Factors that Contribute to Situations of Genuine Inclusion for People with Disabilities

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Declaration of Originality

I, Katie Butler hereby declare that the content of this dissertation is my own work unless otherwise acknowledged. The highest care has been exercised to ensure that the work of others is always correctly acknowledged. This work has not been presented to fulfil the requirements of any other degree at any other educational institution.

Abstract

Australian governments have made a commitment to address the exclusion of people with disabilities from full societal participation with a collection of policy and legislation aiming to advance meaningful inclusion. However, striving for inclusion is made especially complex because no consensus over the meaning of inclusion exists. This study aimed to better equip policy implementers to achieve quality outcomes under current policy by determining a definition of genuine inclusion and investigating and detailing those factors which shape situations of genuine inclusion for people with disabilities. Qualitative interviews with 11 people with a range of disabilities were undertaken to gain a first-hand insight and understanding. The results highlighted the continuing impacts of exclusion in the lives of people with disabilities. Participants also threw light on what inclusion meant to them, contributing to the formation of a definition of genuine inclusion. Factors contributing to genuine inclusion were also identified, including, attitudes and behaviours of inclusive people, inclusive places, the right kinds of supports and the significance of the personal strategies and advocacy people with disabilities employ to advance their own inclusion. With this knowledge, this research makes some preliminary identification of practices which may assist in the planning, creation and delivery of genuinely inclusive environments, programs and communities.

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Chapter 1: Introduction

1.1. The Topic and Purpose

In Australia, significant progress has been made over recent decades to improve the quality of life of people living with disabilities. However, social exclusion continues to have a detrimental impact in the lives of many people with disabilities. Current policy in Australia recognises this continuing exclusion from full societal participation, and as such, demonstrates a clear commitment to advancing the inclusion of people with disabilities in all aspects of social and economic life. The National Disability Strategy 2010-2020 promotes a vision of: “An inclusive Australian society that enables people with disability to fulfil their potential as equal citizens.” (Commonwealth of Australia, 2011, p. 8) This commitment is now reflected in numerous other initiatives, programs, policies and legislation throughout Australia. The presence of this policy presents an unsurpassed opportunity to enable people with disabilities to enjoy true inclusion in community life. However, before people with disabilities experience the full outcomes of this policy, there still remains much planning and project delivery which policy implementers must engage in.

It is the implementation of this policy that this research is concerned with, and in particular how the concept of ‘inclusion’ is interpreted and delivered upon. This concern arises primarily due to the complexity of the concept of inclusion and its tendency for multiple interpretations. It is important that those actioning and implementing this policy, governments, disability service providers, practitioners and community stakeholders have a true understanding of what inclusion for people with disabilities is, and how to help achieve it to enable the best possible outcomes from this social change effort. Therefore, this research seeks to make the task of planning for and delivering genuinely inclusive communities and practices more achievable by investigating and detailing the factors that contribute to situations where people with disabilities feel a sense of genuine inclusion. The term genuine inclusion, conceptualised for this dissertation, and based upon what Clifford Simplican, Leader, Kosciulek and Leahy (2015) would consider a broad approach to inclusion, is intended to understand far more than just the physical presence of people with disabilities in community spaces, but captures those factors that are important in producing true feelings of belonging to a situation.

This topic was formed on the proposition that despite experiencing systemic social exclusion, people with disabilities experience times in their lives where the impact of exclusion is not felt, where it is possible to feel at complete ease in some settings, to not experience barriers to participation and to not feel the impact of stigmatisation. The study therefore aims to learn from these situations where people with disabilities feel totally and completely included for the people they are. With information about what factors shape inclusive situations within whatever spaces they occur, whether public, private or segregated, it is thought that better knowledge of these factors could assist in providing useful, practical direction to assist in the planning for and fostering of genuinely inclusive communities on a broader level. By documenting experiences of genuine inclusion, it can be better assured that the current disability policy reform has an impact that is truly in line with the needs and desires of people with disabilities. Ultimately, it is hoped this information will provide greater knowledge and skill to challenge and overcome the social inequities of stigmatisation and exclusion of people with disabilities.

People with disabilities have been recruited from around Australia to share their perspectives on what environments, circumstances, attitudes, behaviours, supports and personal strategies help make a genuinely inclusive setting. Each participant took part in a qualitative, semi-structured interview. The data provided by the participants of this study has been critically compared and contrasted to existing literature findings while also analysed from a social constructionism framework to understand circumstances of inclusion from their fundamental level. The work of sociologist Erving Goffman concerning stigma and social behaviour has also been drawn upon throughout this study to examine and understand the experiences of exclusion and inclusion as these occur in social situations. From this analysis it is possible to present a set of findings which contribute to understandings of what factors contribute to situations of genuine inclusion for people living with disabilities.

1.2. Objectives and Research Questions

The purpose of this study is consolidated into three primary objectives:

- To increase understandings of the factors that shape genuinely inclusive settings from the perspectives of people with a disability.
- To increase knowledge and capacity to plan for, create and foster truly inclusive environments, communities and programs
- To assist in developing greater knowledge and power to overcome stigmatisation and exclusion of people with disabilities

To satisfy these objectives, this study seeks to answer three key research questions:

- How do people with disabilities define the experience of genuine inclusion?
- What factors contribute to shaping situations of genuine inclusion for people with disabilities?

- How can this knowledge be utilised to plan for, create and deliver genuinely inclusive environments, programs or communities for people with disabilities?

1.3. Outline of The Dissertation

This dissertation is presented over a further five chapters. Chapter 2 provides a detailed literature review of relevant subject matter, forming a background to the present topic and which also assists in illustrating the rationale for the current study. The review was formed after consulting over 100 relevant sources, obtained by keyword searching a number of academic databases, including Google Scholar, Taylor and Francis, Science Direct and ProQuest. Searches were undertaken using various combinations of the following keywords: disability, inclusion, genuine inclusion, social inclusion, community participation, involvement, belonging, barriers, facilitators, exclusion, stigma, places, community, social networks, relationships, actions, behaviours, attitudes and supports. The review forms a current and thorough overview of this topic. It considers the underlying issue of exclusion and how it impacts in the lives of people with disabilities. The current policy framework designed to address this exclusion is examined next. The paper then goes on to investigate issues in understanding, interpreting and delivering upon the goal of ‘inclusion’ for people with disabilities; exploring notions of narrow and broad approaches to inclusion. A critical exploration of those factors that contribute to a broad approach to inclusion thereafter conceptualised as a genuine experience of inclusion is then provided. A summary of literature findings finalises this chapter.

Chapter 3 considers the methodology of this work. It commences with a rationale for the current study, supported by the previous chapter. An exploration into the social constructionism theoretical framework that will be applied during the analysis of findings is provided. The study design, methods employed for the sampling, recruitment and interviewing of participants, ethical considerations, as well as techniques for analysis of the data are then detailed.

The results of this study are presented over the remainder of the dissertation. Chapter 4 takes a narrative approach in identifying the key themes of this dissertation’s findings. The experience of genuine inclusion from the perspectives of the participants is presented. This is followed by an examination into the factors that facilitate genuine inclusion, including: the actions and behaviours of others, environments and activities, supports for inclusion and the personal strategies that people with disabilities employ to advance their inclusion. This chapter also provides information about current experiences of exclusion. Chapter 5 demonstrates a highly critical discussion, interpreting, contrasting and detailing the results of this work while exploring limitations of the current study and areas for future research. Chapter 6 provides the conclusions and summarised recommendations of this study.

Chapter 2: Review of the Literature

2.1. The Problem: Exclusion of People with Disabilities

The SHUT OUT report (National People with Disabilities and Carer Council 2009) documented the experiences of people with disabilities living in Australia. It highlighted frequent experiences of social exclusion, isolation and discrimination (National People with Disability and Carer Council, 2009). Indeed, the experience of exclusion of people with disabilities is well documented throughout the literature. Within community spaces people with disabilities may come up against hostility, avoidance and fear because of their disability, or else may be subject to staring or negative, patronising or inappropriate comments; with such behaviours causing them to feel unwelcome in certain spaces (Connors & Stalker, 2007; Hall, 2004; Hall, 2005; Milner & Kelly, 2009; Pavia & Mason, 2012; Riddick, 2001). Some people with disabilities can also find themselves excluded from forming friendships and relationships with others due to the impact of stigma and stereotypes about their disabilities (Green, Davis, Karshmer, Marsh & Straight 2005; Taub, McLorg & Bartnick, 2009; Wedgwood, Smith, Shuttleworth & Llewellyn, 2013). For some even simple social interactions are curtailed by fear of disability; for example, Welsby and Horsfall (2011) reported the experience of a woman with an intellectual disability, who despite trying to engage in conversation with her neighbour over a period of years was continually rebuffed. Exclusion also occurs in the built environment, with inaccessible facilities acting as barriers to many people with disabilities to participation in social and economic activities (Connors & Stalker, 2007; Kitchen, 1998; Papasotiriou & Windle, 2012; Stancliffe, 2012; Taub, et al. 2009). These findings demonstrate that people with disabilities can experience exclusion in various forms within many areas of day to day life.

These experiences occur throughout the lifespan, commonly impacting upon one's pursuit of an education and a career. From a young age, many children with disabilities begin to experience negative attitudes towards their disabilities in the form of bullying and othering, and may experience exclusion from school activities and social events outside of school (Connors & Stalker, 2007; Curtin & Clarke, 2005; De Vet, Waitt & Gorman-Murray, 2012; McMaugh, 2011; Riddick, 2001; Salmon, 2013). Experiences of exclusion can continue in various forms throughout one's education, for example; at University where some students with disabilities may experience exclusion contributable to a fear on behalf of other students about disability and uncertainties about how to interact (Papasotiriou & Windle, 2012). When People with disabilities reach working age, many frequently experience discrimination by not being considered equally for employment opportunities (Lindsay, 2011; Wedgwood, et al. 2013). Once employed, people with disabilities may experience disadvantage in the workplace, whether by not being granted with responsibility, facing challenges obtaining reasonable adjustments or when competing for promotion and maintaining managerial status (Green, et al. 2005; Lindsay, 2011; Roulstone & Williams, 2014; Welsby & Horsfall, 2011; Wilson-Kovacs, Ryan, Haslam &

Rabinovich, 2008). Exclusion and stigmatisation are therefore notable as experiences that can continue throughout life and significantly impact upon vocational pursuits.

Sociologist, Erving Goffman (1963 B) provides a framework from which to understand the foundations of these forms of social exclusion. Goffman explored the human behaviours of forming normative expectations, categorising and labelling. He theorised that it is through such processes that those individuals who differ from the recognised status of ‘normal’ gain a stigma; a set of associated attributes which can taint, devalue and discredit an individual’s identity (Goffman, 1963 B). These stigmas go on to impact the lives of the people to whom they are assigned; causing exclusion or awkwardness in social interactions, discrimination, pitying attitudes, fear, avoidance and even violence towards people with disabilities (Goffman, 1963 B; Green, et al. 2005; Thornicroft, Rose, Kassam & Sartorius, 2007). These stigmas serve to create a socially constructed reality of life that represents disability as a deviation from the norm, assisted by the societal practices of internalising and re-enacting behaviours of stigmatisation; consequently resulting in attitudes, environments and structures which can effectively deny people with disabilities the same valued benefits of the society that others enjoy (Goffman, 1963 B; Kitchen, 1998; Link & Phelan, 2001; Omansky Gordon & Rosenblum, 2001). From the experiences documented above, it is evident that the impact of stigmatisation continues to be at play in the lives of people with disabilities causing significant exclusion from participating equally in day to day activities.

2.2. Inclusion as a Vision of Australian Policy

In recognition of the continuing social exclusion of people with disabilities, Australia has engaged in significant policy reform to create a better quality of life for people with disabilities. In 2008 Australia ratified the Convention on the Rights of Persons with Disabilities (Commonwealth of Australia, 2011). Ratification acts as a pledge to honour the human rights of people with disabilities by enabling basic freedoms, and eliminating discrimination on the basis of disability (Commonwealth of Australia, 2011; United Nations, 2006). A key principle of the Convention is to enable “Full and effective participation and inclusion in society” (United Nations, 2006). Signatories to the Convention are required to adopt legislation and policy to uphold the principles and objectives of the convention (United Nations, 2006). As such, Australia has made a nation-wide commitment with the National Disability Strategy 2010-2020 which emphasises a strong focus on increasing the meaningful inclusion of people with disabilities in social and economic life (Commonwealth of Australia, 2011).

This commitment to disability policy reform is now evident at all levels of government. The introduction of a National Disability Insurance Scheme is intended to enable better participation and inclusion in Australian society by providing essential supports and equipment to people with disabilities

(Productivity Commission, 2011; Walsh & Johnson, 2013). To support service providers in delivering services under the scheme, the updated National Standards for Disability Services also reiterate the importance of service providers fostering opportunities for inclusion and participation of people with disabilities (Department of Social Services, 2013). The vision of the National Disability Strategy also extends to state-based policy, for example, in New South Wales where the NSW Disability Inclusion Act was introduced in 2014 requiring local councils and state government departments and agencies to actively develop more inclusive services and communities using Disability Inclusion Action Plans (NSW Legislation, 2014). Combined, this suite of social policy reform presents an opportunity to genuinely break down those societal barriers which exclude, marginalise and discriminate against people with disabilities and enable true inclusion in community life. As such, it is an imperative to make this opportunity worthwhile.

2.3. Inclusion: In Interpretation and in Practice

The objectives of the above discussed policy and legislation are clear; governments, service providers and community stakeholders must take steps to ensure their services, policies, programs and activities enable people with disabilities to enjoy full inclusion in social and economic community life. This strong framework of policy and legislation represents an unsurpassed opportunity to make these objectives a reality. Yet, actioning policy centred on the concept of ‘inclusion’ is made particularly complex when inclusion is not an easily understood, nor measurable concept; in fact, no clear single consensus over the term appears to exist (Clement, & Bigby, 2009; Cobigo, Ouellette-Kuntz, Lysaghi & Martin, 2012; Overmars-Marx, Thomese, Verdonschot & Meininger, 2014; Sherwin, 2006). Identifying a consensus on the concept of inclusion is made more complex due to the myriad of terms that have been used over time to strive for similar objectives; integration, involvement, community participation and social inclusion (Clement & Bigby, 2009; Clifford Simplican, Leader, Kosciulek & Leahy, 2015; Dempsy, 2006). Despite this apparent lack of consensus over what inclusion is and how to measure it, the term ‘inclusion’ is cited frequently within the aims of initiatives and programs which involve people with disabilities. The late Stella Young, made the following observation:

> *In disability circles we hear a lot about inclusion. An organisation that employs people with disabilities among its staff is considered an 'inclusive' workplace. We refer to a school that has students with disabilities among the general student body as an 'inclusive' education setting. Sporting programs, community groups, adult education classes - if there's one of us disabled types there, it must be inclusive. (Young, 2014)*

Young seemed to suggest that the use of the word has become so casually used, it is tacked onto any program where a person with a disability is present (2014). She referred to ‘inclusion’ becoming something of a popular “buzzword”

(Young, 2014). Given that a major focus of policy is based upon a concept that varies in interpretation, and which can consequently become seen as tokenistic in its application, a significant problem is evident. How can it be assured that this policy produces outcomes of genuine inclusion?

Contributing to a potential solution to this problem, Clifford Simplican, et al. (2015) worked to define a definition of social inclusion for people with intellectual and developmental disability, which resulted in a useful analysis to understand two distinct determinations of inclusion. They consider that some definitions of inclusion are narrowly focused, in that they recognise only particular interactions and activities as counting towards inclusion and exclude or discredit other factors (Clifford Simplican, et al. 2015; Clifford Simplican & Leader, 2015). Whereas broader definitions of inclusion consider in greater depth the meaning and quality of interactions and activities, paying greater attention to a person's sense of belonging, quality of relationships and participation in meaningful social roles (Clifford Simplican, et al. 2015; Clifford Simplican & Leader, 2015; Cobigo, et al. 2012). The remainder of this section will attempt to critically expand upon these definitions of inclusion in practice to identify shortcomings and strengths in enabling the inclusion of people with disabilities.

2.3.1. A Narrow Approach to Inclusion

Clifford Simplican, et al (2015) propose that a narrow definition of inclusion has a limited scope and only counts particular factors as contributing to a person’s inclusion. A common ideology behind initiatives that employ a narrow definition of inclusion appears to be the intent to integrate people with disabilities into the mainstream way of living and encourage relationships between people with disabilities and people without (Clifford Simplican & Leader, 2015; Cushing, 2015). In a practical sense, such programs may employ objective measures to capture the results of programs and projects, for example, counting the number of relationships that people with disabilities have with people who do not have disabilities and recording the number of hours a person is present in community settings or the community facilities they visit (Clement & Bigby, 2009; Clifford Simplican, et al. 2015; Clifford Simplican & Leader, 2015; Le Boutillier & Croucher, 2010; Lysaght, Cobigo & Hamilton, 2012). Programs which employ narrowly focused definitions of inclusion have been criticised for not permitting true community participation and resulting in only the physical presence of people with disabilities in community settings (Clement & Bigby, 2009; Milner & Kelly, 2009; Sherwin, 2006). For example, Milner and Kelly (2009) discussed the practice of disability service providers escorting people with disabilities to community settings such as cafes and cinemas in the effort to foster community participation and inclusion by putting people ‘out there’ (Milner & Kelly, 2009). They asserted that such practices didn’t allow people with disabilities to truly become citizens integrated with the culture or history of the community, nor to form the reciprocal relationships with others that they wanted (Milner & Kelly, 2009). Sherwin (2006) provides a critical observation in line with this argument:

> *The dominant forms of service continue to be building-based and group-based, as evidenced by group homes, day centres and sheltered workshops. While these may be located within community neighbourhoods, people are not connected to local community life or are only superficially present in community life such as visiting through local shops and parks. People with disabilities might have greater community presence than they did in the days of institutions on the outskirts of town, however the common patterns are that they lack participation in community life and lack the web of relationships that others take for granted.* (Sherwin, 2006, p. 86)

Narrow approaches to inclusion are recognised elsewhere: Studies by Curtin and Clarke (2005) and Morina Di'ez (2010) investigating the educational experiences of children with disabilities, found that attendance in a mainstream school did not alone predict inclusion into the school community, with children who attended mainstream schools speaking of experiences of being socially excluded, feeling lonely and the odd one out. Similarly, Hyder and Tissot (2013) explored the features of a library reading group for people with vision impairments in New Zealand formed in response to policy advocating for the inclusion of people with disabilities. The group activities took part in a public library, but within a segregated room where members had access to a limited supply of audio books, some of which were abridged versions of the original books and were poorly narrated (Hyder & Tissot, 2013). Although the participants of the group were appreciative of the services provided to them, it was also made clear that despite the formation of the group being intended as a practice of inclusion, in reality it fell far short because they were segregated from other library patrons and were not receiving the same quality of service (Hyder & Tissot, 2013). Given these findings, it is evident that these kinds of practices, commonly branded as enabling the inclusion of people with disabilities can have significant shortcomings, and in fact may result in just a different kind of exclusion (Curtin & Clarke, 2005; Hyder & Tissot, 2013; Morina Di'ez, 2010).

Narrow approaches to inclusion may be prone to such shortcomings for several reasons. Although well intentioned, these approaches appear to overlook important factors that contribute to shaping truly inclusive settings (Clifford Simplican & Leader, (2015). Cobigo, et al. (2012) suggest that inclusion is often conceptualised as the opposite of exclusion, which is problematic because exclusion is an equally ill-defined concept (Cobigo, et al. 2012; Morgan, Burns, Fitzpatrick, Pinfold & Priebe, 2007). They argue that a focus on exclusion as the contrasting state to inclusion tends to lead to a focus upon just the barriers to inclusion; rather than the factors that enable it, which in turn leaves service providers without strong resources to facilitate inclusion (Cobigo, et al. 2012). When considering examples of narrow inclusion, this theory gains creditability. The reading group discussed by Hyder and Tissot (2013) was formed in order to address an aspect of exclusion; the inaccessibility of books to readers who were vision impaired. Yet in practice, the program demonstrated a lack of true understanding for facilitating true inclusion in the library because readers were segregated and receiving a lesser service. Likewise, the experiences of the children with disabilities in mainstream schools in the studies by Curtin and Clarke (2005) and Morina Di'ez (2010) demonstrates that although the most fundamental exclusionary barrier to inclusion had been addressed by enabling the actual physical presence of children with disabilities within the schools, the children still experienced exclusion from activities and social relationships (Curtin & Clarke, 2005; Morina Di'ez 2010). The narrow definition can therefore be seen to lack a complete understanding of achieving a fully inclusive experience.

Another primary focus of the narrow model may also be causing a secondary issue. Clifford Simplican, et al (2015) and Clifford Simplican and Leader (2015) noted that narrow approaches tend to emphasise the importance of relationships between people with and people without disabilities, as noted as a primary objective of the program reported upon in Clement and Bigby, (2009). Although this is a perfectly reasonable expectation that people with disabilities should be able to have such relationships, a complex array of negative or exclusionary attitudes and understandings of disability remain rigidly in place within society which, without being addressed and challenged tend to continue to exclude people with disabilities (Metzel, 2001). For example, a study by Craig and Bigby, (2015) which sought to facilitate the inclusion of people with intellectual disabilities into community based activities, found that without some guidance from the researchers or enthusiasm from the community group to have the person with disability present, the person would only experience a superficial kind of inclusion categorised by just their physical presence. Indeed, other studies continue to demonstrate a prevailing misunderstanding of disability among people without disabilities that leads to exclusion (Scior, Addai-Davis, Kenyon & Sheridan, (2013). For example, the preschool age children in the study by Diamond, Hong & To, (2008) were significantly more likely to choose an able-bodied peer to play with over a child with disability due to their perceived inabilities to join in certain activities. The young adults without disabilities in Soffer and Chew (2015) all held views of disability as a negative experience, categorised by a perceived lack of ability, functioning or a deficit. One participant saw disability as causing a burden to society if that person was unable to contribute to valued roles (Soffer & Chew (2015). These findings suggest that the mere presence of a person with disability may not be enough to challenge and overcome deeply entrenched beliefs about disability and hence enable inclusion.

The fundamental problem underscoring narrow approaches to enabling inclusion appears to be the lack of recognition that far more is required to foster inclusion than simply allowing people with disabilities to be present in community spaces (Cushing, 2015; Le Boutillier & Croucher, 2010; Metzel, 2001; Salmon, 2013). This observation is put forward eloquently by Silver (2010), p. 193): "…opening up the door to membership and providing access does not necessarily produce social inclusion. Some effort or outreach may be necessary to bring outsiders in.” The narrow form of enabling inclusion appears to overlook the reality that dominant social constructions continue to have an exclusionary function in the lives of people with disabilities; because it seems that approaches with such features do little to challenge them (Cushing, 2015; Salmon, 2013).

2.3.2. A Broad Approach to Inclusion

These findings lead to the consideration of whether a broad definition can offer a greater sense of inclusion for people with disabilities. Many scholars have drawn attention to the importance of approaches to enabling inclusion that look beyond just enabling a physical presence of people with disabilities; and which value the greater complexities of inclusive situations (Cobigo, et al. 2012; Le Boutillier & Croucher, 2010; Lysaght, et al. 2012; Martin, 2006; Meininger, 2010; Power, 2013). Broad definitions of inclusion attempt to understand such complexities and take into consideration the quality of relationships and activities that an individual engages in and whether they feel a sense of inclusion in these settings and relationships (Clifford Simplican, et al. 2015; Clifford Simplican & Leader, 2015). A broad definition of inclusion may recognise the importance of being known as an individual for factors beyond disability, being able to engage in personally or socially valued roles, having a suitable place to live, participating meaningfully in the community, having meaningful and reciprocal relationships, having access to good formal and informal supports, being trusted and valued, and of central importance, feeling a sense of belonging (Clifford Simplican, et al. 2015; Clifford Simplican & Leader, 2015; Cobigo, et al. 2012; Hall, 2009, cited in Clifford Simplican, et al. 2015); Power, 2013).

The value of a broad definition of inclusion is verified by the many perspectives from people with disabilities who have indicated what true inclusion means to them. The above features of a broad definition of inclusion are frequently cited as important attributes of inclusion by people with disabilities, often coexisting and depending on each other to form a complete experience of inclusion. Being able to participate in valued roles and be involved in the community, such as in study, work placements, employment, voluntary work and leisure activities while feeling welcomed, valued, trusted and receiving adequate support are all important features of inclusion (Bruce, 2006; Cunnah, 2015; Foley, et al. 2012; Hall & Wilton, 2011; Martin, 2006; Spencer-Cavaiiere & Watkinson, 2010). For example, the children in Spencer-Cavaiiere and Watkinson (2010) indicated that having a valued, meaningful role in sport activities enabled them to be included with their peers. Martin, (2006) a man with an intellectual disability, upon discovering sport, for the first time in his life felt like more than just the person with disability, and others recognised that he had something very valuable to offer. Hall and Wilton (2011) shared the experience of a man with a psychosocial disability who experienced trouble finding and maintaining employment; but who finally found a job within a supported employment workplace where he was supported, valued and where he enjoyed a sense of self-worth and a meaningful activity. The young adults in the study by MacIntyre (2014) valued receiving pay, wearing a uniform and being treated equally and with respect not least because these features of participating in a valued role demonstrated their inclusion as adults.

Reciprocal, meaningful relationships and interactions appear to be a central component in feeling a sense of belonging and inclusion, effectively shaping many an experience of true inclusion; whether these relationships are formed with other people with disabilities, or people without (Cole, et al. 2011; De Vet, et al. 2012; Salmon, 2013; Taub, et al. 2009; Wedgwood, et al. 2013). Milner and Kelly (2009) shared the story of a social work student who made the choice to take computing courses at a disability service because he liked feeling comfortable and out of the staring gaze of those who didn’t understand his disability, and instead opted to be somewhere where he felt a sense of belonging within a group of empathetic people. Salmon (2013) shared the stories of youth with disabilities who valued their friendships with one another for the reciprocal nature of their relationships and the shared commonalities between them. Van Asselt, Buchanan and Peterson (2015) shared the experience of a young person with intellectual disability who expressed how nice it was at a particular outing, just to be able to talk unguardedly to people and not be fearful of their response to his difference. In the instance of a case study reported on by Wedgwood, et al. (2013) of a young Australian woman with vision impairment, the significance of relationships and simple interactions with other people also becomes evident as an important contribution to inclusion. The young woman experienced an unusual level of complete inclusion and belonging when studying at University on exchange in an overseas country. Due to the high numbers of people who were blind living in the area, members of the public considered it nothing daunting or unusual to offer assistance (Wedgwood, et al. 2013). All of the above experiences demonstrate features of a broad experience of inclusion. It seems that these features tend not to occur in isolation to produce inclusivity, but when occurring in combination appear to have the greatest benefit.

Approaches which focus on the attainment of a broad experience of inclusion are more likely to be measured from a subjective perspective, as the complexities of a broad definition are frequently overlooked by objective measures (Clifford Simplican, et al. 2015; Cobigo, et al. 2012). For example, an objective measure may be able to identify that a person is employed, has hobbies and visits community facilities; however, it is more difficult to determine whether that person feels a sense of belonging and inclusion in those spaces (Clifford Simplican & Leader, 2015; Power, 2013). Considering inclusion from a subjective perspective ensures that a person's individual perceptions as to their level of inclusion are captured (Cobigo, et al. 2012; Mahar, Cobigo & Stuart, 2013; Martin & Cobigo, 2011; Spencer-Cavaiiere & Watkinson, 2010). It means therefore, that an individual must be consulted with to understand their thoughts, feelings and emotions (Spencer-Cavaiiere & Watkinson, 2010). This can be seen as a weakness of the broad approach to inclusion for several reasons. The variability and individuality of people's experiences makes it difficult to capture and categorise hence it becomes more challenging to measure and identify this kind of inclusion (Cobigo, et al. 2012). It may also be argued that such an approach is too time consuming for service providers and that capturing this information from some people with disability an impossibility due to limited communication. This is presumably why examples of a narrow definition of inclusion, with clearly measurable and objective targets are readily found within the literature, whereas programs which have focused upon achieving a broader experience of inclusion appear to be comparatively limited.

2.4. Genuine Inclusion: A Broad Approach to Inclusion

The above recounts of inclusion often stand out in literature because they are clearly valuable to the people involved. They demonstrate a meaningful sense of inclusion in comparison to narrow approaches where a lack of satisfaction is frequently evident. It is for these reasons that a broad approach to inclusion will, from hereafter be referred to as genuine inclusion because it is seen to offer the most meaningful results to fostering inclusion for people with disabilities. A conceptual definition of genuine inclusion is formed for the purpose of this research to capture the qualities of a broad approach to inclusion (Clifford Simplican, et al. 2015 and Clifford Simplican and Leader, 2015). As well as the components of broad inclusion explored above, established from the work of Clifford Simplican, et al. (2015); Clifford Simplican & Leader, (2015); Cobigo, et al. (2012); Hall, (2009), cited in Clifford Simplican, et al. (2015) and Power, (2013), the definition of belonging provided by Mahar, Cobigo and Stuart, (2013) has also been used to shape the concept of genuine inclusion. According to Mahar, Cobigo and Stuart, (2013), there are five components of belonging: subjectivity, which refers to the individualised nature of feelings related to belonging; groundedness, referring to the need to feel a sense of connection to a place, group or activity; reciprocity, indicative of the sorts of relationships that are important to a sense of belonging; dynamism, which explains the particular features of social and physical environments that contribute to belonging and; self-determination, referring to the actions and choices that individuals make which determine feelings of belonging. Based on a combination of these outlined works, the following conceptualisation of genuine inclusion is proposed:

Genuine Inclusion

The experience of genuine inclusion is categorised by feelings of belonging to a community and an environment, far beyond just being physically present. An individual feels valued, respected and trusted. They feel they are truly allowed to participate as the unique individual they are; recognised for more than disability. They do not need to be afraid or wary of rejection or judgement because of their disability. They are able to meaningfully participate in personally or socially valued roles. It is possible to form meaningful, reciprocal relationships with others who have shared experiences, personal qualities or beliefs (Clifford Simplican, et al. 2015; Clifford Simplican & Leader (2015; Cobigo, et al. 2012; Hall, 2009, cited in Clifford Simplican, et al. 2015; Mahar, et al. 2013; Power, (2013).

2.5. Factors that Contribute to Situations of Genuine Inclusion

With a conceptual understanding of what constitutes an experience of genuine inclusion, it is possible to begin to consider what factors contribute to such experiences. The examples of broad inclusion in section 2.3.2. demonstrate that these experiences often occur in very particular situations. The experience of being genuinely included is not a state once achieved which then carries through to the rest of one’s life, but is highly dependent on the circumstances within an individual situation and the perceptions of disability within those spaces; the experience can therefore be quite fragmented (Cunnah, 2015; Morgan, et al. 2007). It is the mission of this section to begin to identify what factors influence and shape situations of genuine inclusion so as to gain greater knowledge to extend these experiences into broader scenarios.

2.5.1. Places of Inclusion

Warranting investigation are places in which genuine inclusion is experienced, for it is during such investigation of such environments that many clues become evident about contributions to genuine inclusion. For many people with disabilities a clear requirement of being included in community activities is the necessity of physically accessible environments, infrastructure, buildings and information (Abbott & McConkey, 2006; Riddick, 2001). However, beyond this fundamental requirement, a complex array of factors operate serving to make places truly inclusive to people with disabilities. An ultimate example of a genuinely inclusive place comes from the historical recounts of Martha’s Vineyard, whose population for centuries was made up of a high percentage of people who were deaf (Grace, 1980). As a matter of course every person, whether hearing or deaf learnt the local sign language. All people could communicate equally and those who were deaf were not excluded from any activity (Grace, 1980). Hearing members of the community recognised the value of sign language even when not speaking to people who were deaf, opting to use it instead of the spoken language whenever it was convenient (Grace, 1980). A more recent example of an inclusive community is detailed in Wedgwood, et al; (2013) where the young Australian woman with vision impairment in this account experienced a complete sense of inclusion in an overseas country where the environment was perfectly set up to allow people who were blind to navigate easily around the community. There was a large population of people who were blind living in the area and as such other members of the public were not fazed by offering assistance or including people who were blind in activities (Wedgwood, et al. 2013). Sadly, examples such as these which demonstrate a complete inclusion of people with disabilities within entire communities without question are rare. More often it is possible to see glimpses of this inclusion within very small and restricted settings.

Some places within communities demonstrate particular factors that make them inclusive. In a study by Hall, (2005) research participants with intellectual disabilities indicated they felt included in very specific places; for example, a welcoming cafe where they felt a sense of belonging and were not stared at or commented upon. The families with children with disabilities in Pavia and Mason (2012) felt included at destinations where staff and managers were accommodating and sometimes willing to bend rules to ensure their child could participate in activities, for example, allowing a wheelchair on an ice skating rink. Others were able to feel included within places which are traditionally exclusionary when simple adaptations were made; for example, a child who was vision impaired in Foley, et al. (2012) felt included within ball games at school when the players used a large ball that he could see. Within these situations, people with disabilities were not negatively stigmatised, and instead were enabled to participate equally either because proprietors were welcoming and had positive attitudes about disability; or others were happy to make adaptations to the activities to facilitate inclusion (Foley, et al. 2012; Pavia & Mason 2012).

Other examples of places of inclusion have also been identified within settings that would normally be considered places of segregation and exclusion of people with disabilities, namely, within congregations of other people with disabilities, where a sense of safety is commonly reported, along with inclusion (Cole, et al. 2011; Hall, 2004; Hall, 2005; Milner & Kelly, 2009; Taub, et al. 2009). Such places are often immediately discredited as being inclusive because people with disabilities are usually separated from the broader community (Cushing, 2015; Hall, 2005). However, this logic is flawed when considering examples such as those documented in Chenoweth and Stehlik, (2004) who recounted the experiences of many families of people with disabilities, who despite living within a mainstream community for several years never felt included. Similarly, in other instances, where a family member had acquired a disability, some families felt excluded and rejected from the community which had previously included them (Chenoweth & Stehlik, 2004). Instead of discounting segregated gatherings as not being inclusive; it is possible to learn from them in order to gather knowledge about inclusion for application to broader community settings (Cushing, 2015). Within small, segregated places, just as in Grace (1980) and Wedgwood, (2013) there is a high percentage of people with disabilities. As such, disability is seen as a normal component of the gathering (Goffman, 1963 B). This therefore acts as an example of a place where social constructions are different to those within mainstream places, therefore changing the expectations and norms within these spaces (Goffman, 1963 B).

In some instances, places with non-typical social constructs where people with disabilities are included by default, have been drawn upon to facilitate inclusion on a broader level. Places designed with the needs of people with disabilities at the forefront have been deliberately used to foster a kind of reverse approach to inclusion, where people without disabilities are encouraged to come into a gathering of people with disabilities. (Cushing, 2015; Jeanes & Magee, 2012). Jeanes and Magee (2012) reported upon a play place that had been designed from the outset to be inclusive to all children. The play space, built deliberately within the grounds of a school for children with disabilities was immediately situated where children with disabilities felt included (Jeanes & Magee, 2012). The features of the play space were designed to be inclusive of all children and enable collaborative play, rather than segregating some children to the outskirts with specialised equipment (Jeanes & Magee, 2012). The parents of children with disabilities; knowing what it is like to feel excluded from mainstream play spaces, made sure children without disabilities and their parents felt welcome by simply striking up friendly conversation (Jeanes & Magee, 2012). The design of the play equipment also enabled the children with disabilities to demonstrate and model their skills to children without disabilities, further contributing to the all-inclusive nature of the play space (Jeanes & Magee, 2012). Cushing (2015) also discusses an example of reverse inclusion, where a facility designed for people with disabilities opened its walking trails, swimming pool and meeting facilities up to members of the public in order to foster an inclusive place for all people. These examples demonstrate universalistic design; where an environment is established considering the needs of all people, rather than an exceptionalistic design, where adaptations are made later within a place that is not inclusive from the outset (Nisbet, Hagner, Antal, Fox & LaPointe, 2006). Universalistic, inclusive thinking demonstrates an awareness of the power of redefining taken-for-granted social constructions that exclude a large number of people.

2.5.2. Leadership for Inclusion

A theme that has become evident in reviewing literature surrounding effective inclusion for people with disabilities is the exceptional strength of leadership demonstrated by those behind a successful experience of genuine inclusion. For example, in the case study by Wedgwood, et al. (2013) the leadership of the disability support unit at University helped make the young woman's transition and experience at the University straightforward and inclusive. Several authors have made similar observations. Frazeur Cross, Traub, Hutter-Pishgahi and Shelton (2004) studied what factors assisted children with severe disabilities to become best included in school activities using measures of inclusion on par with genuine inclusion. They found that the leadership, enthusiasm and determination of teaching staff played a significant impact in dictating a positive outcome for those children (Frazeur Cross, et al. 2004). A participant in the study was quoted as stating, "If one school staff person is a believer in inclusion, they can motivate others. . . . One enthusiastic person is infectious." (Frazeur Cross, et al. 2004, p. 175). The same was found to be true in Craig and Bigby (2015) who studied the social processes that best facilitated genuine participation and inclusion of people with intellectual disability in community groups. They found that the leadership and ethos of a particular group had a significant impact in the inclusivity of the activities and the way in which a person with disability was accepted into the group (Craig & Bigby, 2015). Similar is seen to be evident within genuinely inclusive workplaces; for example, the case studies reported upon by Kalargyrou (2014) demonstrated that a commitment on behalf of an organisation and its leadership to inclusive employment policies meant that people with disabilities were able to stay engaged in their positions, with many demonstrating great passion and commitment to their jobs and a loyalty to the company. Leadership for inclusion is therefore understood to be an extremely important component of a genuinely inclusive situation.

Sherwin (2006) recognised the importance of leadership in producing truly inclusive practice. Of fundamental importance to fostering inclusion, a leader must recognise that the physical presence of people with disabilities is not enough and they must give consideration to what true inclusion involves, potentially abandoning traditional, narrow ways of thinking about inclusion (Sherwin, 2006). With this awareness, to then achieve an inclusive environment, Slee and Allen (2001) assert that leaders need to recognise the need for a ‘paradigm shift’ to foster inclusion; a new way of doing things, rather than building off structures that are flawed and exclusionary. When considering the above examples, these theories gain validity. The leaders who are successful in conducting their organisations to create genuinely inclusive environments appear to have strong empathy for what true inclusion should look like and they have mindfully employed particular strategies or initiatives. For example; making a concerted effort to develop a model of inclusive practice, recognising and building off the strengths of people with disabilities to optimise outcomes within activities, providing support, training and mentoring to stakeholders with and without disabilities within the organisation and working to create and foster a culture and ethos of inclusion within the organisation (Craig & Bigby, 2015; Frazeur Cross, et al. 2004; Kalargyrou (2014). Perhaps the most notable factor that becomes apparent within these examples is the intent to shift organisational conduct to be inclusive; rather than attempting to fit people with disabilities into situations which are inherently exclusionary.

2.5.3. Support for Inclusion

Many people with disabilities must rely on service provision to manage core daily living activities and to participate in the community. The relationships between support staff and people with disabilities can also have a very powerful impact in dictating an experience of inclusion. McConkey and Collins (2010) found that within individual support arrangements, the ability of support staff to facilitate inclusion of meaning to their clients was greater compared to that in group support arrangements. Indeed, in a study by Abbott and McConkey (2006) people with intellectual disabilities indicated that service provision could help them to enjoy inclusion by listening to their preferences, allowing them to have choice over the activities they participated in and by offering individualised one on one support time. In another scenario, the case study by Wedgwood, et al. (2013) demonstrated how empathetic support was important for the inclusion of the young woman into University. At the overseas University the manager of the disability support unit who also had a disability assisted her seamless inclusion. Just these few examples demonstrate that the right kind of support can contribute significantly to ensuring a person is enabled to enjoy situations of genuine inclusion.

2.6. Key Findings from the Literature

Australia is in the midst of social policy reform focused on increasing the inclusion of people with disabilities in community life. However, inclusion is a poorly defined and understood concept, which can consequently lead to it being seen as a tokenistic gesture (Cobigo, et al. 2012; Young, 2014). A significant problem is therefore apparent; how can it be assured that the current policy will produce truly inclusive communities, programs and services if its implementation is based on a concept with no consistent meaning? Clifford

Simplican, et al (2015) and Clifford Simplican and Leader (2015) assist in providing a clarification of the concept of inclusion and outline the existence of two different types; narrow and broad. This determination highlights a further issue because in detailing the features of a narrow approach to inclusive initiatives, it becomes notable during analysis of the literature that narrow approaches, complete with several shortcomings appear to be a common model of inclusion striven for by policy implementers. Initiatives that take a broad approach to inclusion assist in developing a more genuine sense of inclusion, yet examples of initiatives which have employed methods to bring about such inclusion are harder to identify, with often only glimpses becoming evident. However, where examples have been discovered, there exists powerful learnings contributing to the understandings of factors that have shaped that particular scenario, for example, the importance of the physical environment, the behaviours of the people within it and the supports available to people with disabilities.

Chapter 3: Methodology

3.1. Rationale for This Study

Helping to shape and clarify the rationale and direction of this current study, the literature review highlighted several areas where further investigation is due in order to maximise the outcomes of the current policy agenda for inclusion. The lack of a clear understanding of inclusion appears to be problematic because this allows much scope for error within the delivery of programs, activities and initiatives for inclusion; as seen in the exploration of narrow approaches to inclusion. Although there is current knowledge about what a more genuine experience of inclusion should look and feel like, there are fewer examples of how to achieve this kind of inclusion in practice. Currently it is only possible to piece together ideas. This study therefore seeks to understand more about what contributes to situations where people with disabilities feel genuinely included so that these factors can be replicated in the design and delivery of inclusive communities, projects and programs. Although this small study cannot hope to produce all the answers, it will assist in understanding some workable, realistic strategies for policy implementers to plan for and deliver genuine inclusion.

3.2. Theoretical Framework

A social constructionism framework is used during the analysis of this study. Social constructionism asserts that the reality of individuals is shaped by historical, cultural and social meanings and structures (Burr, 2015; Cunliffe, 2008). This reality is not static however, and is continually shaped by those individuals living in the social reality (Cunliffe, 2008). This theory is helpful in firstly, understanding the social issue that this research essentially hopes to find solutions to tackle, that of exclusion and stigmatisation of people with disabilities. Social constructionism demonstrates how an implicit knowledge around disability has formed over time. Disability is frequently perceived as a deviation from the norm because of the way societal structures have made it so by categorising, labelling, stigmatising and denying people with disabilities the same valued benefits of the society that others enjoy; and in turn, this categorisation entails exclusion and othering (Cushing, 2015; Fitch, 2002; Goffman, 1963 B; Omansky Gordon & Rosenblum, 2001). Secondly, the latter mentioned part of the definition of social construction as offered by Cunliffe, (2008) suggests that social constructions, while powerful in dictating social exclusion, can also be changed and transformed by those within the social reality (Fitch, 2002). Therefore, this study is interested in using social constructionism to understand how transformative change can be brought about to achieve greater inclusion of people with disabilities in everyday life activities. The complementary works of Erving Goffman (1963 A; 1963 B) on stigma and social behaviours have also been consulted to bring greater depth and understanding to the issues and conclusions of this study. The data from this study is therefore analysed using this theoretical framework to understand how and why dominant constructions have shifted to allow situations of genuine inclusion to arise. This is important knowledge to ensure initiatives for inclusion have strong resources to succeed.

3.3. Study Design

This study sought the perspectives, insights and interpretations of individuals with disabilities about their experiences of genuine inclusion, making the study suited to qualitative inquiry (Creswell & Miller, 2000; Yin, 2016). The study used semi-structured interviews to gain these perspectives (see appendix A). The interview schedule gathered some basic demographic data and information relating to the nature of each of the participants ages and disabilities. Open-ended questions captured the participants’ views on what constitutes inclusion and exclusion in order to verify or refute the literature findings. Questions sought to discover in what activities and environments the participants felt most included, and what they thought made those scenarios inclusive. The schedule also asked participants about the people they felt most included with and what actions, behaviours and attitudes those people demonstrate in fostering inclusive interactions. Information was also gathered about the actions participants took themselves to facilitate their own inclusion. Participants provided feedback about the impact of any assistive technology or support services they use in facilitating their inclusion. (See Appendix A for a complete interview schedule.) Interviews were recorded using two digital recording devices and later transcribed verbatim.

3.3.1. Recruitment and Participants

This study employed purposive sampling to capture the experiences of a selection of people with disabilities (Laws, Harper Jones & Marcus, 2013; Sarantakos, 2005). A minimum of ten participants were required to take place in the study. To recruit participants, the assistance of several disability service providers and disability advocacy organisations was sought, asking for a short advert regarding the study to be placed in client newsletters, posted on email lists, published on websites and posted on social media pages. Inclusion criteria of the study required participants to identify as a person with disability, be aged eighteen years or older, be living in Australia and able to independently give informed consent. A snowballing technique (Laws, et al. 2013) was used and encouraged among those participants who took part in the study, asking that the information about the study be passed onto any people they thought may be interested in taking part. Promotion returned many requests from individuals with disabilities asking for further information about the study. Potential participants were then provided with a full information kit.

Eleven participants were interviewed for this study. Five participants were male, and six were female. The age of participants ranged between 30-70 years old. All participants identified as people with disabilities. The disabilities identified by the participants included; epilepsy, physical disability, acquired brain injury, chronic health conditions, speech impairment, vision impairment and hearing impairment. Five participants identified themselves as having more than one disability. The participants represented most states of Australia: Queensland, New South Wales, Victoria, South Australia and Western Australia. Due to the geographic spread, phone interviews proved suitable for most participants. Due to the nature of their disabilities, some participants completed the interview through alternative means, including using the National Relay Service, Skype, or by writing the answers to the interview questions. On average Interviews took approximately one and a half hours in time; however, interviews varied in length from approximately thirty minutes to two hours. Four participants elected to verify their completed transcripts before use in the study. Figure 3.1 displays participant characteristics by pseudonym, disability type and age group.

Figure 3.1. Participant Characteristics

Participant pseudonym	Disability type	Age group
Carolyn	Neurological - epilepsy	Sixties
Mic	Physical (uses wheelchair)	Fifties
Jacqui	Physical (uses wheelchair)	Forties
Louise	Neurological - acquired brain injury Physical	Fifties
Peter	Sensory – vision	Sixties
Holly	Chronic health conditions Physical	Forties

Travis	Sensory - vision, hearing	Sixties
Andy	Physical (uses wheelchair)	Thirties
Kevin	Neurological - acquired brain injury Sensory - speech Physical (uses wheelchair)	Sixties
Beth	Sensory – vision, hearing and anosmia Chronic health conditions	Sixties
Georgie	Physical Chronic health conditions Sensory - hearing	Thirties

3.3.2. Ethical Considerations

A high level of ethical regard and integrity has been demonstrated throughout the process of this research in order to ensure the comfort, anonymity and safety of all participants, as well as to minimise bias within the study. The study has been approved by the Flinders University Social and Behavioural Research Ethics Committee. All potential participants were provided with an official letter of introduction from the supervisors of the project, an information sheet and a consent form, explaining the purpose of the study, its voluntary nature, confidentiality and anonymity assurances, potential risks, benefits and data use and storage. See Appendix B for information sheet and Appendix C for consent form. As inclusion criteria required participants to be able to give their own informed consent, the study therefore excluded those who ordinarily require a guardian to assist in decision making. This was a restriction put in place due to the time restraints of this study and indicates a significant limitation of this study by failing to be representative of all people with disabilities. To help eliminate bias from the study, the researcher, as a person with disability and an active member of disability organisations ensured that any potential participant who was known to the researcher beyond acquaintance level was excluded from taking part in the study.

Upon receiving the information kit, participants were encouraged to make contact with the researcher or the researcher’s supervisors if they had any enquiries. The signing of consent forms was required before an interview taking place. Upon commencing an interview, the researcher reminded participants that despite signing the consent form, they could withdraw at any time and their data would subsequently be destroyed. All participants were provided with the telephone numbers of free counselling services should the interview raise any issues of concern for them. The researcher was also sensitive to any signs of distress during the interviews. Data provided by participants used in the study has been de-identified and a pseudonym given to each participant. Audio recordings of interviews and completed transcripts are kept in a locked filing cabinet. Backup copies of the transcripts are also stored on the Flinders University computer server for safe keeping.

3.3.3. Data Analysis

This study utilised a process of qualitative data analysis based on a set of techniques outlined by Yin, (2016). This process consists of compiling the data, disassembling and reassembling data, forming interpretations and concluding (Yin, 2016). The compiling phase simply called for organisation of the data, in this case, the completed transcripts from qualitative interviews into a functional filing system, from which the researcher could begin a reviewing process (Yin, 2016). At this stage and onwards, analytical memos were kept, noting ideas, trends and interpretations (Yin, 2016). Disassembling data involved a process of coding data; dividing sections of original data up by question type, making it possible to identify secondary level codes and phrases (Yin, 2016). Identification of third and fourth level codes served to reassemble the data into distinct concepts and patterns. Identification of themes was then possible, leading into the interpretive phase where data was presented in a narrative form and later contributed to conclusions as detailed in the discussion and conclusion chapters of this dissertation (Yin, 2016).

Throughout data analysis, the researcher took care to reflect upon possible entries of bias into the data interpretation to ensure the study continued to strive for validity. The coding system as discussed above helped ensure that all concepts were gathered and that no area was given undue attention. Reflexivity was practiced throughout the process by continuously comparing, questioning, critiquing and challenging ideas, patterns, themes and interpretations (Yin, 2016). The researcher, having chosen a social constructionism framework to underpin this study maintains an awareness of ways in which unconscious bias becomes entrenched in human behaviour and hence maintained a high level of mindfulness to this possibility throughout interpretation of data (Creswell & Miller, 2000; Yin, 2016).

Chapter 4: Results

4.1. Overview

The analysis of this research highlighted six broad themes and 20 sub-themes. This chapter provides a discussion of these themes and explores their intricacies in the form of direct quotes from the participants. The first theme highlights how the participants define inclusion. The next four offer insights into the factors which contribute to shaping and influencing situations of genuine inclusion. These include: the attitudes and behaviours of others, environments and activities, supports for inclusion and personal strategies and advocacy. The final theme speaks of the forms of exclusion experienced by the participants. This chapter will conclude with a summary of these results.

4.2. To be Genuinely Included

It was important for this research to learn about what genuine inclusion means to people with disabilities. This theme reports upon the responses of the participants when they specifically discussed what genuine inclusion meant to them and what impact feeling included had in their lives.

4.2.1. Equal and Full Participation

The participants often emphasised the importance of being able to participate fully and equally in whatever pursuit they chose.

> Beth: Um, inclusion means having access to um, education, recreation, leisure, um, training, employment, health, housing. It means, um, full and equal access to all aspects of life.
>
> Peter: Ah, I would think that true inclusion would be when all the barriers are removed which I suppose is utopia what we're looking for. Everyone understands what your needs are. Um, so for instance the built environment should be accessible, should be ah, no physical barriers, no um, information barriers that sort of thing. All ah, within about being inclusive, we should be able to apply for, for most jobs and um, participate in the community.
>
> Mic: … to take part in activities of living, um, work and education and ah, every, recreation, every aspect of life. Um, yeah, to be able to be included, um, along with, on an equal basis with other.
>
> Holly: So, I would say that inclusion would be, first of all, um, to come from a perspective of universal design…

4.2.2. Given Opportunity, Supported, Treated Equally, Respectfully and with Non-judgement

Most participants spoke of other qualities that were important to help them feel included. For many the way they were treated was important.

> Andy: …you know, being given that ability to, whether that's through support or different equipment or something like that. I think that's what true inclusiveness is…
>
> Louise: Real inclusion would be, people having tolerance, respect, um and just giving you opportunities.
>
> Kevin: To me, it means that I am treated as an equal, despite the fact that I am a wheelchair user as well as speech impaired.
>
> Carolyn: Well, I suppose my first reaction would be to say that I would like to know that all who know me um, don't fear my disability and that they don't consider me any less capable than anybody else or less acceptable than anybody else because of it. Certainly don't exclude me because of it.

4.2.3. Contributing with Meaning, Having a Role, a Purpose and Belonging

The importance of being able to contribute meaningfully, to have a real role and purpose in activities, to be valued and to feel a sense of belonging became prominent features of the discussions. Travis highlighted the importance of these experiences.

> Travis: …a sense of belonging in the organisations of my choice.

Later he spoke about making a meaningful contribution.

> Travis: Ah. If I feel really included, it, yes I do feel a sense of worth, I feel a sense that I can still value add.

Beth also made similar observations about inclusive situations.

> Beth: you feel good, you feel, you feel accepted, you feel, um, valued, you feel as though you are part of the team.

Jacqui emphasised the importance of these factors when discussing the experience of not just physically being included, but being emotionally included.

> Jacqui: …I would say inclusion is about have, having a sense of purpose, knowing you're of value, having a role, not just being somewhere, so people go, 'gee wow, look, I've included this person.' But actually a sense of belonging and it's difficult to explain that sense of belonging because it's not physical, it, the emotional feeling of that person who is actually different.

Georgie also made a similar reference to the importance of a complete experience of inclusion.

> Georgie: …inclusion is um, sort of about being included, but actually being included and not necessarily being treated any differently to anybody else.

4.2.4. Ideas on Genuine Inclusion

The results presented in section 4.2 demonstrate that to feel genuinely included, equal and full access to activities of one’s choosing are available. An emotional sense of belonging, being able to contribute meaningfully, having a purpose, being valued, respected and accepted were all identified as important features of feeling genuinely included.

4.3. Factors of Genuine Inclusion

The following section outlines the results of this research that relate to the factors that contribute to genuine inclusion. The below table presents the identified factors and their sub-factors discussed throughout sections 4.3.1. to 4.3.4. The table notes the number of participants out of eleven who referenced each factor as contributing to inclusion.

Figure 4.1. Factors Contributing to Genuine Inclusion

No.	Factors Contributing to Genuine Inclusion	Number of participants
4.3.1.	**Inclusive People: Attitudes and Behaviours**	**11**
4.3.1.1.	Recognising personal qualities beyond disability	6
4.3.1.2.	Ensuring accessibility, participation and involvement	7
4.3.1.3.	Empathy, understanding and willingness to learn about disability	4
4.3.1.4.	Empathetic and reciprocal relationships	7
4.3.2.	**Inclusive Places: Environments and Activities**	**11**
4.3.2.1.	In the company of inclusive people	6
4.3.2.2.	Contributing meaningfully in a valued role	5
4.3.2.3.	Physically accessible	10
4.3.2.4.	Suits individual accessibility needs	8
4.3.2.5.	Confined or restricted settings	6
4.3.3.	**Supports for Inclusion**	**10**
4.3.3.1.	Interpersonal qualities of disability support staff	8
4.3.3.2.	Complementary supports	8
4.3.3.3.	Assistive technology	10
4.3.4.	**Personal Strategies and Advocacy for Inclusion**	**11**
4.3.4.1.	Involvement in Systemic advocacy	7
4.3.4.2.	Planning, self-advocacy and education	11

Figure 4.1. shows that there was almost entirely a consensus among the participants as to four key factors that contribute to inclusion. These four factors are: Inclusive people, inclusive places, supports for inclusion and personal strategies and advocacy. Within these factors, however, not all participants

equally identified the same sub-factors; highlighting the variety of factors which can be helpful in contributing to genuine inclusion. These results will be explored in narrative form over the remainder of this chapter.

4.3.1. Inclusive People: Attitudes and Behaviours

All the participants of this study spoke about actions, attitudes or behaviours of other people that had a powerful impact in contributing to a genuinely inclusive situation. Often the first people the participants identified as feeling most included with were family members, partners, friends and sometimes work colleagues. When identifying why they felt included with these people, many noted similar reasons.

4.3.1.1. Recognising personal qualities beyond disability

A significant finding was the importance of recognising personal characteristics beyond a person’s disability.

> Mic: Well my friends, my friends, um, ‘cause they um, see me for who I am, and not just disability.
>
> Louise: …they treat me like a normal person.

> Kevin: …they see me as a person, not as a person with disabilities. Mostly, they take time to “hear” what I am saying...
>
> Holly: …they just get used to me. So, I carry around this blow up cushion with me everywhere and they go, ‘oh your little cushion.’ You know, so they sometimes tease me in a nice way (laughter). Um, and, yeah, it’s yeah, it, it’s, one thing to understand, you as a person, not, not the disability. They don’t have to understand everything about the disability.
>
> Andy: …they don’t really treat me any um, any differently or talk to me any differently that they would to any of their other friends.
>
> Jacqui: Um, I guess really colleagues because er, my colleagues I know I’ve got the job I’ve got because of the capable work I do. So, you know, I, I don’t feel I’ve got anything to prove. Um, I don’t feel I need to validate myself. Of course, family, definitely. You know, um, and um, I guess, er, yeah, there’s a very, very small circle of people who I do feel very comfortable with, but once again it’s those people who don’t see the wheelchair, they see a human being and interact with me as a human being.

Clearly, the ability of others to see more than disability and appreciate other skills, qualities and traits of their friend, family member or colleague was an essential factor in producing inclusive behaviours. Jacqui expanded upon the importance of this.

> Jacqui: We’re there for a reason and the, the, er, attention isn’t centred around, ‘Oh my god, you can’t walk,’ or, ‘you’re in a wheelchair,’ or, ‘tell

> me more,' it's, we're here to undertake a task and I think that's a really important thing. It goes hand in hand with this concept of inclusion. It's about having roles; it's about having identity other than disability.

4.3.1.2. Ensuring accessibility, participation and involvement

Beyond the recognition of their personal attributes apart from disability, the participants frequently identified specific actions or behaviours of people both within their inner circle of family and friends and within the broader community. Making sure they could participate in activities and be genuinely involved was a behaviour that was frequently identified as meaningful.

> Andy: …people that are close to me try their best to um, to ensure that I can do what um, that I can participate.

> Peter: Ah…Well probably with, in my case it just main, mainly turning what they're doing into a narrative. So, they providing narrative information to either a presentation, to objects around, or, describing the environment as we walk along. Um, and one work colleague who um, he just had a natural way of telling me what was going on conversationally as we drove along…

The pastor at Travis's church had updated technology and rearranged the seating so that Travis could continue to hear and see what was going on during proceedings.

> Travis: …thankfully, the senior pastor there has devised various ways to work around that. So he's moved everyone's seat two metres forward. So I'm sitting very, very close to the wall to try to see the words.

Georgie's husband had assisted her to participate in everyday activities by building her equipment and by bringing activities to her when she was unable to leave her bed.

> Georgie: …my husband, I feel fine with him. He makes me feel included. He, he'll go out of his way to make sure that I am included in anything that we're doing. Um, no matter, no matter what that means, so um, yeah. Um, we've had um, birthday parties in our bedroom, um, so that I can stay in bed because I'm too sick to get out of bed, that sort of thing.

Georgie had many other stories to share about people who had demonstrated actions and behaviours which served to help her feel more included. Georgie is a musician, however, with her deteriorating disability, she became unable to play her instrument. She valued the actions of a friend who recognised the importance of her being able to play music, and who set her up with a new instrument to play. One of her support workers, at the time of the interview was helping Georgie to realise another dream and teach music via video link. When Georgie used to perform, she needed another performer to wear the microphone of her FM hearing system so that she could participate. It was valuable to Georgie when other people volunteered to do this.

> Georgie: …there were definitely a couple of people, who, sort of offered. Um, so that sort of made me feel included…

Louise spoke about the inclusive behaviours of her exercise physiologist.

> Louise: …I'm part of a um, fitness group on Saturdays and the exercise physiologist that runs that group, she's great. She um gives me alternative, alternative exercises when I can't do what other people are doing. So she just like makes allowances. So there are some people who can do it well, but she's very rare.

At other times it was the welcoming nature of people that was important to foster inclusivity. Beth spoke about staff at the airport or on other public transport who were welcoming and well trained who provided her with support to access their services.

> Beth: …makes me feel totally included. You're, you know, you're part of an inclusive community when the people are well trained.

Jacqui told a story that demonstrated the inclusive actions of the president of her local sports club. When a new player came to the club who was overtly disconcerted by the inclusion of a wheelchair user in the competition. The president of the club personally went to explain to the new comer that Jacqui was a welcome participant, and inferred that unwelcome behaviour was not tolerated.

4.3.1.3. Empathy, understanding and willingness to learn about disability

Travis, Andy and Holly suggested that one reason they suspected some people were good at being inclusive was their level of empathy and understanding about disability.

> Holly: …I suppose for people to, to, understand, it has to be meaningful for them. So it might be that someone’s experienced it themselves, or, they know somebody that’s experienced it, or they just have, an understanding of diversity, you know, and, and, and that we’re all different. And they’re just open to, that somebody else might feel a little bit different than them, themselves.

Seeking to gain empathy and understanding, become informed and knowledgeable could serve to create inclusive situations and demonstrated welcoming behaviours for Carolyn. She discussed a time at the local market when she had a seizure. She valued the way that the nearest people demonstrated interest and concern and wanted to learn about her epilepsy.

> Carolyn: Um, so those are the sorts of ways that you do feel included, when people don’t recoil and, you know, well… when it’s not the reaction of somebody saying, ‘Oh, she’s drunk.’ You know, ‘Leave her alone.’ Um, instead, it’s people saying, ‘is there anything we can do to help?’ listening to the advice that’s given to them and then afterwards seeing if, if, they can learn more… if they can learn about what happened and, why it

> happened, and if it happens again, is there any way they could contribute positively.

4.3.1.4. Empathetic and reciprocal relationships

A number of participants made inferences to the importance of reciprocal and empathetic relationships.   For Andy, this was a very clearly identified factor.

> Andy: With friendship and um, you know it’s about finding good people that are, understand it and, and will stick with you through tough times, but um, at the same time when things are going well you should ah, make the most of them and um, you know, you gotta’, you’ve gotta’ give and take. You’ve gotta’ help your friends as well.

Often the participants identified experiencing a sense of inclusion categorised by such empathy, common experience and reciprocity when in the company of other people with disabilities.

> Mic: …a lot of, other people with disabilities ah… Feel comfortable with ‘cause they relate to where I’m coming from.

> Beth: …I feel much more comfortable when I’m in a group of people who are blind or vision impaired.

> Holly: it’s an innate understanding with some people. Like, other people who have chronic fatigue…

> Jacqui: …I do love to mix with my own people because we have our own language and our own in jokes and I feel it’s a sense of empowerment, it’s a lift to the spirits, it, it really fills you up, makes you feel good to be in an environment where you’re one of many of the same.
>
> Georgie: …I almost feel more included with people online than I do in person. Um, if that’s a category, but um, like groups online that are, that have other people with disabilities in it.

Later Georgie demonstrated how these relationships were reciprocal and empathetic.

> Georgie: I think that they make me feel more included because they’ve also got disabilities themselves. Some have the same disability so we have a lot in common and because we have a lot in common we can go, ‘oh yeah, this happened to me,’ and then she’ll say, ‘oh yeah, that happened to me too.’ You know, and we’re sort of talk about symptoms and sort of, compare notes shall we say…

Travis spoke about spending time with a friend who has a very similar disability to himself.

> Travis: So, we can enter each other’s world, enter the frustration of each other’s world and equally he’s lost his sense of smell, taste and hearing and sight, and so therefore we have a, very, very strong parallel of picking each other up when the need is there, to be there for each other.

The experiences of the participants demonstrate that the behaviours, actions and attitudes of others play an integral role in shaping a situation of genuine inclusion. Highlighted very strongly was the importance of others appreciating them for qualities, skills and attributes other than their disabilities. It was also valued when others made sure that they could participate in activities, sometimes by adapting or innovating, and sometimes just by making sure they felt welcome. Some participants identified that some people were good at being inclusive due to an empathy and understanding they had for disability, and commonly this was found with other people who lived with disabilities.

4.3.2. Places of Inclusion: Environments and Activities

The participants identified certain environments or activities in which they felt particularly included.

4.3.2.1. In the company of inclusive people

While the participants identified specific places where they felt included, it also became clear in many instances that the inclusivity was also due to the presence of inclusive people who were also present in that environment. Jacqui spoke about her complete inclusion in a local sporting community. In this space she feels totally included and plays equally with the able-bodied athletes.

> Jacqui: And I play to win and my opponents play to win. It's very rare that I can be in an environment where I'm just seen as another person, without, 'gee, that's the wheelchair user.'

Georgie referred to feeling best included in virtual online environments with her friends with disabilities.

> Georgie: We have a, a sort of chat group, chat thing on Skype every week and um, I think that, and, and, also the support groups that I'm on, on Facebook and the email list, I think the reason why those environments help is because of the people that I'm talking to.

Apart from this virtual space, Georgie also enjoyed a sense of inclusion when her and her husband hosted a birthday party in their bedroom. This was the only way Georgie could see other people as she was unable to leave her bed. It could also be made completely accessible to her with the right equipment.

> Georgie: …the only other scenario at the moment while I'm bedridden that I would feel included, is being at a group of people in my bedroom 'cause then I'm in my bed, and it's all set up so that I can hear and with the table and all that sort of thing.

For Beth, inclusive environments or activities were linked with welcoming staff who were prepared to be helpful if needed.

> Beth: Um, ah probably a good café that’s um, you know, that’s either willing to have their staff come and read their menu to you, or have, allowed you to have it by email.

Similarly, Kevin felt included in board meetings when he was given adequate time to communicate using his alternative communication device. Travis felt included within working groups of people who displayed faith and confidence in him to do a good job. Louise also felt included in spaces where she was respected by others for her skill.

4.3.2.2. Contributing meaningfully in a valued role

A number of participants spoke of feeling included when they were contributing meaningfully to an activity. Kevin felt included on the boards and committees that he attended regularly. he spoke about how at these meetings he felt he was raising awareness and understanding. For other participants too, they spoke of feeling included in environments where they made a meaningful contribution. Jacqui discussed feeling included within her workplace where she was recognised for her good work and genuine contributions. Andy spoke about feeling included in the voluntary activities he participates in.

> Andy: I guess I’m, I feel really included there because, I’ve found a niche where I can contribute… …by doing that um, you know, you get rewards in terms um, satisfaction that you can do something and contribute.

> Travis: …I have found that although society as a whole seems to have excluded me, niches where there is a commonality of that disability have tended to say, “you’re a workaholic, you’re happy to do the work, let’s take you on, let’s include you, go for it.” And so I have.

Louise also talks about feeling included on boards and committees.

> Louise: …they’re my strength areas. Um, I’m good at it, and so people treat me with respect.

4.3.2.3. Physically accessible

Kevin, Peter, Georgie, Mic, Travis, Jacqui, Louise, Holly, Beth and Andy all mentioned that physical accessibility was important to create inclusive environments and activities. Clear, uncluttered paths of travel, accessibility equipment such as audio description units, compliant ramps, accessible parking and toilets and audio announcements all became notable as important features.

4.3.2.4. Suits individual accessibility needs

As well as the necessity of a physically accessible environment, Andy, Mic, Louise, Georgie, Holly, Travis, Jacqui and Carolyn noted that they felt especially included in environments where the impacts of their disabilities were reduced. For example, Andy often needed to be indoors where it was cool, Holly preferred being outdoors and away from florescent lighting. Travis preferred going to events during the day as he felt less confident traveling with less vision at night. Carolyn preferred visiting small, quiet venues like the local markets or community picture theatre rather than going to busy noisy establishments where risk of seizure was greater. Carolyn, Jacqui and Holly worked from home which suited their individual accessibility needs. Most of the participants noted that their friends, family or employer helped accommodate these requirements.

4.3.2.5. Confined or restricted settings

As can be seen from some of the examples above from Jacqui, Louise, Georgie and Carolyn many of the environments of inclusion they referred to were very particular scenarios. Jacqui recognised this phenomenon and aptly summed up this experience when asked about what made an environment inclusive.

> Jacqui: Oh look I'd have to say with every environment I've mentioned it's, um, it's, it's that, that, that ah, narrowness or that safety of a confined environment.

This confined nature of inclusive situations was also specifically observed by other participants.

> Beth: …I went to TAFE, TAFE college, um, I found that was a place where you didn’t feel included. Um, in the wider community of the TAFE college. But in my actual classes I did. I was always part of the class.

Travis too spoke about despite his pastor creating an inclusive experience within the church’s services, this inclusivity didn’t extend to other parts of the experience.

> Travis: …when there’s a break you kinda’ think, “yeah, everyone’s gone to whoever they want to talk to and I’m just going to sit here. Hmmm…” And so, yeah, even in, like they try to make the effort, there’s still that divide that is very real.

4.3.3. Supports for Inclusion

As well as inclusive places and interactions with inclusive people, other factors became apparent as being essential parts of the puzzle to form genuine inclusion. One such factor is the importance of having appropriate support. Many of the participants required the assistance of support services to undertake tasks of daily living. As Travis noted, these services often played an integral role in assisting them to be included in their community.

> Travis: …my greatest social inclusivity is actually via my carer.

4.3.3.1. Interpersonal qualities of disability support staff

Andy, Mic, Holly, Georgie, Peter, Kevin and Jacqui, noted such qualities as friendliness, engagement, reliability, understanding of needs, person centeredness, flexibility, willingness to listen, initiative and common sense as important factors in assisting them to be included in various pursuits. It was also important for some participants that their support workers allowed them to do as much as possible on their own and only helped when required.

> Mic: …if they um, don't try and tell me what to but are happy to take um, direction and are um, adaptable enough to do that.

> Louise: She lets me work it out myself. Um, the most important thing for me, is to work out how to do things myself and people not trying to tell me how to do it.

Kevin spoke about the support he requires to do his job.

> Kevin: Although a (company name) worker accompanies me, they keep in the background and allow me to do the assessment.

4.3.3.2. Complementary supports

Many participants identified other complementary supports as also being crucial to facilitating their inclusion. Jacqui for example explained how having housekeeping assistance was important so that she still had energy to go out and do social activities. Andy, Mic and Beth all found the companion card a necessary support. The importance of having funding available to purchase supports and assistive equipment was also noted by Louise, Mic, Georgie, Travis and Holly.

4.3.3.3. Assistive Technology

Most participants mentioned the importance of their assistive technology and having timely access to what they needed. This technology often played an integral role in allowing them to participate and be included in activities of their choice. For example, Mic spoke about the value of his hand-cycle tricycle allowing him to cycle on bike tracks with other people and Georgie used a custom-made stand to play her musical instrument which enabled her to continue playing with deteriorating disability. Peter, Mic, Louise, Holly Beth and Jacqui valued assistive technology that either looked normal, did not draw attention to itself or else which was incorporated into mainstream technologies. It was important that they were also enabled to use their assistive technology. For example, Georgie needed other people to be prepared to use her hearing augmentation system and Kevin needed others to allow him time to use his alternative communication device.

These findings demonstrate that apart from the essential components of inclusive places and inclusive people; the importance of those supports which must occur in parallel for many people, such as appropriate support services and assistive technology must not go unappreciated.

4.3.4. Personal Strategies and Advocacy for Inclusion

A significant theme which became prominent throughout the interviews with participants was the substantial effort they all contributed to advancing their own inclusion and that of others. They often engaged in self-advocacy to maximise their own comfort and inclusion and also contributed to efforts to improve inclusion of people with disabilities on a societal level.

4.3.4.1. Involvement in Systemic advocacy

Mic, Travis, Kevin, Louise, Carolyn, Beth and Georgie had all worked on disability access committees, sat on boards, participated in projects or contributed to awareness raising activities to advocate for and bring about better inclusion of people with disabilities. Some participants dedicated themselves to tackling individual or systemic discrimination or access problems. Kevin and Mic both said they lodged human rights complaints if required. Whereas Beth worked closely with an educational institution to try to make their services more inclusive to students with disabilities.

4.3.4.2. Planning, self-advocacy and education

In their own lives, Georgie, Louise, Peter, Carolyn, Holly, Travis, Beth, Kevin, Jacqui, Mic and Andy talked about the planning or consideration they put into ensuring they would be able to participate in activities, while maximising their comfort within these settings. Deciding whether to disclose disability, preparing supports, requesting access arrangements or making choices about what was and was not possible for them to do were all common personal strategies.

> Andy: …working out what you can do, what your capabilities are and then um… I think um, you know, maximising your opportunities within that…
>
> Louise: I guess I always prepare to not fail. So when I go out, I, I'm prepared to go somewhere where I can manage. So, not much walking, where I can sit.

Some participants invested time into educating others about their disability. Holly made information about her disability available to her colleagues.

> Holly: So, um, I would, um, yeah, hand around my file or I would say, the file is in my office, if you want to read the file, then you can. And so, I, I do give people a lot of information.

Educating others was also important for Kevin and Carolyn.

> Kevin: …there have been occasions where the person asks a companion, rather than me. This annoys me so I wave at them and point to myself.

Carolyn spoke about her role as a spokesperson educating about Epilepsy.

> Carolyn: …I've actually embraced my disability more. In order to be a spokesperson. And in order to use opportunities to be more public and to say more than I ever have 'I'm disabled' and to actually be quite proud of that.

These demonstrations of systemic and self-advocacy illustrate that people with disabilities are very much invested in improving things for themselves and for other people living with disabilities. They are at the forefront of the movement to advance genuine inclusion in a number of ways.

4.4. Experiences of Exclusion

This study gathered some information about the kinds of exclusion the participants came up against. This information provided an up-to-date idea of the kinds of barriers that continue to be experienced by people living with disabilities. The recounts of the participants demonstrated that exclusion is a common experience.

4.4.1. Physical Barriers and Inaccessibility

Often physical barriers were identified as excluders. Mic, Andy, Kevin, Jacqui, Louise, Georgie and Travis made references to difficulties getting around and facing inaccessible facilities, accessing accessible toilets, or else, experiencing limited availability to transport. When asked if he ever felt excluded, Andy explained the impact of physical barriers.

> Andy: Um, yeah I do I guess, that’s inevitable I think. Um, if you’ve got an, you know a high level disability like I have, um, there’s just, there are physical limitations of what you can’t and can do and there’s going be a flight of stairs somewhere that you can’t get up, no matter how much you wish you could.

These barriers could also prevent him from being able to do things with his young daughter.

> Andy: …she goes swimming today. I can’t go…I can go to the pool but I can’t go swimming with her…

Jacqui illustrated the inconvenience of having to deal with a less than ideal physical environment.

> Jacqui: …for me to get from point A to point B, it’s generally the longest distance. It’s not just down the back flight of stairs and I’m there. …Um or things like, you know, if I wanted to go to the bathroom, it was in another building; whereas if you’re able-bodied there’d be probably eight other choices to go to the toilet.

Georgie spoke about when she used to perform in a choir. She experienced frequent accessibility barriers both at the performances and at related social events.

> Georgie: …all of the venues were just completely inaccessible. So, I sort of felt excluded from the choir because I wasn’t actually next to anybody, like I would be on the floor, and they would be like, up on the stage and so I just like stick out like a sore thumb really.

Mic came up against frequent accessibility challenges, from visiting shops, going to restaurants with family or attending a work trip.

> Mic: …you know when things on in places I can’t get to. Or I just want to go to somewhere I can’t get in to… …Obviously, ah, I feel excluded then.

Travis spoke about coming up against numerous physical barriers and the subsequent impact on his confidence to go out.

> Travis: Falling down potholes or falling down drains without caps, tend to make you feel like you don't want to put yourself out there. You don't want to explore the world…

4.4.2. Excluding Attitudes; Inaccurate Expectations, Fear, Avoidance, Judgement

Participants also frequently identified attitudes of other people as having an impact in causing exclusion.

> Travis: …I found that society had a degree of interpretation that white cane equals no brain. And so gradually I found there was a loss of confidence in independence as well as a societal prejudice towards their interpretation of what was still active inside my body as in, my brain.

Louise spoke about others having taken advantage of her disability.

> Louise: …in the workplace, because I'm not like really quick, um, people will have advantage over you and they'll jump over you. Um, so yeah, the workplace is one of the worst places.

Travis, Beth, Carolyn and Jacqui discussed how some people demonstrate fear or unease in their presence, and may even avoid having interactions.

> Jacqui: …the mere fact that you're sitting in a wheelchair tends to bring out strange behaviour and comments and unease with people. People are uneasy with us. Um, so I find that very isolating…

Some participants have experienced misunderstandings and judgements about their disabilities. Holly, Travis, Andy and Georgie spoke about instances when others had over or under estimated what they were able to do. Whereas Carolyn had experienced accusations about her behaviour.

> Carolyn: I've been accused of being drunk for instance in public… in a public place.

Georgie spoke about her experiences attending a group activity, at which the members started to exclude her by questioning why she was coming.

> Georgie: …it just got to the point where they were, they were like questioning why I was actually coming. 'Cause I couldn't come for very long. I could only come for an hour, 'cause of fatigue.

Holly had experienced misunderstandings and judgements about her disability in previous employment which had caused exclusion. Holly understood this judgement came about due to the inability to categorise her disability.

> Holly: …part of it is trying to fit a person into a box and say well, they've got a physical disability, that means, you know, they, they you know, they're not very mobile, but then, they, you know, see me running around…

4.4.3. When ‘Inclusion’ Isn’t Inclusive

Sometimes participants identified times when they had been in situations that were intended to be inclusive; however, the reality was quite different. Beth for instance, spoke of her participation on a disability access committee. Although demonstrating a front of inclusivity, the actions of the facilitators could fall far short. Despite requests, the group failed to do a rollcall at the commencement of meetings; a simple action which would have assisted Beth, who is vision impaired.

> Beth: And I would sit there and feel, they don’t want me here.

Similarly, she discussed her experience being a consumer representative on disability services boards.

> Beth: …during the meeting [the consumers are consulted] …., they are accepted. But when it comes to the social side, such as having lunch, or making arrangements to go out to dinner afterwards, we’re never included.

In fact, Holly, Peter, Beth, Travis and Georgie all noted that events or programs for people with disabilities, although they could be inclusive in some respects, they commonly did not cater well for all people with disabilities. Jacqui also discussed an instance of a sporting association attempting to become inclusive. The effort fell short due to the relegation of the players with disabilities to the sport’s facilities separated by a great distance from the main events. Likewise, Holly attended a course which aimed to provide an inclusive opportunity for people with disabilities. Holly discussed however how the attempt acted as a kind of segregation because it was a course especially for people with disabilities.

> Holly: …they were doing it for… from the perspective of integration so. So they were looking to sort of, yeah, use that program, but, but integrate people with disability into that program, but still kinda' separate them.

4.4.4. Experiences of Exclusion

In summary, the above demonstrates how inaccessibility problems in the built environment can make participating in activities challenging or sometimes prevent participation altogether. For many participants the experience of being avoided, feared, judged or misunderstood also served to cause exclusion. Additionally, exclusion could also be experienced within spaces where inclusiveness had been promoted, but had fallen short of producing a genuine sense of inclusivity.

4.5. Summary of Results

The results of this research offer an insight into the lives of Australians with disabilities. The participants illustrated that while exclusion can be felt in day to day activities; they also had plentiful examples of feeling included and were able to identify factors that contributed to those scenarios. The participants demonstrated that to feel included, physical access is just one component; they also need to feel emotionally included. The factors that shaped those scenarios could include the attitudes and behaviours of other people, the qualities within a particular environment or activity, the supports that they had available and the actions they had undertaken for themselves to ensure their own comfort and inclusion. These results and their significance will be discussed further in the next chapter.

Chapter 5: Discussion

5.1. Overview

This study was formed on the premise that people with disabilities, while they frequently experience exclusion, stigmatisation and discrimination, they also experience times of true and genuine inclusion. The purpose of the study was to learn about this sense of inclusion and increase understandings of the factors that shape those situations in order to better plan for and deliver inclusive communities on a broader level. To guide the study, three research questions were devised to address the purpose and objectives of the study: How do people with disabilities define the experience of genuine inclusion? What factors contribute to shaping situations of genuine inclusion for people with disabilities? How can this knowledge be utilised to plan for, create and deliver genuinely inclusive environments, programs or communities for people with disabilities? The study's findings contribute new knowledge to answer these questions, while other results correspond strongly with other findings already available. This assists in developing current understandings as well as introducing new ideas. Some of these ideas may benefit from further critique and development in future research.

5.2. Closed Doors and Closed Minds

The experience of exclusion in the day to day lives of people with disabilities is often a pervasive reality. Many of the forms of exclusion the participants spoke about were a result of inaccessible infrastructure or problems accessing services like public transport and toilets. At times these were just inconvenient, as Jacqui discussed; having to go longer distances to get where she needed to go. At other times the barriers could stop people from being able to do what they wanted and needed to do, for example, being with family or attending work events. While these barriers were significant enough on their own, they also sometimes seemed to have been compounded by a disinclination on behalf of others to change the situation. For example, Georgie's choir repeatedly chose inaccessible venues for performances and social events. This circumstance was most aptly pointed out by Mic; "…some people just don't want to be bothered about making spec, any special accommodations." Other attitudes which served to cause exclusion included an apparent fear of disability which could result in unease or avoidance and many participants had experienced judgement or misunderstanding about their disabilities. The close minded attitudes and the metaphoric closed doors the participants had come up against caused significant impacts from a loss of confidence to impenetrable barriers to enjoying social connections and inclusion.

These are not new discoveries. They serve to only reconfirm existing findings, such as those of the SHUT OUT report (National People with Disability and Carer Council, 2009). The knowledge that these barriers continue to be notable and frequent experiences of Australians living with disabilities almost eight years later, demonstrates that much progress is still required to change this reality. The findings of the current study demonstrate that the social behaviours of stigmatisation as discussed by Goffman, (1963 B) continue to exist as a social reality as predicted by social constructionism theory (Burr, 2015). This illustrates the pressing need to consider how social constructions can be challenged and new norms created.

5.3. Not Quite Hitting the Mark

During a number of interviews when discussing problems of exclusion, it was concerning that stories arose of occasions where these participants had been present in a program, event or initiative where efforts had been made to make it inclusive to people with disabilities, however it had fallen painfully short of actual inclusivity. For these participants these experiences had resulted in a sense of exclusion rather than achieving the intended outcome. In the instances discussed by Holly and Jacqui, programs had been created especially for people with disabilities within a mainstream setting; however, they had been physically removed from the other programs causing a notable segregation. The experiences that Beth shared of being a consumer representative on committees, demonstrated that people with disabilities had been superficially included; but a genuine valuing or respect for their presence was lacking. Many participants noted that at events or programs for people with disabilities, while they were inclusive to a point, they commonly didn’t cater well for all people with disabilities.

These experiences related closely to those discussed by Hyder and Tissot, (2013) Milner and Kelly, (2009) Morina Di'ez (2010) and Curtin and Clarke, (2005) because in all scenarios an attempt had been made to make an activity or program inclusive, however the effort had produced only a different form of exclusion. The discovery that the participants of the current study had had similar experiences strengthens and validates the theory of Clifford Simplican et al. (2015) who assert the existence of narrow and broad forms of inclusion. These instances of striving for inclusion are examples of narrow approaches to inclusion because they have only considered and addressed some elements of an inclusive scenario and neglected or overlooked several other important factors of inclusivity (Clifford Simplican, et al. 2015; Clifford Simplican & Leader, 2015). Narrow forms of inclusion can result in only the physical presence of people with disabilities in community settings (Clement & Bigby, 2009; Milner & Kelly, 2009; Sherwin, 2006). This is an observation that Jacqui also recognised, when she referred to the common practice of people with disabilities only getting to enjoy a kind of “fringe dwelling”. As noted previously in this paper, narrow approaches to facilitating the inclusion of people with disabilities appear to do little to address negative social constructions of disability and hence is one reason for their limited effectiveness (Cushing, 2015; Salmon, 2013). These findings indicate the significant importance of policy implementers reflecting upon the definition of inclusion from which they design and deliver programs and projects in order to bring about an outcome of genuine inclusivity.

5.4. What is Genuine Inclusion?

In the search for a definition of inclusion which has strong potential to bring about a genuinely inclusive outcome when applied, this study compiled a preliminary concept of genuine inclusion, developed with contributions from a number of scholars. When talking to people with disabilities, it was sought to test this concept and verify, refine or refute it all together by gaining the opinions of the participants as to what they thought genuine inclusion was. The semi-structured interview schedule included this concept to prompt discussion if required. However, it was not used as all participants had their own, unprompted ideas about what genuine inclusion was. The original concept, compiled from the findings of Clifford Simplican, et al. (2015) Clifford Simplican & Leader, (2015), Cobigo, et al. (2012), Hall, (2009), cited in Clifford Simplican, et al. (2015), Mahar, et al. (2013) and Power, (2013) noted the importance of: having a sense of belonging in a community and environment, beyond just being physically present, being valued, respected and trusted, being recognised for more than a person with a disability, not having to fear being judged or rejected because of disability, participating meaningfully in socially or personally valued roles and having meaningful, reciprocal relationships with others. The subsequent findings of the current study did not vary greatly from these components of inclusion; and serve to only develop and refine the concept of genuine inclusion further.

One major point of difference becoming overt in the current results was the fundamental importance of having full and equal access in both activities that the participants wanted to participate in; and in those they had a right to access. This access needed to be free of physical and information barriers. Aligning in many respects to the original concept, the participants identified that in situations of genuine inclusion they felt a sense of belonging in a community or environment, far beyond just being physically present. They were accepted, respected, recognised as equal, given opportunities, their contributions valued and they were adequately supported. It was important that the participants could partake in socially or personally valuable roles where they had a purpose, where they could demonstrate their skills, and where they made a difference. Later in the interviews when discussing the inclusive behaviours of those in their lives many participants noted that being recognised for factors beyond just their disability helped them feel included. Some participants noted the importance of not having to worry about being feared or judged because of their disability. The value of meaningful relationships built off reciprocity and or empathy also became apparent as essential components of situations of genuine inclusion. The original conceptualisation developed in section 2.4. of this dissertation is provided here in its revised form and consolidated into seven key points.

Figure 5.1. Meaning of Genuine Inclusion

Genuine Inclusion

- Equal and full access to activities of choice or right
- Sense of belonging to a community and environment, beyond just being physically present
- Being accepted, valued, respected, trusted, given opportunity and adequately supported
- Meaningful participation in personally or socially valued roles and activities
- Participation as a unique individual, recognised for more than disability
- A lack of concern about being feared, rejected or judged due to disability
- Meaningful, empathetic, reciprocal relationships and interactions with others

(Clifford Simplican, et al. 2015; Clifford Simplican & Leader, 2015; Cobigo, et al. 2012; Hall, 2009, cited in Clifford Simplican, et al. 2015; Mahar, et al. 2013 & Power, 2013).

5.5. Factors Contributing to Genuine Inclusion and Directions for Future Practice

This study gained much information about those factors that help contribute to and shape situations of genuine inclusion. As noted previously, the experience of genuine inclusion is not a static state, it occurs in specific scenarios and is highly dependent on the factors within that social situation (Cunnah, 2015; Morgan, et al. 2007). The experiences of the participants confirmed this observation. For some they experienced genuine inclusion in many scenarios; whereas others experienced it only occasionally. Jacqui noted that situations of genuine inclusion are very confined. This was also inferred by Beth who discussed feeling included in her TAFE class itself; but not in the broader student community and by Travis, who was included in church services, but not in the social gatherings afterwards. Confirmation of this finding indicated that several factors must rely on each other for inclusion to be a reality. The four main factors contributing to genuine inclusion, inclusive people, inclusive places, supports for inclusion and personal strategies and advocacy were almost equally important to all participants. This indicates how these factors rely on one another to influence genuine inclusion. This section will discuss these factors and the ways in which they interact with one another. Additionally, this section will begin to consider some directions for future practices in planning for creating and delivering inclusive environments, programs and communities for people with disabilities.

5.5.1. Inclusive People

The people present in the lives of the participants played a central role in dictating experiences of inclusion. This finding was not unexpected as existing literature strongly demonstrates that reciprocal relationships and interactions are essential components of enjoying genuine inclusion (Milner & Kelly, 2009; Salmon, 2013; Van Asselt, et al. 2015; Wedgwood, et al. 2013). The current study provides some further insight and clarification into the factors behind those relationships and interactions that serve to foster inclusivity. When participants identified who they felt most included with, they often referenced those who they had most familiarity, such as; friends, family, colleagues and sometimes support staff. The fundamental actions of these people in being inclusive were straight forward; they recognised and valued their individual qualities and skills. They also spoke to and treated them normally. These people were often also recognised as having a degree of empathy towards them and their disability. Such were their significance, the value of relationships with other people living with disabilities justifies a particular mention. As also emphasised in Cole, et al. (2011) Milner and Kelly, (2009) Salmon, (2013) Taub, et al. (2009) the sense of commonality and empathy within these relationships played a valuable role in dictating feelings of inclusion. Other significant people were also identified as being inclusive, such as; the president at Jacqui's sports club, Louise's physiologist, the pastor at Travis's church and the staff at the airport where Beth frequented. In common among all these people was a clear demonstration of a genuine valuing of the participants.

5.5.2. Interactions Between Inclusive People and Inclusive Places

Presenting a fundamental opportunity to enjoy an inclusive situation was the necessity of accessible environments and an absence of exclusionary physical or informational barriers, as previously recognised by Abbott and McConkey (2006) and Riddick, (2001). Beyond these factors, the relationship between an inclusive place and the people within it became strongly apparent. Both within their more familiar networks and when in the company of other acquaintances, several actions and behaviours were noted as being important factors for fostering inclusion within particular places. Often the participants mentioned instances of the people around them showing an understanding for their needs and acting accordingly. They planned activities with the needs of the participants in mind, providing any accommodations that were necessary, demonstrated a willingness to cooperate with the use of assistive devices for communication and often physically changed environments or altered and adapted activities to make them accessible.

Within these actions, there were often demonstrations of flexible, innovative and creative thinking. For example, the friend of Georgie's who found a musical instrument that Georgie could play when unable to leave her bed and the physiologist who devised alternative fitness exercises for Louise but which still had the same physical benefit. Many of the participants mentioned that it was important for them to be in places which didn’t trigger particular impacts of their disabilities and where they could consequently be most comfortable. The participants often noted that their friends, family or employer recognised these requirements and would willingly accommodate with thoughtful solutions to enable their participation. For example; to enable Georgie to be comfortable and to see her friends, her husband helped to host birthday parties in their bedroom for all their friends to attend; and Holly’s employer allowed her to work from home to enable her to best manage her chronic health condition. Some participants of the current study stated that inclusion was not purely about giving the same treatment to people with disabilities as for people without. Jacqui aptly illustrated this point: “…inclusion isn’t taking square pegs and putting them in round holes.” The above innovative solutions demonstrate application of a concept discussed by both McPhail and Freeman (2005) and Grenier (2007). They emphasised that it is essential not to just fit people with disabilities into activities and practices just because they are the normative way of doing things; but instead consideration should be given to how a traditional social construct could be changed to suit more people.

In many situations, the people around the participants demonstrated a kind of leadership in demonstrating inclusivity which appeared to go some way in shaping the overall inclusivity of the environment or activity. For example, the president of Jacqui’s sports club personally addressed the prejudicial behaviour of a new club member and conveyed that such behaviour was unacceptable in that space. This was one environment where Jacqui could identify she felt completely included. At her regular group fitness classes, Louise’s physiologist demonstrated a rare ability to adapt her teaching methods and cater for Louise’s needs within the group classes. This seemed to help foster an inclusive environment where Louise felt accepted and respected by everyone in the group. Beth talked about many scenarios where inclusive staff had been welcoming and accommodated her needs without fuss. With these behaviours, Beth was then able to enjoy feeling included. The power of these actions should not go under-appreciated in shaping inclusive environments and activities. Social constructionism theory demonstrates how social realities are shaped by the language and the actions of people in those situations (Burr, 2015). Just as exclusionary behaviours are reinforced; inclusive behaviours and actions towards disability can also become reinforced (Burr, 2015; Fitch, 2002). Here are seen examples of situations where language and behaviours have helped construct an inclusive situation (Fitch, 2002). Sherwin, (2006) offers some insight into how some individuals become equipped to act as leaders for inclusion. Sherwin (2006) suggests that leaders for inclusion need to have some empathy for the meaning of inclusion. Within the experiences of the participants, it is certainly easy to see that those who have acted in a leadership role for producing inclusivity have demonstrated an understanding of what it means to be included.

Examples of these transformations to social constructs are notable elsewhere. The leadership behaviour discussed by Frazeur Cross, et al (2004) and Kalargyrou (2014) demonstrated that leaders can play a powerful role in shifting social constructions from excluding by default, to seeing the value of inclusion and inspiring others to see the same. As a result of this leadership, they managed to foster inclusive workplaces and education settings (Frazeur Cross, et al. 2004; Kalargyrou, 2014). Similarly, when considering the case studies examined by Cushing (2015) and Jeanes and Magee, (2012) it can be seen how dominant social constructs were recognised and then challenged by creating an inclusive place where such traditional constructions could not exist. Those who therefore demonstrate a valuing of people with disabilities and the qualities and skills they bring to an activity demonstrate a form of leadership that can transform social constructions and create different constructions of inclusion.

In order to foster the inclusiveness of community groups and organisations, it may be beneficial to specifically work to develop the above discussed interpersonal and leadership behaviours of individuals through existing programs such as disability awareness or inclusion training projects. Within organisations seeking to improve their customer service or to make their workplace more inclusive to employees with disabilities, it may be a beneficial practice to consider whether applicants to open vacancies possess some of these qualities and values in order to shape an inclusive culture. As conveyed by Soresi, Nota and Wehmeyer (2011) multiple stakeholders need to be involved to best make inclusion a reality.

Environments where people with disabilities could spend time together also proved to form inclusive situations. For example, Georgie felt very included in a virtual online space where people with similar disabilities could interact. Their common experiences and empathy for one another created a safe, empathetic and accessible place, just as in the historical account of Martha’s Vineyard (Grace, 1980) and within the more recent account discussed by Wedgwood, et al; (2013). In these social scenarios disability is socially constructed as a normal phenomenon, and hence the situation is naturally inclusive (Goffman, 1963 A; Goffman, 1963 B). One danger of many common approaches to improving the inclusion of people with disabilities is the perception that people with disabilities should be striving for friendships with people without disabilities. This infers an undervaluing of the very important and already inclusive bonds that people with disabilities often form within their own social gatherings (Cushing, 2015).

5.5.3. The Right Supports

Arising as important complementary factors to inclusive environments and inclusive people were the right kinds of supports. Many participants identified important qualities and behaviours in their support staff that enabled them to be included. All such participants had individual support arrangements, which according to McConkey and Collins (2010) is more likely to assist a person to enjoy inclusion compared to other support arrangements. Abbott and McConkey

(2006) found that service provision could sometimes inhibit opportunities for inclusion for people with intellectual disability due to a lack of availability and by setting down rules which prevented the clients from having choice about the things they did. These were problems that the participants of the current study seemed to have recognised themselves and had therefore developed specific requirements of their support which helped them avoid such problems. For example, requiring support workers to work from a person-centred approach, be reliable, have common sense, initiative, flexibility and the ability to listen helped ensure that they would be able to support them in a variety of situations and maximise their opportunities to be included. Such interpersonal skills are also important for understanding where boundaries within support work need to be established. In studies by Kamenopoulou (2012) and Meyer, (2001) it was noted that support staff in schools could impede the opportunity for inclusion and friendship development by staying with the children with disabilities even when not requiring support. Some participants in the current study had recognised the impact of such behaviours in their own lives and required their support staff to maintain distance where they were not required at the time. Worryingly, studies by Clement and Bigby (2009) and McConkey and Collins (2010) found that support staff did not always view facilitating inclusion as a high priority within their work or else as irrelevant to their clients. The current study emphasises the significance and importance of the right kind of support in enabling inclusion. The appropriate interpersonal qualities for promoting inclusion could be considered in the recruitment and training of disability services support staff and other professionals and practitioners. As well as developing these behaviours and skills, it also seems important that support staff remain reflexive about their role in shaping and influencing social situations and that they are not unconsciously contributing to exclusion (Burr, 2015).

Assistive technology can play a powerful role in enabling people with disabilities to participate in and be included in their communities. The role of these supports was not often considered in the consulted literature; however, the participants of the current study frequently noted the significant importance; from having the right wheelchair to get around independently, having access to specialist equipment that could enable them to participate in hobbies along-side others and having the importance of equipment such as hearing augmentation systems and alternative communication devices recognised and their use willingly accommodated. The importance of assistive technologies which appeared like everyday objects, or else were disguised within mainstream technologies also became notable as important features of assistive technology for many participants. It may be argued that assistive technology plays a role in enabling people with disabilities to fit into socially constructed norms and maintain a state of being included because these devices help them to interact and get around in ways which are socially permissible and in line with the conduct of others (Goffman, 1963 A). Therefore, this is an important point to consider in the assignment of assistive technologies because particular features of equipment may have importance in enabling people with disabilities to conduct themselves within the social rules of involvement for that situation (Burr, 2015; Goffman, 1963 A).

5.5.4. Everyday Activism for Inclusion

A factor which is under-represented in the contemporary literature considering inclusion is the significant role and responsibility people with disabilities take themselves for ensuring their inclusion. The participants of this research clearly recognised the possibility for positive change and the potential impact of their own actions. This is not surprising; after all, people with disabilities have always been at the forefront of disability rights movements and provoking change (Cooper, 1999; McCarthy, 2003; Morris, 1991). These movements have created great social change, acting as examples of successful shifts of social constructions which served to exclude or discriminate against people with disabilities. The present impact in contributing towards genuine inclusion should therefore not be underestimated. The participants of the current research all identified ways that they contributed to their own inclusion and that of others. Many participated on disability access committees or disability services boards. Others were not afraid to tackle discrimination head-on by lodging disability discrimination complaints. Participation in projects, and awareness campaigns were also often noted. Finally, individuals engaged in everyday education of those around them; informing about their disability and correcting exclusionary behaviours, for example; Kevin would wave at a person talking to his support worker instead of him and initiate a more appropriate interaction. These findings demonstrate that people with disabilities take a leading role in advocating for inclusion. They are actively involved in advocating for change in their everyday lives. Given these findings, it is crucial that the evidence for the effectiveness of consumer-led action is recognised within the current efforts for inclusion through continued support to consumer led initiatives, peak disability groups and Disabled Persons Organisations. It also seems reasonable that projects which strive to build the skills of people with disabilities to self-advocate could strengthen the abilities of individuals to become included in everyday activities.

5.6. Limitations and Areas for Future Research

As a small study completed in a short timeframe, it was only possible to recruit a small number of research participants. As a consequence of this limited sample, this research entailed several limitations. Of greatest concern, the study excluded participants who required a guardian to consent to the research due to the short timeframe and ethical permissions granted for this study. The study did not exclude those with intellectual, psychosocial or other cognitive disabilities who could independently give informed consent, however the recruitment methods fell short of capturing anyone who identified with these particular disabilities. In future studies with greater timeframes, different recruitment methods will be used that better engage people who experience these disabilities. These shortcomings are problematic because it means this study is not fully representative and it is likely it has overlooked important factors. The significance of not capturing the views of some people is illustrated in the article by Johnson, Douglas, Bigby & Iacono, (2009) as they demonstrate how the goal of inclusion can be far more complex for people with severe intellectual and communication disabilities to achieve. A further shortcoming of this research relates to the use of a sole coder completing the analysis of the findings. With greater timeframes, the study would have benefited from the use of a second coder to better triangulate findings.

This study does not suggest it has all the answers to create genuinely inclusive situations, it merely provides a small contribution to the expansion of knowledge. It also helped indicate areas where future research would be valuable to advancing the genuine inclusion of people with disabilities. For example, although this study makes an exploration into the specific factors of genuine inclusion and begins to take a look into ideas for using this knowledge to plan for inclusive spaces; strategies which enable these factors will need to be applied and evaluated to understand if they are indeed valid and can be replicated on a broader scale. While this study had the ambition of identifying ways of using the knowledge gained by understanding the factors of genuine inclusion, a future study could use different methods to bring about greater insights into strategies and practices for developing genuine inclusion in communities and organisations. While several attitudes, behaviours and actions of inclusive people were identified and their application in producing inclusive situations explored in this study; it is not always clear why these people demonstrate such qualities and how they have come to value their execution. It would therefore be beneficial for future studies to explore this.

More knowledge here would assist in being able to effectively train and educate for inclusion.

Chapter 6: Conclusion

Presently, Australia has a great opportunity to make momentous social change. All levels of government have commitments under current policy to make social and economic life more inclusive to people living with disabilities. Individual government departments, disability service providers, practitioners and other community stakeholders must now contribute to making that change a reality. The underlying ambition of this research was to play a role in helping ensure that this opportunity is not squandered and that real, positive outcomes are achieved to shape a better society for people with disabilities. The purpose and objectives of the study were to increase understandings of those factors that shape situations of genuine inclusion for people with disabilities and then to learn about what could be done to plan for, create and deliver genuinely inclusive environments, communities and programs for people with disabilities on a broader level. It is hoped with these findings, some contribution, however small can be made to challenge and overcome the stigmatisation and exclusion that people with disabilities continue to experience in their day to day lives.

A set of specific research questions were used to achieve these objectives. The study sought to understand how people with disabilities define the experience of genuine inclusion. Secondly, the most important question asked what factors contribute to situations where people with disabilities experience genuine inclusion? These questions were addressed by talking to people with disabilities about those times in their lives where they already experienced a sense of true inclusion. By learning about the circumstances, environments, attitudes and behaviours that shaped these situations; the study was then able to make some preliminary investigations into answering the third question: How can this knowledge be used to plan for, create and deliver inclusive environments, communities and programs for people with disabilities?

In seeking to learn how more genuine experiences of inclusion can be created, this study employed a preliminary definition of genuine inclusion, based upon a broad definition of inclusion, compiled from the findings of Clifford Simplican, et al. (2015), Clifford Simplican and Leader (2015), Cobigo, et al. (2012), Hall, 2009, cited in Clifford Simplican (2015) Mahar, et al. (2013) and Power (2013) and which is in direct contrast with a narrow definition. The primary data produced from this study refined the definition of genuine inclusion. To be genuinely included, it is important to feel a sense of belonging, to be able to fully participate in activities of right, and of choice. It is important to have a purpose in socially or personally valued roles. Within these situations it is essential to not just be physically included; but truly accepted, valued, respected and appreciated for one’s skills and qualities apart from one’s identity as a person with disability. Not being concerned about judgement or feared because of disability is also an important element. Finally, to have meaningful interactions and relationships with others is a crucial feature of genuine inclusion. With this information about what constituted genuine inclusion, it was then possible to learn about factors that led to those situations and start to formulate preliminary ideas for practice that can be applied to improve inclusion on a day to day basis.

The experience of genuine inclusion depends on a combination of factors. It appears this is why the experience is fragmented and can change with even a small shift in circumstances. Participants identified places they felt most included and often within those places, the actions and behaviours of other people became notable as helping to truly shape that scenario into an inclusive situation. Inclusive people came from their close networks and from broader community connections. Sometimes these people were other people with disabilities, underscoring the importance of not devaluing these relationships (Cushing, 2015). All these people demonstrated qualities in common, including; a genuine valuing of people with disabilities, empathy, responding to needs through the design or adaptation of activities and environments, a willingness to accommodate assistive technology use and often they demonstrated creativity and innovative thinking. It is therefore indicated that developing such behaviours and ways of thinking among communities and within organisations would be beneficial to foster inclusive practice.

Beyond the necessity of accessible infrastructure and information, many participants identified other factors that helped make environments inclusive. They valued the actions of others who willingly accommodated their needs, for example, employers implementing flexible work arrangements. They also valued having different choices for places to go in the community. For example, some participants chose quieter and less busy destinations. These findings led to the understanding that a one size fits all approach to inclusion cannot work. Those seeking to make their services and activities inclusive need to allow for flexibility and also to be open to thinking outside the square of what is normal, to what might be unusual; but which will create a better experience for more people.

A significant finding of this research was the importance of leadership for inspiring inclusion. This was demonstrated through the actions of people in community contexts, who by demonstrating qualities of inclusivity, helped shape the inclusivity of entire situations. While the examples of such leadership provided in this study were often within small contexts, findings in the literature have demonstrated the efficacy of leadership for inclusion in the management of much larger contexts, such as in educational institutions, workplaces, playgrounds and recreation facilities (Cushing, 2015; Frazeur Cross, et al. 2004; Jeanes & Magee, 2012; Kalargyrou, 2014). In demonstrating this leadership, the instigators have effectively reshaped those traditional social constructions that exclude people with disabilities and created new constructions, redefined by inclusivity (Burr, 2015). These findings suggest that in the development of inclusive programs, environments and communities, it would be beneficial to assign leaders to projects who have an understanding for genuine inclusion and who can demonstrate the behaviours and attitudes of inclusivity and inspire others to do the same.

The participants illustrated the importance of having the right supports to achieve inclusion. For some this meant having support staff who demonstrated a set of appropriate interpersonal skills for enabling inclusion. It was also notable that it was important for them to be mindful of their impact in influencing inclusive, or exclusionary situations. For many participants too, the impact of their assistive technology was very powerful in dictating situations of inclusion. Assistive technology should be prescribed with the recognition of its particular importance in allowing inclusive situations to unfold. This may be because it will help equal and full participation in activities with others; but if they wish, may also serve to help people with disabilities fit into social situations without feeling the unease of having disrupted a social expectation or norm (Goffman, 1963 A). These findings underscore the need for flexibility and choice to be granted throughout the process of prescribing, funding or allocating support services or equipment, as the impacts of the right supports can be so crucial to achieving an appropriate state of inclusion.

The participants of this study all demonstrated a personal dedication to helping improve inclusion for themselves and for others through the provision of day to day education and self-advocacy or through more formal participation on committees or projects. These findings demonstrate that people with disabilities are not passive recipients of policy, but are actively taking a role themselves in bringing about this change. Continued investment into the self-advocacy skills of individuals with disabilities may be of benefit to enabling people with disabilities to strengthen their own inclusion.

This study confirmed that people with disabilities still face day to day experiences of stigmatisation and exclusion. Additionally, some participants also identified that they experienced exclusion within programs or projects which had been designed with the goal of inclusivity. In understanding why this had occurred, it was concluded that these programs are based upon a narrowly focused definition of inclusion (Clifford Simplican, et al. 2015) and consequently they can overlook important factors of inclusion. If the problems of narrow approaches to inclusion are not recognised and addressed; such projects are likely to continue to be delivered, potentially producing a type of exclusion little better than outward exclusion. This problem suggests that if inclusive situations are to be created, an approach needs to be taken that actively takes into consideration the factors that foster genuine inclusivity.

In acknowledgement of the confusion surrounding the meaning of inclusion; this study sought to verify from the perspectives of people with disabilities what inclusion meant to them. A concept of what was considered to be genuine inclusion was presented. The study then went on to discover what factors contribute to such experiences of inclusion in order to better enable the planning for and delivery of inclusive communities. Ideas for strategies and actions were gathered from these findings that policy implementers could use to contribute to advancing the inclusion of people with disabilities. From fostering empathy for genuine inclusion, developing inclusive attitudes and behaviours, developing leaders for inclusion, practicing innovation, to ensuring people with disabilities have the best possible supports to enable inclusion and recognising and supporting the activism of people with disabilities themselves, there is much that can be done to contribute to bringing about genuine inclusion of people with disabilities in Australian society. In this current movement of policy reform and social change, there is tremendous opportunity to make a true difference.

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Appendices

Appendix A Interview Schedule

Semi-Structured Interview Schedule
Factors That Contribute to Situations of Genuine Inclusion for People with Disabilities

Although these questions form the framework of the interview, additional questions may be asked depending on the context and direction of conversation

1. If you are happy to share, how do you describe your disability?
2. What age group do you belong to? 20s, 30s etc?
3. Do you ever feel excluded from activities because you have a disability?
4. What things make you feel excluded?
5. What do you feel is the true meaning of inclusion as a person who lives with a disability?
6. How would you describe the way you feel when you are genuinely included?

If these questions yield limited response, the below concept of genuine inclusion will be shown to the participant

> The experience of genuine inclusion is categorised by feelings of true belonging to a community and an environment, far beyond just being physically present. An individual feels valued and respected. They feel they are truly allowed to participate as the unique individual they are and they do not need to be afraid or wary of rejection or judgement because of their disability. They are in these situations by choice. It is possible to form meaningful, reciprocal relationships with others who have shared experiences, personal qualities or beliefs. And in such spaces it is possible to participate meaningfully and completely (Cobigo, et al. 2012; Mahar, et al. 2013).
>
> The experience of genuine inclusion is categorised by:
> - Sense of belonging to a community and environment
> - Feelings of being valued, respected and trusted
> - Participation as a unique individual, recognised for more than disability
> - Participation in valued roles of one’s choosing
> - Meaningful participation
> - Meaningful, reciprocal relationships with others

Questions after reading concept:

1. Do you feel this concept of genuine inclusion is accurate?
2. What would you change about this concept to reflect your experiences of genuine inclusion?

Return to schedule:

7. How do you feel about yourself as a person with a disability when you feel included?
8. What kind of impact does your disability have in a scenario when you feel included?
9. With what people do you feel included? Ie, friends, family, other people with disabilities, strangers, work colleagues?
10. Why do you think those people are particularly good at enabling you to feel included?
11. What do the people around you do that help you feel included?
12. What things do people say to you, or not say to you that help you feel included?
13. What assistive technology or mobility aids are you using, or not using when you feel included?
14. What supports or assistance are you receiving or not receiving when you feel included?
15. What qualities or behaviours in a disability support worker/personal assistant help you feel included?
16. What actions do you take in order to help yourself feel included?
17. Do you feel more or less included if your disability is not obvious to those you are with? For example, you are sitting in a chair instead of your wheelchair, or you have your mobility cane folded up out of sight.
18. In what environments do you feel most included?
19. What do you think it is about those environments which help you feel included?
20. In what activities do you feel included? For example, at work, at TAFE, going out to dinner?
21. What do you think it is about those activities that make you feel included?
22. Say at a community event, like an outdoor movie night for example, what factors help you to feel included?
23. At events and programs planned for people with disabilities do you feel included?
24. What makes you feel included or not included in those programs?
25. Overall, what factors do you consider to be the most powerful in enabling you to feel the most included in your community?
26. Is there anything else you would like to add or comment on?

Appendix B Participant Information Sheet

INFORMATION SHEET FOR PARTICIPANTS

Factors that Contribute to Situations of Genuine Inclusion for People with Disabilities

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Description of the study:
This study is part of a research project considering factors that contribute to situations of genuine inclusion for people with disabilities.

This project will identify and examine factors and circumstances that help to shape situations where people with disabilities feel genuinely included. It will do this by gaining the perspectives of people with disabilities who will share their experiences on what environments, attitudes, behaviours, supports or personal strategies help to shape truly inclusive settings. This project is supported by Flinders University Disability and Community Inclusion unit.

Purpose of the study:

- To increase understandings of the factors that shape genuinely inclusive settings for people with disabilities.
- To increase knowledge and capacity to plan for, create and foster truly inclusive environments, communities and programs.
- To assist in developing greater knowledge and power to overcome stigmatisation and exclusion of people with disabilities.

What will I be asked to do?

You are invited to attend a one-on-one interview either in person, or over the phone to talk about what you think helps to create a genuinely inclusive setting. You will be asked a series of questions about what environments, attitudes, behaviours, supports or personal strategies help you to feel truly included. The interview will take about one and a half hours (1 ½ hours) and will take place at a time and in a location you find convenient. The interview will be recorded using a digital voice recorder to enable accurate records of your interview to be kept. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file. The study will then use sections and comments from your transcribed interview in the write-up of the research report. Your participation in this research is entirely voluntary and you can withdraw at any time during the research. If you choose to do so your interview data will be destroyed immediately.

What benefit will I gain from being involved in this study?

You will not receive any immediate benefits from participating in this study. However, the sharing of your experiences will help to improve understandings of inclusion, what it means for people with disabilities and how it can be achieved. It is intended that the findings of this research will be published in academic journals or other publications and discussed at conferences. Therefore, it is hoped that it will raise awareness of what factors contribute to genuine inclusion for people with disabilities among people who plan for, or help to create inclusive communities and programs.

Will I be identifiable by being involved in this study?

You will only be identifiable to the primary researcher of this study. Your real name will not be used in the transcription of your interview, or in the research report. You will be given a pseudonym (a fake name). All efforts will also be made to ensure that any additional identifiable information is not used in the research report. As such, you will remain anonymous to others reading the study. The identifiable information will be kept confidential and the researcher will not talk about the content of your interview with others in a way that would identify you. However, if you disclose information about involvement in or knowledge of a serious crime, the researcher may need to report this crime, therefore breaking the confidentiality agreement. Once your interview has been typed-up, it will be saved on a hard drive and stored in a locked cabinet. The voice file of your interview will be retained in the same way and destroyed once the research project is finalised. Only the primary researcher will have access to the recording of your interview and only the researcher’s supervisors will see the complete transcription of your interview with your pseudonym. In the final research report which will be publicly available, your comments from your interview will be associated with your pseudonym.

Am I eligible to participate in this study?

You are eligible to participate if you are:

- A person who identifies as having a disability,
- are 18 years of age or older,
- are able to give informed consent,

- live in Australia
- and are either available for an interview via phone or face to face.

Disability encompasses physical, sensory, intellectual, neurological, cognitive or learning disabilities, acquired brain injuries, autism spectrum disorder or mental health conditions.

If you know someone eligible who may be interested in participating in this study, you may pass on a copy of this information sheet to them. Please do not pass on an individual's contact details onto the researcher; they must make contact if they wish to participate.

Are there any risks or discomforts if I am involved?

The researcher anticipates few risks from your involvement in this study. It is possible that talking about inclusion and exclusion may raise some discomfort. If at any time you feel uncomfortable or distressed you can withdraw from the study immediately. If you have any concerns regarding anticipated or actual risks or discomfort, please raise them with the researcher or the researcher's supervisors. Additionally, if you feel distressed after the interview you may wish to contact any of these free support services:

Lifeline: 13 11 14 **|** Beyondblue: 1300 22 4636 **|** Headspace: 1800 650 890

How do I agree to participate?

Participation in this study is completely voluntary. A consent form accompanies this information sheet. If you wish to participate, please carefully read and sign the consent form. Signing of the consent form also confirms that you have read and understood all the conditions in this information sheet.

You can email the sign consent form to the researcher at: butl0164@flinders.edu.au or give it to the researcher if you are attending a face to face interview.

If you require any additional assistance to understand the consent form, or the information in this information sheet, please contact the researcher or the researcher's supervisors. You are also welcome to have a support person attend a meeting with you and the researcher to discuss the research and the conditions of participation; likewise, you are welcome to discuss participating in this research with friends or family.

Even if you have signed the consent form, you can withdraw yourself from the study at any time, up until finalisation of the research project. During the interview you may answer 'no comment' or refuse to answer any questions if you do not wish to answer. You are free to withdraw from the study at any time, including during the interview. If you withdraw, you will not suffer any consequences or negative effects as a result.

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved. If you have any further

questions about the research, please contact the researcher on the contact details above.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7095). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix C Participant Consent Form

CONSENT FORM FOR PARTICIPATION IN RESEARCH

by interview

Factors that Contribute to Situations of Genuine Inclusion for People with Disabilities

I …...

being over the age of 18 years hereby consent to participate as requested in the letter of introduction and information sheet for the research project on factors that contribute to situations of genuine inclusion for people with disabilities.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
    - I may not directly benefit from taking part in this research.
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
    - I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant’s signature…………………………………Date…………………...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher’s name…………………………….……………………................

Researcher’s signature………………………………..Date…………………….

NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Item 7 as appropriate.

7. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

Participant’s signature…………………………………Date…………………...