attempted to improve one's own circumstances through individual betterment, and those actions through which oppressive relations were resisted in interactions with others. In the former case, although the causes of an individual's disadvantage might have been regarded as consequence of social organisation, the appropriate response for learners was to manage its effects through an individual cognitive-behavioural response.

All four of the women in the study who acknowledged perspective transformation also changed how they acted on the world. Debbie changed how she approached her public policy work. Elizabeth's new self-image made it possible for her to go to school. Gene's new perspective on community made government more accessible to her. Danielle's experience made her more tolerant of people who had been in jail. (Jeanetta, 2006, p. 280)

Actions at an interpersonal level focused on transforming oppressive social relationships by purposefully altering the usual course of interactions with others. This included strategies of confronting or interrupting language containing oppressive ideologies (Atkinson, 2012; Bondy et al., 2015; Wallin-Ruschman, 2014), resisting the tendency to assume subordinate roles within interactions (Bhukhanwala & Allexaht-Snyder, 2012; Bhukhanwala et al., 2017), or exerting control over the terms of social interactions (Bowers & Buzzanell, 2002; Kosutic et al., 2009; Paxton, 2003; Zion, Allen, & Jean, 2015). A more complete analysis of these interpersonal interactions is not possible because these interactions were self-reported by individual learners (via interview or writing) rather than directly observed. This means it is not possible to identify what discursive strategies were being used and under what conditions these strategies might be more or less effective. It is also unclear what effect this might have had on others participating in the interaction.

Group-based action processes were less commonly reported and occurred exclusively within the context of educational interventions delivered as a component within larger community development projects (George, 2007; Hess et al., 2014; Jeanetta, 2006; Travers, 1997; Wiggins et al., 2009). This made it difficult to identify whether community organisation was a spontaneous outcome of critical reflection or whether it was the consequence of other concurrently used frameworks for social change. The excerpt below, taken from one such community development project, demonstrates how social action might occur in the absence of a socio-structural analysis of social disadvantage. In this case, the focus of analysis was on the abandoned building and its symbolic meaning, rather than on those social processes that expose poorer populations to such conditions.



During her reflection that week, she shared her negative feelings about the [derelict] building and discussed its effect on her neighborhood. Four weeks later, the same participant brought in another photo of the same building that was now cleaned up as part of a neighbourhood beautification project she had organized. (Foster-Fishman et al. 2005, p. 284)

This last point raises important questions about the relationship between reflective outcomes (related to changes in an individual's frame of reference and their perception of possibilities for change), social action, and the modification of social inequalities. If the espoused theory of a critical pedagogy is true, then we would expect to observe some evidence of development of a critical praxis, that is, a cyclical process of self-reflection, social action, and social change (Shapiro, 1999). However, only a limited number of studies examined the relationship between self-reflection and social action (Bondy et al., 2015; Bowers & Buzzanell, 2002; Foster-Fishman et al., 2005; Kosutic et al., 2009; Paxton, 2003; Travers, 1997; Wallin-Ruschman, 2014). Within these studies, individuals began to interpret the actions of others in quite different ways following a revision of their frames of reference, with observation of these actions providing information that prompted further reflection and revision of these frames of reference. For example, one study reported on an organised visit of a low-income parent centre by a government minister for social services, in which the attending media worked to reproduce the stereotype of a low-income mother. This observation of media tactics was used by group members to further reflect on the way in which stereotypes were reproduced within society (Travers, 1997). However, no study offered a discussion about the implications this might have for future social action and how this might contribute to social change.

### ***Adverse effects***

Several studies acknowledged the potential harms that might emerge from participating in these educational interventions (Brown, 2004; Carlson, Engebretson, & Chamberlain, 2006; Rondini, 2015; Wallin-Ruschman, 2014). Although some studies observed moderate levels of discomfort associated with engaging in personal reflections (for example, Brown, 2004), one study reported high levels of emotional distress experienced by some individuals as formerly valued relationships were reframed as having an oppressive quality (Wallin-Ruschman, 2014). In another study, a sense of frustration and hopelessness was evident amongst some individuals, who perceived the task of social change to be overwhelming and unattainable (Rondini, 2015). Although these individuals maintained a desire for social change, rooted in justice-oriented beliefs, they felt that a socio-structural understanding of marginalisation excluded the possibility of human agency, reflecting broader questions regarding the relative influence of human agency and social structure (Crespi, 1992).

In one study (Wallin-Ruschman, 2014), some participants showed evidence of an uncritical acceptance of frameworks used to conceptualise marginalisation (as an infallible 'truth'), contributing to pseudo-religious conversion experiences and precluding further critical analysis of

the issues involved. This runs counter to the earlier observation that an analysis of and unsettling of 'truths' is required for the development of critical thought.

Similar outcomes of indoctrination were not reported in interventions involving members of disadvantaged groups, which may be attributed to the more experiential and action-based educational methods used within these interventions and their tendency to be learner rather than facilitator-driven. Within this group however, there appeared to be some difficulty in disrupting naturalised individual-level explanations for disadvantage or oppression, acting to conceal the socio-structural basis of marginalisation and contributing to victim-blaming (Carlson, Engebretson, & Chamberlain, 2006).

## **Discussion**

The purpose of this review was to identify changes in thinking and behaviour occurring when members of marginalised social groups (and those working with members of these groups) participate in educational interventions informed by critical pedagogies, and to determine how these processes might contribute to social change.

Although no single study offered a comprehensive account of these outcomes and the relationship between them, interpreted together they did contribute a detailed understanding of how individual learners revise their beliefs about social reality, how they position themselves within their social world, and how they envisage action to address oppressive social relationships. Learners consistently articulated a sociostructural understanding of oppression and their location within it, based upon an understanding of their own group identity. However, in the absence of a detailed examination of the process of reflection, it becomes difficult to determine to what extent this is a reflective outcome based on the interpretation and critique of personal experience (constructivism) or an interpretation of reality through the lens of an adopted sociological framework (Persell, Pfeiffer, & Syed, 2008). Evidence of the latter was shown in one case to promote rigid modes of conceptualising social inequality, which led to inflexible ways of thinking and behaving within socially unequal/oppressive contexts (Wallin-Ruschman, 2014). Although the neglect of constructivism has been demonstrated to lead to outcomes of indoctrination within this review, overly constructivist approaches may also neglect recognition of the systematic organisation of privilege and disadvantage that sociological thinking may offer. A middle ground may provide a more helpful appraisal of social organisation and power within local contexts; therefore, future studies clearly need to better articulate the relationship between constructivist, experiential, and sociological ways of thinking and how this contributes to reflective processes.

Although there is little empirical evidence within reviewed studies to suggest that educational interventions are resulting in concrete actions towards the modification of oppressive or unequal social relations, this finding should be interpreted in the context of the methodological and reporting

limitations of reviewed studies. Limitations include the dominance of cross-sectional study designs, with data collected either during or shortly after participation, and poor reporting of the specifics of action where longitudinal data did exist. Reviewed studies do however, provide insight into the forms of action that might occur following participation. In particular, despite the sociostructural content of reflection, action tended to focus at the level of interpersonal interaction. It is also possible that the dialogical methods used to facilitate reflection within group environments might predispose individuals to interpersonal actions given that efficacy is built within an interpersonal context rather than in contexts supportive of political activism and advocacy. A consequence of these methodological and reporting limitations is that it is difficult to identify evidence of a critical praxis, which in the context of this paper was considered to represent the processes connecting self-reflection, social action, and social change aimed towards reducing social marginalisation (Shapiro, 1999). This is an important omission given primacy of the concept of praxis within critical pedagogies. As it is, this review's results are more consistent with a 'modest pedagogy', for which a meaningful educational outcome would include a rational critique of taken-for-granted beliefs and practices and an emotional commitment for change (Tinning, 2002).

The review methodology itself also had several limitations. Because of the interdisciplinarity of the study and application of critical education, the systematic search may have missed certain studies due to differences in disciplinary terminology and differences in conventions for the dissemination of research. However, we attempted to minimise the likelihood of missed studies by searching across a large number of academic and non-academic repositories and through examination of the reference lists of included studies. We also reduced the specificity of the search (through the selection of and explosion of search terms) in order to capture a greater number of studies in the initial search, followed by an extensive screening process. While the best fit framework synthesis approach was useful for synthesising the effects of critical education in a systematic and rigorous manner (Carroll et al., 2013), it may also have acted to reduce the analyst's sensitivity to relationships between themes within individual studies and the interaction between learning processes and interventional contexts.

Importantly for this review, no study was identified that used critical methods of education to explicitly examine the process of stigmatisation. However, these findings do suggest that educational interventions informed by a critical pedagogy are able to support a structural analysis of social marginalisation or disadvantage, which may prove useful in expanding understandings of stigmatisation as a phenomenon realised through interaction (involving exchanges between the stigmatiser and the stigmatised) towards understandings of stigma that implicate policy and legislation, media, community attitudes, and ideology in maintaining stigmatising beliefs, attitudes, and behaviours (Pescosolido, Martin, Lang, & Olafsdottir, 2008). Despite this, there is limited evidence to suggest how these structural processes might be challenged following such analyses.

In addressing this limitation, future interventional research should prioritise longitudinal methods of data collection to better evaluate the relationship between reflection and action and examine how a critical praxis may develop over time. Further research involving members of stigmatised groups and with the process of stigmatisation as its analytical focus is required to determine whether educational interventions informed by a critical pedagogy represents a viable stigma-reduction strategy. Such evidence will be required by policy makers before they might seriously consider a socially critical form of education that risks becoming unpopular when held up against dominant ideological beliefs of the free-acting and free-choosing individual. For public health and health promotion practitioners interested in or already applying these methods of education within their own practice, this review suggests some areas of caution. Firstly, care should be taken to avoid overselling the promises of their method, particularly with respect to its purported capacity for achieving social change. Secondly, practitioners need to be mindful of how certain frameworks for understanding social marginalisation might unwittingly act to downplay human agency or stifle individual capacity for critical reflection. Finally, more attention needs to be devoted to evaluating and developing the method within public health contexts, because although critical pedagogies promise much in the way of reducing social inequalities, questions still remain about their ability of educational interventions to contribute to socio-structural change.

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**Table 1. Characteristics of included studies**

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
Ares (2015) (USA)	Feminist action research	Caribbean and Central American women (30-53yrs) who had recently immigrated to the USA (n = 8)	To facilitate a critical understanding of intersections of oppression using participatory theatre	Locations hosted by Latina/Latina immigrant communities and at a nearby university	Latina Critical Race Theory	Examination of artefacts (drawings, newspaper articles, poetry, visits to museums/theatres/libraries) and dramatisations
Atkinson (2012) (USA)	Participatory ethnographic study	Youth (14-17yrs) from neighbourhoods considered as 'poor' and 'violent' (n=9)	To foster socio-political consciousness through education on social issues, leadership skill building, and engagement in social justice activism	Chicago Freedom School (CFS), which offers year-round non-formal education courses for youth and adults interested in social justice issues	Community youth development and transformative social work practice (incorporating radical, critical, feminist and anti-oppression frameworks)	Discussion regarding histories and legacies of social change and how these inform contemporary youth activism. Use of documentary films, non-fiction readings, issue-based debates, games and role plays, poetry and art-based activities, and talks with allied activist organisations
Bhukhanwala and Alexsaht-Snider (2012) (USA)	Qualitative case study	Students (25-35yrs) attending an alternative education certification program with undergraduate degrees in areas other than education (n=7)	For teachers to negotiate cultural differences in developing relationships with students and make sense of their teacher identities	Program delivered via a university-based alternative teaching certification program	Conscientisation	Use of Augusto Boal's Forum Theatre, with the content of one session informing the following
Bhukhanwala, Dean and Troyer (2017) (USA)	Qualitative case study	Mostly female (33) and Caucasian (30) adults (22-50yrs) (n=34)	To support and engage student teachers in reflecting on their student teaching experiences	Arts-based student teaching seminars offered to undergraduate and post-graduate student teachers in areas of	Mezirow's theory of transformative learning and Boal's Theatre of the Oppressed	Image/forum theatre, art-based inquiry, and reflective journaling

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
Bondy et al. (2015) (USA)	Qualitative case study	Teachers and school administrators, with between 4 and 31 years of experience in educational settings (n=14)	To develop a critical social justice perspective and critical social justice praxis among educators using an online graduate education programme	early childhood, elementary, and special education Topic delivered in an online format one year in to a four-year professional doctorate programme	Mezirow's theory of adult transformative learning and Cooperative Inquiry	Group discussions of theoretical and practical readings related to the role of power in curriculum design. Group discussions informed by the content of applied assignments and reflective journals. Also included service learning for the final four weeks of the course and a reflective response to letters written at the beginning of the semester
Bowers and Buzzanell (2002) (USA)	Auto-ethnography	Inner-city African-American youth (15-19yrs) living in a large metropolitan area (n=15)	For participants to communicate learnings about sex and HIV to their respective communities (funded aim), and to enable participants to engage in feminist transformation (secondary aim)	Peer theatre intervention funded to provide sex education and raise awareness of HIV amongst inner-city African American youth	Consciousness raising framework - based on critical feminist perspectives	Peer Theatre
Brown (2004) (USA)	Qualitative document analysis	Students enrolled in a 2-year masters in school administration programme (n=40)	To support the development of a social justice orientation for future leaders in education	Participants enrolled as full-time students in the two-year Masters of School Administration Program	Transformative Learning Theory and Critical Social Theory	Cultural autobiographies, life histories, prejudice reduction workshops, reflective analysis journals, cross-cultural interviews, cultural plunges, diversity panels, and activist action plans
Brown (2006) (USA)	Mixed methods study	Students enrolled in 2-year masters in school	To challenge students to explore various constructs from numerous, diverse,	Participants enrolled as full-time students in the two-year Masters of	Elements of Knowles adult learning theory, Mezirow's	Cultural autobiographies, life histories, prejudice reduction workshops, cross-cultural interviews, educational plunges,

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
		administration programme (n=40)	and changing perspectives.	School Administration Programme	transformative learning theory, and Freire's critical social theory	diversity panel, and development of activist action plans
Byrd (2004) (USA)	Mixed-methods: qualitative case studies and single arm pre-test post-test experimental design	Participants in a counsellor preparation program (n=24). Six (n=6) participants were selected for qualitative study according to their classification by "conforming," "reforming" or "transforming" behaviors and "high" or "low" agency.	To prepare multicultural counsellors to work with multicultural communities	Delivered as part of a year-long multicultural counsellor preparation programme	Transformative social consciousness and multicultural change agency	Service learning
Carlson, Engebretson and Chamberlain (2006) (USA)	Ethnographic case study	Participants recruited from low-income African American neighbourhoods (n=45)	To document community health concerns through storytelling and photography	University partnership with a low-income urban African American neighbourhood	Freire's concept of critical consciousness raising	Photovoice and storytelling
Foster-Fishman et al. (2005) (USA)	Qualitative case study	Adults and youth recruited from neighbourhoods with high rates of poverty and poor educational attainment (n=29, with 16 participating in interviews)	To promote reflection and discourse among residents regarding neighbourhood and community life	Delivered as part of the 'Yes We Can' project, which attempted to build neighbourhood social capital	Photovoice action and reflection, informed by Freire's approach to liberating education	Photovoice
George (2007) (USA)	Qualitative case study	Technologists in areas of radiography or	For students to begin to form alliances with their patients and co-workers to rethink the	Classroom programme designed to educate	Whiteness and Freirean critical pedagogy	Guided dialogue and teaching

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
		nuclear medicine (n=6)	meaning of health in the current system and change it	future medical technologists		
Hess et al. (2014) (USA)	Qualitative component of broader mixed-methods study	African refugees that had recently (<12 months) settled in the Southern USA (n=72) and 53 undergraduate students participating in the Refugee Well-being Project	Foster transformative learning among refugee and student participants in support of mutual learning and advocacy to address social determinants of refugee mental health	Set within the broader Refugee Well-Being Project, which attempts to prevent further psychological distress and promote refugee well-being. Involved pairing refugee families with a self-selected group of undergraduate students (mostly psychology or anthropology majors)	Transformative learning and Freire's conscientisation	Culture circles and one-to-one student-participant mentoring
Houser (2008) (USA)	Ethnographic case study	Mostly young, middle-class European-American women (n=131)	To promote critical reflection among historically privileged members of society	Assignment within an undergraduate course in social studies and multicultural/global education	Disequilibrium (Piaget) and existence of the 'other' (Said)	Cultural plunge, reflective writing, and group discussion
Jeanetta (2006) (USA)	Qualitative case studies	Women who were members of WomanSpirit for at least 3 years (n=7, with 5 participating in focus groups)	To help women educate themselves, understand the issues affecting their lives, make plans that address these issues, and implement projects in a supportive environment	Delivered by WomanSpirit, a community development and education organisation	Critical and black feminism - drawing on theories related to social support, community organisation, and popular/community education	Dialogue and support group
Kased (2013) (USA)	Qualitative case study, embedded	First-generation university attenders from central	To teach and reinforce academic skills whilst empowering students	Delivered as part of the Metro programme - a	Critical pedagogy	Not specified

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
	within a larger mixed-methods study	American, African American, and Asian American backgrounds (n=15, selected from broader population of yearly program intake of 65-70 students)	to become social critics and agents of change	year-long learning-community model		
King (2003) (USA)	Qualitative case study	Early childhood education majors (n=5, self-selected from 22 course participants)	To promote critical reflection amongst undergraduate teachers attending an early childhood education course	Delivered as part of an undergraduate introductory topic in early childhood education	Critical pedagogy	Reflective journaling, small group activities, whole-class/large-group discussion
Kosutic et al. (2009) (USA)	Participatory case study	Graduate students participating in a family therapy program (n=9)	To use the Critical Genogram (CritG) as a tool for helping family therapists move toward critical consciousness	Presented as an exercise within a family therapy graduate course	Critical consciousness	Critical Genogram (CritG)
Kraehe and Brown (2011) (USA)	Qualitative case study	Undergraduate and graduate education students (n=20)	To use arts-based inquiry to provide spaces for developing critical sociocultural knowledge in social justice-oriented teacher education courses	Semester long topic within the course titled 'Sociocultural Influences on Learning'	Interpretive and critical theories of aesthetic learning	Arts-based inquiry
Krogh (1998) (USA)	Qualitative interviews	Representatives of people with a disability (n=9) or employed within a	To facilitate an examination of partnership issues between persons with	Examination of the 3rd of a series of workshops addressing issues	Critical theory	Sociometry, role play, mural making, body sculptures, lecture, storytelling, exploring metaphors, and group discussion

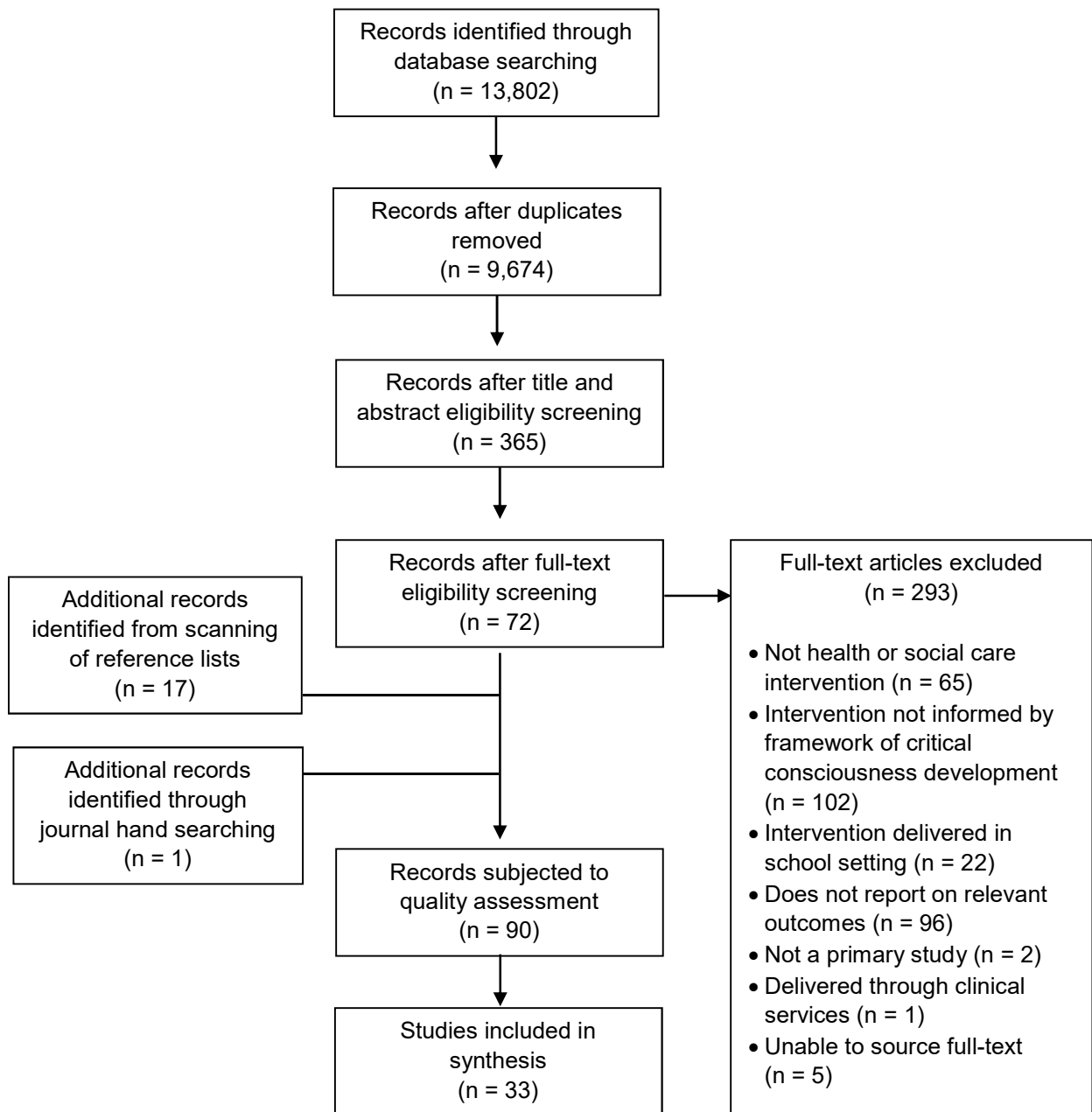
Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
Paxton (2003) (USA)	Qualitative case study	disability service agency (n=1) Doctoral or masters students in the Transformative Learning and Change in Human Systems program (n=6)	a disability and service providers To use cooperative inquiry to achieve a perspective transformation with respect to racial power/whiteness amongst White European Americans	relevant to persons with a disability Course on cultural consciousness	Cooperative Inquiry	Group discussion, online discussion board participation, reflective journaling, and written assignments
Rondini (2015) (USA)	Qualitative case study	Sociology majors and non-majors (n=12)	To cultivate critical consciousness by framing the study of health in terms of social justice issues	Service-learning sociology course titled 'Health, Illness, and Community'	Critical consciousness	Bell hooks' concepts of engaged pedagogy and conversation-based learning
Shaw (1999) (Canada)	Qualitative case study	Graduate students or professionals in practice who were considered role models for successful aging (n=7, selected from group of 20)	To support 'successful aging'	Three day Group Counselling and Psychodrama workshop offered to graduate students and psychology/counselling professionals	Transformative learning	Guided autobiography, small group discussion, and group psychodrama
Teti et al. (2013) (USA)	Qualitative case study	Mostly African American women living with HIV (mean time of 11 years) (n=30)	To help women living with HIV to counter the helplessness and powerlessness they experience	Participants were recruited from AIDS service organisations across three US cities	Photovoice action and reflection cycles as described by Wang and Burris (1994)	Photovoice using the SHOWeD technique for questioning and exploration of meaning
Thompson, Lamont-Robinson and	Qualitative case study	Students at the end of either the third or fourth year of a 5-	To prompt attitudinal change in relation to	Organisation offering voyages in tall ships, which provided an opportunity for persons	Transformative learning	Audio-diaries, written reflections, reflective group discussion, and a formal written reflective piece

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
Williams (2016) (UK)		year medical programme (n=16)	disability amongst medical students	with and without a disability to live and work together in a challenging environment		
Travers (1997) (Canada)	Qualitative case study	Low-income mothers attending a women's coffee group (n=33)	Not specified	Community drop-in parent centre group - providing free child care, refreshments, and free groceries	Emancipatory education	Self-help group, action research, and activism
Van Wijnendaele (2011) (El Salvador)	Qualitative case study	El Salvadorian youth arranged into four demographically and socially distinct groups	To stimulate young people to question unjust and oppressive structural power relations and social systems	Programme provided by a social service organisation inspired by liberation theory	Conscientisation	Participatory action research
Wallin-Ruschman (2014) (USA)	Qualitative case study	Mostly female (16) college students of varying ethnic backgrounds and sexual orientation (n=17)	The development of critical consciousness	The Girl Power capstone programme	Critical consciousness	Small group discussion/dialogue, service learning, social identity mapping, and use of 'interruptions'
Wiarsih (2002) (Indonesia)	Participatory action research	Pregnant women (between 2 and 6 months gestation) of lower socioeconomic status. Also included village health volunteers (n=14)	To develop and implement a prenatal education program that would empower lower socioeconomic pregnant women to improve their nutritional intake	The study is part of a larger project entitled 'Nursing, Women's Health and Community Outreach in Indonesia'	Freire's educational approach	Participatory action research
Wiggins et al. (2009) (USA)	Qualitative case study	Mostly female community health workers of Central American or African	To improve health and decrease disparities in African American and Latino communities by increasing the	The Poder es Salud / Power for Health project	Popular/Freirean education involving action-reflection cycles	Educational/exploratory games and dramatised learning



Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
		American ethnic backgrounds (n=5)	capacity of community members to address the underlying causes of health problems			
Zanchetta et al. (2014b) (Brazil)	Qualitative evaluation	Mostly female (74) community health workers (n=82)	To enhance community health agents' critical reflection on their health promotion work	Delivered in the context of Brazil's community health agent (CHA) programme, delivered within community development and social justice frameworks	Critical consciousness / Freirean critical pedagogy	Dialogue through examination of evocative objects
Zanchetta et al. (2014a) (Canada)	Qualitative evaluation	Francophone Canadian health care and social services professionals (n=41)	To update professionals' knowledge of health literacy and the problems associated with its application to the francophone population	Evaluation of the 6-hour workshop "Placing Health Literacy at the Core of Your Practice" provided to francophone health and social services professionals	Freire's concept of critical consciousness	Dialogue through examination of evocative objects
Zion, Allen and Jean (2015) (USA)	Qualitative case study	White middle-school educators in their first three years of teaching	To facilitate sociopolitical development among student teachers	Year-long graduate education course	Critical Civic Inquiry - informed by critical pedagogy, antiracist education, sociocultural learning theory, and action research	Service learning and written reflections

**Figure 1. PRISMA diagram for systematic search**



### Appendix 3. Search string (PsycINFO) for a systematic search of critical pedagogies in health and social care

1. exp Health Care Services/ or exp Well Being/
2. marginalization/ or social justice/ or "equity (social)"/
3. unemployment/ or employment status/
4. (health\* adj3 quality).tw.
5. (health adj2 (well being or wellbeing or illness)).tw.
6. (health status or health care or healthcare or violence or employ\* or unemploy\* or work welfare or disadvantage\* or marginali#ed or marginali#ation or oppress\* or disempowered or inequit\* or equity or disparit\* or structural injustice or social injustice).tw.
7. exp DISCRIMINATION/
8. exp PREJUDICE/
9. racism/ or "race and ethnic discrimination"/
10. sexuality/
11. exp DISABILITIES/
12. disadvantaged/ or social deprivation/ or socioeconomic status/
13. (discriminat\* or prejudice\* or gender\* or abuse or racism or racial\* or race or colo#r or ethnic\* or sexual\* or disabilit\* or disabled or handicapped or illness or sizeis\* or fat\* or socioeconomic or socio-economic).tw.
14. or/1-13
15. empowerment/
16. (critical consciousness or conscienti#ation or conscientizacao or conscientizacion or critical social analysis or sociopolitical theory or sociopolitical development or freire\* or critical pedagogy or transformative learning or social consciousness or political consciousness or emancipatory pedagogy or (psychological adj3 empowerment) or (individual adj3 empowerment) or (personal adj3 empowerment) or (group adj3 empowerment) or (collective adj3 empowerment) or (political adj3 empowerment) or (sociopolitical adj3 empowerment) or (social adj3 empowerment) or (theory adj3 empowerment) or (theories adj3 empowerment)).tw.
17. or/15-16
18. reflectiveness/
19. social change/
20. self-efficacy/
21. exp Political Participation/
22. political processes/
23. activism/
24. (reflect\* or agency or efficacy or self-efficacy or action\* or activism or empower\* or critical social analysis or community organi#ing or community organi#ation or sociopolitical control or social action or praxis or political action or advocacy or social change or campaign\* or awareness raising).tw.
25. intention adj3 (act or change)).tw.
26. or/18-25
27. (intervention\* or program\* or experiment\* or trial\* or project\* or initiative\* or strateg\* or implementation\* or group\* or pedagogical practice\* or camp or action research or par\* or research or random\* or control\*).tw.
28. experimental design/ or clinical trials/ or hypothesis testing/ or experiment controls/ or experimental methods/ or qualitative research/ or quantitative methods/
29. 27 or 28
30. and/14,17,26,29
31. school\*.mp.
32. 30 not 31

## Appendix 4. Characteristics of included studies – critical pedagogies in health and social care

Table adapted from Pillen, McNaughton and Ward (2019, pp. 473-479)

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
Ares (2015) (USA)	Feminist action research	Caribbean and Central American women (30-53yrs) who had recently immigrated to the USA (n = 8)	To facilitate a critical understanding of intersections of oppression using participatory theatre	Locations hosted by Latina/Latina immigrant communities and at a nearby university	Latina Critical Race Theory	Examination of artefacts (drawings, newspaper articles, poetry, visits to museums/theatres/libraries) and dramatisations
Atkinson (2012) (USA)	Participatory ethnographic study	Youth (14-17yrs) from neighbourhoods considered as 'poor' and 'violent' (n=9)	To foster socio-political consciousness through education on social issues, leadership skill building, and engagement in social justice activism	Chicago Freedom School (CFS), which offers year-round non-formal education courses for youth and adults interested in social justice issues	Community youth development and transformative social work practice (incorporating radical, critical, feminist and anti-oppression frameworks)	Discussion regarding histories and legacies of social change and how these inform contemporary youth activism. Use of documentary films, non-fiction readings, issue-based debates, games and role plays, poetry and art-based activities, and talks with allied activist organisations
Bhukhanwala and Alexsaht-Snider (2012) (USA)	Qualitative case study	Students (25-35yrs) attending an alternative education certification program with undergraduate degrees in areas other than education (n=7)	For teachers to negotiate cultural differences in developing relationships with students and make sense of their teacher identities	Program delivered via a university-based alternative teaching certification program	Conscientisation	Use of Augusto Boal's Forum Theatre, with the content of one session informing the following

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
Bhukhanwala, Dean and Troyer (2017) (USA)	Qualitative case study	Mostly female (33) and Caucasian (30) adults (22-50yrs) (n=34)	To support and engage student teachers in reflecting on their student teaching experiences	Arts-based student teaching seminars offered to undergraduate and post-graduate student teachers in areas of early childhood, elementary, and special education	Mezirow's theory of transformative learning and Boal's Theatre of the Oppressed	Image/forum theatre, art-based inquiry, and reflective journaling
Bondy et al. (2015) (USA)	Qualitative case study	Teachers and school administrators, with between 4 and 31 years of experience in educational settings (n=14)	To develop a critical social justice perspective and critical social justice praxis among educators using an online graduate education programme	Topic delivered in an online format one year in to a four-year professional doctorate programme	Mezirow's theory of adult transformative learning and Cooperative Inquiry	Group discussions of theoretical and practical readings related to the role of power in curriculum design. Group discussions informed by the content of applied assignments and reflective journals. Also included service learning for the final four weeks of the course and a reflective response to letters written at the beginning of the semester
Bowers and Buzzanell (2002) (USA)	Auto-ethnography	Inner-city African-American youth (15-19yrs) living in a large metropolitan area (n=15)	For participants to communicate learnings about sex and HIV to their respective communities (funded aim), and to enable participants to engage in feminist transformation (secondary aim)	Peer theatre intervention funded to provide sex education and raise awareness of HIV amongst inner-city African American youth	Consciousness raising framework - based on critical feminist perspectives	Peer Theatre
Brown (2004) (USA)	Qualitative document analysis	Students enrolled in a 2-year masters in school	To support the development of a social justice	Participants enrolled as full-time students in the two-year Masters of	Transformative Learning Theory	Cultural autobiographies, life histories, prejudice reduction workshops, reflective analysis journals, cross-cultural interviews,

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
Brown (2006) (USA)	Mixed methods study	administration programme (n=40) Students enrolled in 2-year masters in school administration programme (n=40)	orientation for future leaders in education To challenge students to explore various constructs from numerous, diverse, and changing perspectives.	School Administration Program Participants enrolled as full-time students in the two-year Masters of School Administration Programme	and Critical Social Theory Elements of Knowles adult learning theory, Mezirow's transformative learning theory, and Freire's critical social theory	cultural plunges, diversity panels, and activist action plans Cultural autobiographies, life histories, prejudice reduction workshops, cross-cultural interviews, educational plunges, diversity panel, and development of activist action plans
Byrd (2004) (USA)	Mixed-methods: qualitative case studies and single arm pre-test post-test experimental design	Participants in a counsellor preparation program (n=24). Six (n=6) participants were selected for qualitative study according to their classification by "conforming," "reforming" or "transforming" behaviors and "high" or "low" agency.	To prepare multicultural counsellors to work with multicultural communities	Delivered as part of a year-long multicultural counsellor preparation programme	Transformative social consciousness and multicultural change agency	Service learning
Carlson, Engebretson and Chamberlain (2006) (USA)	Ethnographic case study	Participants recruited from low-income African American neighbourhoods (n=45)	To document community health concerns through storytelling and photography	University partnership with a low-income urban African American neighbourhood	Freire's concept of critical consciousness raising	Photovoice and storytelling
Foster-Fishman et al. (2005) (USA)	Qualitative case study	Adults and youth recruited from neighbourhoods with high rates of poverty and poor educational attainment (n=29,	To promote reflection and discourse among residents regarding neighbourhood and community life	Delivered as part of the 'Yes We Can' project, which attempted to build neighbourhood social capital	Photovoice action and reflection, informed by Freire's approach to liberating education	Photovoice

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
George (2007) (USA)	Qualitative case study	Technologists in areas of radiography or nuclear medicine (n=6) with 16 participating in interviews)	For students to begin to form alliances with their patients and co-workers to rethink the meaning of health in the current system and change it	Classroom programme designed to educate future medical technologists	Whiteness and Freirean critical pedagogy	Guided dialogue and teaching
Hess et al. (2014) (USA)	Qualitative component of broader mixed-methods study	African refugees that had recently (<12 months) settled in the Southern USA (n=72) and 53 undergraduate students participating in the Refugee Well-being Project	Foster transformative learning among refugee and student participants in support of mutual learning and advocacy to address social determinants of refugee mental health	Set within the broader Refugee Well-Being Project, which attempts to prevent further psychological distress and promote refugee well-being. Involved pairing refugee families with a self-selected group of undergraduate students (mostly psychology or anthropology majors)	Transformative learning and Freire's conscientisation	Culture circles and one-to-one student-participant mentoring
Houser (2008) (USA)	Ethnographic case study	Mostly young, middle-class European-American women (n=131)	To promote critical reflection among historically privileged members of society	Assignment within an undergraduate course in social studies and multicultural/global education	Disequilibrium (Piaget) and existence of the 'other' (Said)	Cultural plunge, reflective writing, and group discussion
Jeanetta (2006) (USA)	Qualitative case studies	Women who were members of WomanSpirit for at least 3 years (n=7, with 5 participating in focus groups)	To help women educate themselves, understand the issues affecting their lives, make plans that address these issues, and implement projects in a	Delivered by WomanSpirit, a community development and education organisation	Critical and black feminism - drawing on theories related to social support, community organisation, and popular/community education	Dialogue and support group

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
			supportive environment			
Kased (2013) (USA)	Qualitative case study, embedded within a larger mixed-methods study	First-generation university attenders from central American, African American, and Asian American backgrounds (n=15, selected from broader population of yearly program intake of 65-70 students)	To teach and reinforce academic skills whilst empowering students to become social critics and agents of change	Delivered as part of the Metro programme - a year-long learning-community model	Critical pedagogy	Not specified
King (2003) (USA)	Qualitative case study	Early childhood education majors (n=5, self-selected from 22 course participants)	To promote critical reflection amongst undergraduate teachers attending an early childhood education course	Delivered as part of an undergraduate introductory topic in early childhood education	Critical pedagogy	Reflective journaling, small group activities, whole-class/large-group discussion
Kosutic et al. (2009) (USA)	Participatory case study	Graduate students participating in a family therapy program (n=9)	To use the Critical Genogram (CritG) as a tool for helping family therapists move toward critical consciousness	Presented as an exercise within a family therapy graduate course	Critical consciousness	Critical Genogram (CritG)
Kraehe and Brown (2011) (USA)	Qualitative case study	Undergraduate and graduate education students (n=20)	To use arts-based inquiry to provide spaces for developing critical sociocultural knowledge in social justice-oriented teacher education courses	Semester long topic within the course titled 'Sociocultural Influences on Learning'	Interpretive and critical theories of aesthetic learning	Arts-based inquiry



Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
Krogh (1998) (USA)	Qualitative interviews	Representatives of people with a disability (n=9) or employed within a disability service agency (n=1)	To facilitate an examination of partnership issues between persons with a disability and service providers	Examination of the 3rd of a series of workshops addressing issues relevant to persons with a disability	Critical theory	Sociometry, role play, mural making, body sculptures, lecture, storytelling, exploring metaphors, and group discussion
Paxton (2003) (USA)	Qualitative case study	Doctoral or masters students in the Transformative Learning and Change in Human Systems program (n=6)	To use cooperative inquiry to achieve a perspective transformation with respect to racial power/whiteness amongst White European Americans	Course on cultural consciousness	Cooperative Inquiry	Group discussion, online discussion board participation, reflective journaling, and written assignments
Rondini (2015) (USA)	Qualitative case study	Sociology majors and non-majors (n=12)	To cultivate critical consciousness by framing the study of health in terms of social justice issues	Service-learning sociology course titled 'Health, Illness, and Community'	Critical consciousness	Bell hooks' concepts of engaged pedagogy and conversation-based learning
Shaw (1999) (Canada)	Qualitative case study	Graduate students or professionals in practice who were considered role models for successful aging (n=7, selected from group of 20)	To support 'successful aging'	Three day Group Counselling and Psychodrama workshop offered to graduate students and psychology/counselling professionals	Transformative learning	Guided autobiography, small group discussion, and group psychodrama
Teti et al. (2013) (USA)	Qualitative case study	Mostly African American women living with HIV (mean time of 11 years) (n=30)	To help women living with HIV to counter the helplessness and powerlessness they experience	Participants were recruited from AIDS service organisations across three US cities	Photovoice action and reflection cycles as described by	Photovoice using the SHOWeD technique for questioning and exploration of meaning

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
					Wang and Burris (1994)	
Thompson, Lamont-Robinson and Williams (2016) (UK)	Qualitative case study	Students at the end of either the third or fourth year of a 5-year medical programme (n=16)	To prompt attitudinal change in relation to disability amongst medical students	Organisation offering voyages in tall ships, which provided an opportunity for persons with and without a disability to live and work together in a challenging environment	Transformative learning	Audio-diaries, written reflections, reflective group discussion, and a formal written reflective piece
Travers (1997) (Canada)	Qualitative case study	Low-income mothers attending a women's coffee group (n=33)	Not specified	Community drop-in parent centre group - providing free child care, refreshments, and free groceries	Emancipatory education	Self-help group, action research, and activism
Van Wijnendaele (2011) (El Salvador)	Qualitative case study	El Salvadorian youth arranged into four demographically and socially distinct groups	To stimulate young people to question unjust and oppressive structural power relations and social systems	Programme provided by a social service organisation inspired by liberation theory	Conscientisation	Participatory action research
Wallin-Ruschman (2014) (USA)	Qualitative case study	Mostly female (16) college students of varying ethnic backgrounds and sexual orientation (n=17)	The development of critical consciousness	The Girl Power capstone programme	Critical consciousness	Small group discussion/dialogue, service learning, social identity mapping, and use of 'interruptions'
Wiarsih (2002) (Indonesia)	Participatory action research	Pregnant women (between 2 and 6 months gestation) of lower socioeconomic status. Also included village	To develop and implement a prenatal education program that would empower lower socioeconomic pregnant women to	The study is part of a larger project entitled 'Nursing, Women's Health and Community Outreach in Indonesia'	Freire's educational approach	Participatory action research

Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
Wiggins et al. (2009) (USA)	Qualitative case study	health volunteers (n=14) Mostly female community health workers of Central American or African American ethnic backgrounds (n=5)	improve their nutritional intake To improve health and decrease disparities in African American and Latino communities by increasing the capacity of community members to address the underlying causes of health problems	The Poder es Salud / Power for Health project	Popular/Freirean education involving action-reflection cycles	Educational/exploratory games and dramatised learning
Zanchetta et al. (2014b) (Brazil)	Qualitative evaluation	Mostly female (74) community health workers (n=82)	To enhance community health agents' critical reflection on their health promotion work	Delivered in the context of Brazil's community health agent (CHA) programme, delivered within community development and social justice frameworks	Critical consciousness / Freirean critical pedagogy	Dialogue through examination of evocative objects
Zanchetta et al. (2014a) (Canada)	Qualitative evaluation	Francophone Canadian health care and social services professionals (n=41)	To update professionals' knowledge of health literacy and the problems associated with its application to the francophone population	Evaluation of the 6-hour workshop "Placing Health Literacy at the Core of Your Practice" provided to francophone health and social services professionals	Freire's concept of critical consciousness	Dialogue through examination of evocative objects
Zion, Allen and Jean (2015) (USA)	Qualitative case study	White middle-school educators in their first three years of teaching	To facilitate sociopolitical development among student teachers	Year-long graduate education course	Critical Civic Inquiry - informed by critical pedagogy, antiracist education, sociocultural learning theory,	Service learning and written reflections

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Study (country)	Study design	Participant characteristics	Purpose of intervention	Setting for intervention	Theoretical framework	Techniques used
					and action research	

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## **Appendix 5. Examples of content from the participant workbook**

### **Part One – Choosing a Critical Incident**

A critical incident is a specific experience that made you feel embarrassed, blamed, shamed, or otherwise bad on account of your diabetes.

Tips for identifying a relevant experience:

- It made you feel emotional or negative about yourself and/or diabetes
- The incident was unexpected or 'stopped you in your tracks'
- You might have blamed yourself in finding the event challenging, telling yourself that others seem to cope OK in similar circumstances
- The incident resulted in you trying to downplay, conceal, or divert attention away from your diabetes, or trying to side-step negative reactions by being 'loud and proud' about your diabetes

Double checking that the incident is relevant:

- You can relate the experience to being labelled, use of generalisations or stereotypes, experiencing negative reactions from others, or feeling devalued (for example, feeling different from or inferior to others, ashamed, or blamed)
- Is important to you
- Is an incident that you want to learn from
- Is an incident you are prepared to expose to the group
- Protects the confidentiality of others involved in the incident

**In your own words, provide a concrete description of the incident itself (what happened, who was involved)**

**In your own words, provide a concrete description of the background to the incident (what led to this incident and what personal baggage you brought to it)**

**Describe why the incident was significant to you**

Think of in what form you might present this incident to the group:

- Story – verbal or written
- Object that represents or symbolises the incident (e.g. a glucometer)
- Photograph of an object or environment that encapsulates the incident
- Artwork (drawing, painting – either new or existing)
- Online media (e.g. YouTube clip, printout of internet forum)
- Other forms of expression

**Outline a brief plan for how you might discuss this with the group. You will have about 5 minutes to present your critical incident**

## Part Two – Analysing Your Critical Incident

Critical Reflection Question Guide		Focus			
		You (in your own shoes)	Others (in the other person's shoes)	Assumptions (commonly-held ideas)	Causes (how assumptions are created)
Process of Stigmatisation	Generalised beliefs	Were you aware of any diabetes-related beliefs going into the situation?	What beliefs about diabetes were made explicit by the other person?	What do these beliefs say about people with diabetes?	Where do these beliefs come from?
		Did you feel that this belief applied to you in this situation?	Why did the other person feel that this stereotype applied to you in this situation?	What is assumed in applying this stereotype to you?	Who is able to apply these beliefs to you and why?
		Did you anticipate negative reactions from others?	What beliefs about diabetes were made implicit by the other person?	How did you detect these beliefs?	Why are these beliefs assumed to be correct?
			How do you think the other person sees you?	What beliefs make them see you in this way?	Where do these beliefs come from?
	Labelling	What personal characteristics might make your diabetes more visible?	How did the person relate these characteristics to assumptions about your diabetes?	What was assumed about these characteristics?	How has society connected these characteristics to these assumptions/beliefs?
		What physical/visible features made your diabetes more visible?	Why are these characteristics visible in the first place?	What does this 'visibility' say about the person's beliefs about diabetes?	How has society made these characteristics more visible?
	Making different	What does the incident say about how you see yourself?	What does the incident say about how you see others?	What binaries are being used? (e.g. victim/perpetrator, powerful/powerless, good/bad)	How does society function to create separation between those with diabetes and those without?
		How are you being portrayed in this incident?	How is the other person being portrayed?	What binaries are being used? (e.g. patient/provider, powerful/powerless, good/bad)	Whose portrayal has the most weight and why?
		How did you want to behave in this situation?	How did the other person expect you to behave?	Why did they want you to behave in this way?	What is motivating them to think in this way?
	Feeling devalued	How might who you are have affected what you noticed or felt what was important?	How did the other person make you feel devalued?	What does the incident say about your beliefs or values?	How does society work to value or devalue certain people?
		Do other personal characteristics influence how you feel about your diabetes?	How did the other person respond to these characteristics?	What is assumed about these characteristics?	How does society work to devalue these characteristics?
	Being devalued	What was your response to being devalued?	Who was controlling the situation and how? Did this change at all?	Who has power/influence/control to discriminate?	Where does this power come from?
		How might you have acted differently if there was something different about the situation?	Were there characteristics of the other person that contributed to this discrimination?	Are there certain beliefs or assumptions about the status of the stigmatiser?	What maintains this person's status?
		What words or language did you use and how might this have influenced the situation?	What was the intention of the other person?	What beliefs informed these intentions?	Where do these beliefs come from?

### Part Three – Planning for Action

#### Provide a summary of your critical incident

- What assumptions were informing the situation?
- How were these assumptions produced?
- How did assumptions get under your skin?

#### What has changed in your thinking since the previous session?

How you might want to be different or act differently if you encountered the same situation again?

#### In answering the question, you might want to ask yourself the following questions:

- What do I want to change about my beliefs or actions?
- What beliefs might allow me to being more open to other ways of seeing the situation?
- How might I have *thought* or *acted* differently in order to influence the situation the way I wanted to?
- How might I change my language to be more consistent with my desired thoughts and actions?
- What else needs to change?

<i>What can you change?</i>	<i>Why can you change it?</i>	<i>How can you change it?</i>
<i>What can't you change?</i>	<i>Why can't you change it?</i>	<i>How can you manage it?</i>

## Part Four – Forum Theatre

Forum Theatre is a game and therefore there are (loose) rules:


- The aim is to win the game – avoid being blamed or shamed or contribute to it
- No interruptions for first run-through – watch carefully
- On second run-through the actors (person with diabetes or the stigmatiser) can be replaced by yelling 'stop' when an action contributes to blaming or devaluing the person with diabetes.
- After yelling stop – a) try to describe the problem and/or b) suggest a new way of acting to overcome the problem
- Act out the scene again in improvised form, telling the actor where you want to start from
- No interrupting the new actor until their action is complete
- May also take the role of the stigmatiser at any stage to introduce new forms of power or control
- Try to make the exchange 'real' (get into character)



## Appendix 6. Unit and lesson plans for the modified Model for Critical Reflection

### Unit Plan: Reflecting Critically on Diabetes-related Stigma

Adapted from unit and lesson plan templates developed by Pagliaro (2012) and Fautley and Savage (2013).

Learning objectives <sup>1</sup>	Cognitive		Affective	Psychomotor	
<i>Lower order</i>  <i>Higher order<sup>1</sup></i>	The learner can describe the three-step process of critical reflection (remembering)		The learner listens to the narratives and perspectives offered by other group members (receiving)	The learner is able to explain their experience of diabetes-related stigma to others (communication)	
	The learner can describe questions that may be used to facilitate critical reflection (remembering)				
	The learner is able to demonstrate use of critical reflection as a tool for understanding diabetes-related stigma (applying)		The learner engages in discussion with others in response to their narratives and actions (responding)	The learner is able to explain their process of learning and reflection to others (communication)	
	The learner independently applies a framework of critical reflection for addressing problems outside of the group setting (applying)		The learner relates stigma or related processes to their own experience of living with diabetes (valuing and organising)	The learner participates in the creation of novel discourses and practices via role play (communication and creation)	
	The learner is able to identify assumptions underpinning their experience of stigma (analysing)		The learner influences others within the group to transform stigmatising discourses and practices (characterisation)		
	The learner evaluates and refines their understanding of stigma and the operation of power following reflection on interpersonal interactions (analysing and evaluating)				
	The learner constructs a behavioural plan of action for challenging assumptions that underwrite stigmatising practices (creating)				
Instructional procedures <sup>2</sup>	Session 1	Session 2	Session 3	Session 4	Session 5
<i>Problem context/situation</i>	Summary of the issue of diabetes-related stigma	Identify key actors or groups involved in the problem and representation/simulation of the problem via narrative	Action planning provides the opportunity to start thinking about how learners might affect the problem via creation of 'problem manipulation spaces'	Role play provides the opportunity to affect the problem in a meaningful way	Provision of practical strategies to provide ongoing opportunities to affect the problem in a meaningful way
<i>Related cases/bridging knowledge</i>	Selection of cases that are representative of the current problem – serving a scaffolding function	Discussion of narratives used to connect existing and new knowledge	Facilitated discussion regarding what has worked in other contexts to disrupt stigma	Role play script features annotations to assist learners to help related the situation to information and concepts discussed within the group	Use reflective journal as a practiced example of strategies to facilitate ongoing reflection
<i>Information resources</i>	Provision of comprehensive information about the technique of critical reflection	Provision of question guide that may be used to identify	Provision of examples of action plans constructed within other contexts	Provision of list of assumptions that have been	Provision of written list of practical strategies for supporting ongoing reflection

		and examine assumptions informing personal narratives		generated in the group thus far	
<i>Cognitive tools</i>	Discussion of conceptual model of stigma – based on FINIS stigma framework. Note taking enables learner's to begin to relate personal experience to abstract concepts	Provision of a form to assist learners with critical questioning and analysis of critical incidents	Provision of an action planning form to complete prior to the session	Rules for role play/forum theatre act to establish clear procedures for participation	Summary of the tools introduced in previous sessions – which can be used within other interactions to make sense of and transform stigmatising experiences.
<i>Collaborative tools</i>	Providing opportunities for informal introductions and establishment of clear rules for participation and group conduct	Ensuring each person has the opportunity to present their critical incident to the group	Ensuring each person has the opportunity to present their action plan to the group	Interactive role play provides opportunities for all learners to participate in response to a common problem	Opportunities provided for open-ended and directed discussion regarding the learning process
<i>Contextual support</i>	<ul style="list-style-type: none"> <li>- Learners formally provided with opportunity to reflect on the process of learning and development of meaning at the start and end of each session</li> <li>- Group ground rules re-established at the start of each group</li> <li>- Educator able to be contacted individually by participants outside of the group setting to further discuss any content, procedures, or experiences from within the group</li> </ul>				
<b>Differentiation strategies<sup>2</sup></b>	<b>Session 1</b>	<b>Session 2 and 3</b>	<b>Session 4</b>	<b>Session 5</b>	<b>Session 6</b>
<i>Content</i>	Presenting material in audio, visual, and tactile modes. Providing learners with vocabulary lists for future reference	Demonstrating skills following instruction (cognitive modelling and coaching)	Demonstrating skills following instruction (cognitive modelling and coaching)	Demonstrating skills following instruction (cognitive modelling and coaching)	Reteaching in a different way for learners who are having difficulty
<i>Process</i>	Not applicable for this session	<p>Making tasks more specific for some and more open-ended for others</p> <p>Conducting activities which seek multiple perspectives on content</p>	<p>Making tasks more specific for some and more open for others</p> <p>Conducting activities which seek multiple perspectives on content</p>	<p>Making tasks more specific for some and more open for others</p> <p>Conducting activities which seek multiple perspectives on content</p> <p>Offering different ways to demonstrate learning</p>	Using tiered learning processes (providing activities at different difficulty levels but addressing the same goals)
<i>Outcome</i>	Not applicable for this session	Offering (learning) product options that are analytic/creative/pragmatic	Offering (learning) product options that are analytic/creative/pragmatic	Offering (learning) product options that are analytic/creative/pragmatic	Offering (learning) product options that are analytic/creative/pragmatic
<b>Formative assessment</b> (determined using observer field notes and learner responses)	<i>Relevant learning objectives</i> - The learner can describe the three-step process of critical reflection	<i>Relevant learning objectives</i> -The learner can describe questions that may be used to facilitate critical reflection	<i>Relevant learning objectives</i> -The learner constructs a behavioural plan of action for challenging assumptions	<i>Relevant learning objectives</i> -The learner listens to the narratives and perspectives offered by other group members	<i>Relevant learning objectives</i> -The learner independently applies a framework of critical reflection for

to guided session reflection)		<ul style="list-style-type: none"> <li>- The learner is able to identify assumptions underpinning their experience of stigma</li> <li>- The learner is able to demonstrate use of critical reflection as a tool for understanding diabetes-related stigma</li> <li>- The learner listens to the narratives and perspectives offered by other group members</li> <li>- The learner engages in discussion with others in response to their narratives and actions</li> <li>- The learner relates stigma to their own experience of living with diabetes</li> <li>- The learner is able to explain their experience of diabetes-related stigma to others</li> <li>- The learner is able to explain their process of learning and reflection to others</li> </ul>	<ul style="list-style-type: none"> <li>that underwrite stigmatising practices</li> <li>- The learner listens to the narratives and perspectives offered by other group members</li> <li>- The learner engages in discussion with others in response to their narratives and actions</li> <li>- The learner is able to explain their process of learning and reflection to others</li> </ul>	<ul style="list-style-type: none"> <li>- The learner engages in discussion with others in response to their narratives and actions</li> <li>- The learner participates in the creation of novel discourses via role play</li> <li>- The learner evaluates and refines their understanding of stigma and the operation of power following reflection on interpersonal interactions</li> <li>- The learner is able to explain their process of learning and reflection to others</li> </ul>	<ul style="list-style-type: none"> <li>addressing problems outside of the group setting</li> <li>- The learner relates stigma to their own experience of living with diabetes</li> <li>- The learner is able to explain their process of learning and reflection to others</li> </ul>
<b>Summative assessment</b>	Interview and reflective journal content. Examine changes in discourse (interviews) and learning (interviews and reflective journals)				

<sup>1</sup> According to hierarchies of Anderson et al (2001) (cognitive), Krathwohl, Bloom, and Masia (1964) (affective), and Harrow (1977) (psychomotor) – as described by Pagliaro (2012, pp. 106-15)

<sup>2</sup> According to strategies for the design of constructivist learning environments, as described by Jonassen (2009)

## Lesson Plan: Session 1 – Reflecting Critically about Diabetes Stigma

Organisation					
<b>Topic analysis</b>	Closely follows Fook and Gardner's introductory session plan. Focus on what is critical reflection, why it is useful, and what it involves. Also establish group norms and communicate clear expectations regarding participation. Additionally, this session will introduce diabetes-related stigma and different ways of understanding it.				
<b>Learner prior knowledge</b>	Although learners are expected to have rich experiences of living with diabetes with variable positive/negative thoughts and feelings attached to this experience, they might naturalise this experience (i.e. not question the validity of these thoughts) and/or lack the language required to relate these experiences to more abstract processes (such as scare-tactics as a media genre in preventative health).				
<b>Context of lesson</b>	Learners enter the group for the first time – acquainted with the facilitator/researcher but still unsure of exactly what will be expected of them. Some may experience some anxiety about meeting new people (all with diabetes – which may present some issues of identity) and sharing their experiences within a group setting. Heightened anxiety and vulnerability likely to present a barrier to sharing in first session. Learners are also likely to have had previous experiences with behaviourist models of education (particularly within healthcare contexts) and so the concept of constructivist forms of education may appear quite foreign at first. There may exist gendered differences in learning.				
<b>Session objectives</b>	As a result of this session, participants will be able to: <ol style="list-style-type: none"> <li>1. Recognise the personal relevance of critical reflection in helping them make sense of and challenge the stigma of diabetes</li> <li>2. Understand what is expected of them in the upcoming group sessions</li> <li>3. Manage anxieties related to group participation</li> </ol>				
<b>Relationship with learning objectives</b>	The learner can describe the three-step process of critical reflection				
Procedure					
Time	Stage	Facilitator action	Participant tasks	Scaffolding	Differentiation
0:05	Introduction	Introduce facilitator and the research  Discuss the role of learners  Describe the content of the session  Provide an overview of housekeeping requirements  Ask if there are any questions or comments about the program	Listen to facilitator – raising questions when necessarily	Encourage note taking and scribbling on provided pad	Provide regular opportunities for persons to ask questions or provide input into discussion
0:20	Diabetes stigma	Discuss the stigma concept as it relates to diabetes	To reflect on how personal experiences might be shared by others. To reflect on accuracy of researcher's interpretation	Establishing boundaries around the examination of diabetes and stigma	Opportunity for oral/visual engagement with concepts
0:40	Critical reflection	Discuss what critical reflection is and what it involves  Provide an overview of the process of critical reflection	Listen to story  Ask questions or provide comments in pauses (either by speaking or raising hand)	Using stories to illustrate connections between experience and abstract concepts (realising the relationship between the self and the social)	Providing visual/diagrammatic and narrative tools for learning
1:00	Choosing a critical incident	Discuss the role of the critical incident in the education program	Listen to explanation of process and to ask questions of facilitator if unsure of the process	N/A	N/A

		Describe the process for selecting an appropriate critical incident			
1:15	Reflective Journaling	Overview of the purpose and method of reflective journaling	Listen to explanation of process and to ask questions of facilitator if unsure of the process	N/A	N/A
1:25	Group Culture	Provide an overview of group culture and group norms	Ask questions or provide comments in pauses (either by speaking or raising hand)  Contribute to other group norms (post-it notes on board)	Provide ground rules to structure non-negotiable expectations of group participation	Opportunity provided for learners to contribute additional ground rules either verbally or in written form
1:30	Conclusion and transition	Provide an overview of the next session and what is expected of learners  Provide guidance on contacting the facilitator between sessions  Provide opportunity for participants to raise questions, thoughts, doubts	Learners to reflect and verbalise to group their thoughts about the reflective process	N/A	N/A

## Lesson Plan: Session 2 – Decoding and Deconstructing

Organisation					
<b>Topic analysis</b>	This session allows each learner to present their critical incident to the group, with the group then assisting the learner to identify assumptions contained within their critical incident. This process is repeated for all learners, providing an opportunity to practice and habitualise critical reflection.				
<b>Learner prior knowledge</b>	Learners will enter this session with a basic understanding of concepts related to diabetes-stigma and the process of critical reflection. Most participants will have selected a critical incident for discussion. However, learners are unlikely to possess language and concepts that can readily be used to express new ideas and perspectives.				
<b>Context of lesson</b>	Although participants are expected to be familiar with the group environment, group members (to some extent), and the task itself, they are likely to be anxious about presenting their own critical incident to the group. There is likely to be a fear of public speaking coexisting with a fear of blame and judgement.				
<b>Session objectives</b>	<ul style="list-style-type: none"> <li>- By examining their own critical incident and the critical incidents of others, each learner is able to identify assumptions underpinning their experience of stigma</li> <li>- To demonstrate a habitual practice of critical reflection</li> </ul>				
<b>Relationship with learning objectives</b>	Relevant learning objectives <ul style="list-style-type: none"> <li>- The learner can describe questions that may be used to facilitate critical reflection</li> <li>- The learner is able to identify assumptions underpinning their experience of stigma</li> <li>- The learner is able to demonstrate use of critical reflection as a tool for understanding diabetes-related stigma</li> <li>- The learner listens to the narratives and perspectives offered by other group members</li> <li>- The learner engages in discussion with others in response to their narratives and actions</li> <li>- The learner relates stigma to their own experience of living with diabetes</li> <li>- The learner is able to explain their experience of diabetes-related stigma to others</li> <li>- The learner is able to explain their process of learning and reflection to others</li> </ul>				
Procedure					
Time	Stage	Facilitator action	Participant tasks	Scaffolding	Differentiation
0:00	Overview of previous session	Provide an overview of the content of the previous session: <ul style="list-style-type: none"> <li>- Stigma and diabetes</li> <li>- Critical reflection</li> <li>- Selecting a critical incident</li> <li>- Reflective journaling</li> </ul> Reflections on journal writing: <ul style="list-style-type: none"> <li>- How did it <b>feel</b> to write?</li> <li>- What did you write about?</li> <li>- How well do you feel you were able to express your thoughts?</li> </ul> Check if there are any questions about anything from previous week	Raise questions regarding content from previous week	N/A	N/A
0:15	Introduction	Purpose of current session – presentation and examination of each other’s critical incidents. Provide an overview of the procedure for the session	Listen to explanation of process and to ask questions of facilitator if unsure of the process	N/A	N/A
0:30	Group Culture	Re-iterate group norms and culture	Ask questions or provide comments in pauses (either by speaking or raising hand)	Provide ground rules to structure non-negotiable expectations of group participation	Opportunity provided for learners to contribute additional ground rules
0:35	Critical Incidents	Ask each participant to introduce themselves and their critical incident	- Present critical incident to group	Participants provided with a list of	Multiple questions and lines of inquiry may be

		<p>Group asks questions to understand the influence of:</p> <ul style="list-style-type: none"> <li>- The self</li> <li>- Others involved in the incident</li> <li>- Assumptions about diabetes</li> <li>- Practices affecting PWD</li> </ul> <p>Each presenter responds to these questions</p> <p>Each presenter attempts to:</p> <ul style="list-style-type: none"> <li>- Identify an important assumption</li> <li>- Describe how this assumption might be formed</li> </ul>	<ul style="list-style-type: none"> <li>- Listen attentively and without interruption to the learner's story</li> <li>- Use questioning guide to help facilitate examination of assumptions</li> <li>- Encourage group interaction and dialogue</li> <li>- Participant makes notes on the critical incident form for future reference at the end of their turn</li> </ul>	questioning techniques and critical incident analysis form	applied to problem – suiting the needs of ideas of individual learners
1:45	Conclusion	<p>Respond to any queries or concerns about critical reflection (e.g. what sort of questions helped, what did people like/not like about the process, doubts)</p> <p>Ensure all participants have something to take to the next session regarding their own incident</p> <p>Overview and instructions for next session</p>	<p>Learners to notify facilitator is unclear about their incident</p> <p>Learners to reflect and verbalise to group their thoughts about the reflective process</p>	N/A	N/A

## Lesson Plan: Session 3 – Planning for Action

Organisation					
<b>Topic analysis</b>	This session focuses on planning for an action-oriented response to stigmatising interactions, informed by reflections from the previous week.				
<b>Learner prior knowledge</b>	All learners are expected to have a preliminary understanding of assumptions underpinning their critical incident, which embodies (at least partially) their experience of stigma related to diabetes. Prior to the session, learners are expected to have thought about behavioural options for challenging the legitimacy of harmful assumptions, and to have identified one response considered most likely to be helpful and successful in resisting stigmatisation.				
<b>Context of lesson</b>	Learners are now becoming more familiar with procedures of group sharing and dialogue; however, until this point there has been limited opportunity for discussing concrete actions for change. This is a time when learners may become overwhelmed or disillusioned at the scope of the task and their ability to contribute to change.				
<b>Session objectives</b>	<ul style="list-style-type: none"> <li>- Learners develop a specific behavioural plan of action for challenging assumptions that underwrite stigmatising practices relevant to themselves</li> <li>- Learners become aware of multiple strategies for challenging stigmatising practices</li> </ul>				
<b>Relationship with learning objectives</b>	<ul style="list-style-type: none"> <li>- The learner constructs a behavioural plan of action for challenging assumptions that underwrite stigmatising practices</li> <li>- The learner listens to the narratives and perspectives offered by other group members</li> <li>- The learner engages in discussion with others in response to their narratives and actions</li> <li>- The learner is able to explain their process of learning and reflection to others</li> </ul>				
Procedure					
Time	Stage	Facilitator action	Participant tasks	Scaffolding	Differentiation
0:00	Overview of previous session	<p>Provide an overview of previous session</p> <p>Ask if there are any questions or thoughts about this process?</p> <p>Reflections on journal writing:</p> <ul style="list-style-type: none"> <li>- How did it feel to write this time?</li> <li>- What did you write about?</li> <li>- How well do you feel you were able to express your thoughts?</li> </ul>	<p>Raise questions about content from previous week</p> <p>Raise questions about procedure for current session</p>	N/A	N/A
0:05	Introduction	<p>Describe purpose of session – to identify alternatives to the status quo of thinking about and acting in response to stigmatisation</p> <p>Describe procedure for participation</p>	<p>Listen to explanation of process and to ask questions of facilitator if unsure of the process</p>	N/A	N/A
0:45	Presentation of incidents (15 minutes per person)	<p>Each participant reminds group of their critical incident and their analysis of their incident, then presents their alternative plan of action (15 minutes each)</p> <p>Encourage group to question the action plan, drawing on questions contained within the participant workbook.</p>	<p>In turns, each learner is allowed up to 15 uninterrupted minutes to present their agenda for change</p>	<p>Presentation of incidents guided by four-point summary</p>	<p>Learners may respond in flexibly manner to the four-point summary</p>
1:55	Conclusion	<p>Respond to any queries or concerns about action plans:</p> <ul style="list-style-type: none"> <li>- What sort of actions dominated?</li> <li>- What did people like/not like about the process?</li> <li>- How confident are you that your plan will work?</li> <li>- Do you have any doubts?</li> </ul> <p>Provide a summary of the next session</p>	<p>Learners to notify facilitator if unclear about their action plan</p>	N/A	N/A



## Lesson Plan: Session 4 – Refining Action

Organisation					
<b>Topic analysis</b>	Forum theatre provides learners with the opportunity to enact their plans of action in a flexible manner – requiring the ability to reflect-in-action in response to the dynamics of interpersonal interaction. This is important in clarifying/refining understandings of the operation of power within interpersonal interactions and to build efficacy for action.				
<b>Learner prior knowledge</b>	Learners are expected to enter the session with a preliminary understanding of some the harmful assumptions that inform stigmatising practices within interpersonal relationships. From the previous week, they will also have developed a yet untested action plan for challenging the production of stigma. At this point, learners are expected to have the basic cognitive tools to engage in both reflection-on-action and reflection-in-action.				
<b>Context</b>	As a theatrical method, learners may be unsure of their ability to portray a realistic exchange in front of other group members. This may be alleviated by framing Forum Theatre as a game – in which multiple persons might contribute to overall 'success' of the game.				
<b>Relationship with learning objectives</b>	<ul style="list-style-type: none"> <li>- The learner listens to the narratives and perspectives offered by other group members</li> <li>- The learner engages in discussion with others in response to their narratives and actions</li> <li>- The learner participates in the creation of novel discourses via role play</li> <li>- The learner evaluates and refines their understanding of stigma and the operation of power following reflection on interpersonal interactions</li> <li>- The learner is able to explain their process of learning and reflection to others</li> </ul>				
Procedure					
Time	Stage	Facilitator action	Participant tasks	Scaffolding	Differentiation
0:00	Overview of previous session	Summarise the content of the previous session  Ask if there are any questions or thoughts about this process?  Reflections on journal writing: - What did you write about? - How well do you feel you were able to express your thoughts/feelings? - How did it feel writing a reflective journal?	Raise questions about content from previous week	N/A	N/A
0:10	Introduction	Describe the purpose of the session - to practise and refine strategies of resistance to a stigmatising incident.  Provide an overview of the purpose and procedure for Forum Theatre	Raise questions about procedure for current session	N/A	N/A
0:30	Act One	Facilitator to set context using narrative  Facilitator and observer act out role play  Commence second (interactive) role play  Reflections - How was the 'game'? What sort of questions helped? What did you like/not like about the process? - What were the main issues? - How did power/influence operate within the role play? - How did you use your own power/influence to challenge this stigmatisation? - What might be the short and long-term effects of this action on the people involved?	Learners listen to role play without interruption in first reading. Create interruptions in second reading	Form provided to learners to make notes during the first reading.  Exclamations made in script to highlight potentially relevant exchanges	Freedom to contribute novel content or interpretations of the role play or limit discussion to more familiar concepts
1:10	Act Two	Facilitator to set context using narrative	Learners listen to role play without	Form provided to learners to make	Freedom to contribute novel

		<p>Facilitator and observer act out role play</p> <p>Commence second (interactive) role play</p> <p>Reflections (10 minutes)</p> <ul style="list-style-type: none"> <li>- How was the 'game'? What sort of questions helped? What did you like/not like about the process?</li> <li>- What were the main issues?</li> <li>- How did power/influence operate within the role play?</li> <li>- How did you use your own power/influence to challenge this stigmatisation?</li> <li>- What might be the short and long-term effects of this action on the people involved?</li> </ul>	<p>interruption in first reading. Create interruptions in second reading</p>	<p>notes during the first reading.</p> <p>Exclamations made in script to highlight potentially relevant exchanges</p>	<p>content or interpretations of the role play or limit discussion to more familiar concepts</p>
1:40	Summary	<p>Ask participants:</p> <ul style="list-style-type: none"> <li>- How they found these role plays?</li> <li>- Did it change their thinking about the best way to resist stigmatisation?</li> <li>- Did they learn anything new or unexpected?</li> <li>- Are they more or less confident in your ability to resist stigmatisation after this session?</li> </ul>	<p>Learners respond to facilitators questions in open-ended manner</p>	N/A	N/A
1:50	Conclusion	<p>Summary of and expectations for next session</p>			

## Lesson Plan: Session 5 – Sustaining Action

Organisation					
<b>Topic analysis</b>	This final session will offer participants a chance to collectively reflect on their process of learning and to examine their construction of diabetes-related stigma. It will also provide the opportunity to discuss future actions, including how participants might be able to incorporate their learnings into daily life and identify opportunities to further challenge the reproduction of stigma.				
<b>Learner prior knowledge</b>	Learners are expected to have a working knowledge of assumptions underpinning stigmatising practices and have developed options for challenging these practices within the context of interpersonal interactions.				
<b>Context of lesson</b>	Termination of a group may bring about a sense of loss and grief amongst some members. Therefore, a final group session is required to provide a sense of closure and to help manage these challenging emotions. A critical consciousness of oppression has also been shown to exist as an ongoing developmental process, therefore it is important to provide a framework for managing future developmental needs.				
<b>Session objectives</b>	<ul style="list-style-type: none"> <li>- Learners recognise that critical reflection is an ongoing and developmental process</li> <li>- Learners possess frameworks that may be used beyond the group for supporting critical reflection</li> <li>- Learners are aware of the range of opportunities available for using their learnings from within the group</li> <li>- Learners are able to manage the challenging emotions associated with group termination</li> </ul>				
<b>Relationship with learning objectives</b>	<ul style="list-style-type: none"> <li>- The learner independently applies a framework of critical reflection for addressing problems outside of the group setting</li> <li>- The learner relates stigma to their own experience of living with diabetes</li> <li>- The learner is able to explain their process of learning and reflection to others</li> </ul>				
Procedure					
Time	Stage	Facilitator action	Participant tasks	Scaffolding	Differentiation
0:00	Introduction	Provide an overview of the session: <ul style="list-style-type: none"> <li>- Clarifying what we've actually learned about diabetes and stigma over the last few weeks</li> <li>- Examining ways that you can continue to reflect critically on your experiences with diabetes</li> <li>- Reflecting on the process of learning itself</li> </ul>	Raise questions about content from previous week  Raise questions about procedure for current session	N/A	N/A
0:10	What was achieved	Ask questions about learning occurring from session two: <ul style="list-style-type: none"> <li>- What assumptions have we identified?</li> <li>- How did these assumptions influence the situation?</li> <li>- How are these assumptions maintained?</li> </ul> Ask questions about learning occurring from session three: <ul style="list-style-type: none"> <li>- What actions might be useful?</li> <li>- Who or what has the power to stigmatise?</li> <li>- What power do you have to de-stigmatise diabetes?</li> </ul> Ask questions about learning occurring from session four: <ul style="list-style-type: none"> <li>- What did you learn from the role plays?</li> <li>- How did you feel when trying to challenge stigmatisation within the role plays?</li> </ul> Ask questions about the process of critical reflection: <ul style="list-style-type: none"> <li>- What aspects of this process were useful to you?</li> </ul>	Learners respond to facilitators questions in open-ended manner	N/A	N/A

		<ul style="list-style-type: none"> <li>- What aspects of the process were problematic (e.g. didn't make sense, wasn't useful, or didn't seem relevant)?</li> <li>- Have you changed the way that you think about diabetes?</li> </ul>			
1:00	Sustaining action	<p>Describe how critical reflection reflects an ongoing developmental process</p> <p>Discuss opportunities for advocacy and connecting with other PWD</p>	Raise questions as required	N/A	N/A
1:15	Conclusion and follow-up	<p>Describe content and purpose of follow-up interviews</p> <p>Thank participants for their group contributions</p> <p>Ask if there are any other questions or comments related to diabetes and/or stigma that participants would like to raise within the group</p>	Raise questions about follow-up interviews	N/A	N/A

**FINAL PAGE**