



“I hate group homes. They suck.”

Why people with disabilities deploy YouTube to disclose experiences of group home violence, abuse and neglect.

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## **DEDICATION**

I dedicate this research to the exceptional men that I have come alongside and supported while working in community services. Thank you for welcoming me into your homes and inviting me to journey with you. Thank you for sharing your stories with me and trusting me. Thank you for your kindness and friendship. On behalf of the system, I apologise for any mistreatment and oppression that you have experienced. My prayer is that you know your rights and that your voice is heard. That justice be executed in your life.

## ABSTRACT

This doctoral research analyzes and respects the voices of men and women with disabilities, their families and carers, with the aim of theorizing and understanding disability group home violence, abuse and neglect. This research sought to capture people with disabilities, their families and carers in their own way, expressing their views on what they felt were the most important aspects of their group home experience.

Social workers are often activating research into sensitive social areas of interest and are bound by the ethical code to do no harm. Social research into sensitive issues and the principle of doing no harm can be in conflict for social workers. This thesis argues that social workers should consider research methods that seek to understand, to respect and to do no harm. This thesis summons unobtrusive research methods and uses data that already exist. Therefore, re-traumatization is not enacted. The material available on digitized platforms can offer ethical options and research care – and care in research - when investigating sensitive issues. This unobtrusive research activates social media, an information-rich data set, that is unique in nature and disengaged from the limitations of the Hawthorne effect, where participants changing their behaviour because they are being observed. Unobtrusive research methods were deployed to thematically analyze over one hundred disintermediated videos uploaded on YouTube by members of the disability community, expressing their views about community housing. Using English search terms, the data set deployed in this doctoral research captured and investigated experiences from men and women with disabilities, their families and carers. Data saturation was achieved once a total of one hundred and five videos were summoned from a total of thirty-three YouTube channels. These disintermediated videos were transcribed and then thematically analyzed. The linguistic limitation of this study was also reinforced by the requirement for access to the online environment generally, and YouTube specifically. Noting these variables, this data set transcended national boundaries, but excluded the experiences of people whom did not have internet accessibility.



This research demonstrated how the disability community has used YouTube to challenge silences, build communities and empower themselves. The advantages of deploying YouTube as a public media broadcasting platform were considered. This research provided evidence from people with disabilities, their families and carers, to support the argument that internet accessibility is an essential safeguarding measure for vulnerable, hidden, disempowered and disenfranchised communities. This thesis demonstrates how YouTube has been leveraged by the disability community to expose the gross violations of human rights and injustices they have suffered in disability group homes. The data set revealed that this vulnerable community was not safe in their own homes and that their family members felt powerless to help. The narratives of men and women, their families and carers, were used in the configuration of violence, abuse and neglect against people with disabilities living in group homes. This research highlighted the ability of YouTube as a social media platform to understand hard-to-reach communities.

Search term strategies were used to summon over one hundred disintermediated videos about group home experiences by men and women with disabilities, their families and carers. The men and women whose disintermediated YouTube videos were deployed in this research were unified in their experiences that disability group homes were environments that perpetrated and perpetuated violence, abuse and neglect towards this vulnerable community. Men and women with disabilities, their families and carers, were frustrated by daily experiences of violence, abuse and neglect and deployed YouTube to expose these injustices. Thematic analysis was used to identify four main overarching themes that emerged from the data set; the disadvantage of the neoliberal group home, disheartening re-institutionalization of the disability sector, harmful interpersonal relationships and breaking the silence of disability. An integrated literature review was used to contextualize the findings within existing disability theory. The narrative of the disability community was used to affirm and extend existing disability theory.

My original contribution to knowledge is the development of a trauma-sensitive social media research method that included and affirmed the already existing narrative of the disability community into the theorization of disability group home violence, abuse and neglect. This thesis demonstrated that YouTube as a data set

provided quality information that was rich and robust. Thoughts, feelings and perceptions of people with disabilities, their families and carers, were freely conveyed through the video format in a way that was appropriate and 'owned' by the individuals themselves. This quality of information would be unlikely to be sourced from obtrusive research methods such as interviews or surveys. This was a strength of the unobtrusive research method used in the field of disability research. The researcher did not create, shape or frame data. Instead, autonomy and rights were confirmed for those with disabilities. Their voice was respected, as it was their ability to express their views on their own terms. Further, the video format enabled data to be captured that flowed freely and was not restricted by a keyboard or literacy levels. People with disabilities spoke at their own pace, in their own time. The disability community itself was in control of what they disclosed about their group home living experiences. This rich information was used to affirm and extend existing disability theory about harmful group home experiences.

## DECLARATION

Thesis title: "I hate group homes! They suck." Why people with disabilities used YouTube to disclose group home violence, abuse and neglect.

Candidate's Name: Tania Anna Hall

I certify that this thesis:

1. Does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and
2. To the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

An editor has not been used in this thesis.

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Tania Anna Hall

## **LIST OF PUBLICATIONS SUBMITTED, ACCEPTED AND PUBLISHED DURING CANDIDATURE**

Hall, T., & Brabazon, T. (2020). Freedom from choice? The rollout of person-centred disability funding and the National Disability Insurance Scheme. *INKLUSI Journal of Disability Studies*, 7(1), 21-46.

# **INTRODUCTION: HOW TECHNOLOGY CAN PUSH DISABILITY STUDIES FORWARD**

Nothing about us without us! (Charlton, 2000).

Inspired by this empowering slogan, this thesis draws upon the experiences of men and women with disabilities, their families and carers, to explore the issue of group home violence, abuse and neglect. Activists within the disability rights movement challenged the oppression rooted in degradation, dependency and powerlessness experienced by people with physical, sensory, cognitive and developmental disabilities. Charlton's (2000) slogan captured the expression that people with disabilities knew what was best for them. The slogan framed a moment of consciousness for citizens with disabilities, summoning empowerment and self-reliance. The disability rights movement sparked moments of consciousness, recognizing that people with disabilities were excluded from policy and decision-making that shaped their lives, calling for barrier removal and social inclusion. This slogan is a reminder that no group of people should be researched without the full and direct participation of that group itself. Thirty years later, disability studies continues to research issues about disability excluding the voices of people with disabilities. It is imperative that researchers continue to centre the experiences of people with disabilities so that specific strategies can be implemented to support the disability community (James, Bustamante, Lamons, Scanlon, & Chini, 2020). Excuses are often provided, rationalizing the exclusion of men and women with disabilities from research. People with disabilities may have difficulty communicating within ableist structures, and this may be cited as an acceptable reason for their exclusion in disability research. Regardless of the excuse, disability studies scholars must address a diversity of communication needs, strategies and interfaces.

My original contribution to knowledge is a trauma-sensitive social media research method that includes and empowers the already existing narrative of people with disabilities into the theorization of group home violence, abuse and neglect. This research extends upon the work of other disability researchers that have already

recognised the value of engaging people with disabilities in multimodal inquiries in the field of disability research.

This research transforms the theorization of social media use in disability studies. In 2020 alone, disability studies research has sought to understand social media usage by individuals with disabilities. Sweet, LeBlanc, Stough, and Sweany (2020) sought to explore how social media are used by individuals with disabilities in the design, learning and building of community in formal and informal education through a systematic study of literature. Buchholz, Ferm, and Holmgren (2020) investigated support persons' views on remote communication as well as factors enabling self-determination and participation. Frielink, Oudshoorn, and Embregts (2020) probed the use of eHealth for service users with disability in support of daily functioning. Current research acknowledges the significance of social media in the lives of people with disabilities. YouTube is not only the most widely used video hosting website in the world, it is also the second most popular website in the world following Google (Saffi, Do, Hansen, Dodick, & Ashina, 2020). Considering the popularity of YouTube, it holds a significant potential to impact disability studies. This research demonstrates how YouTube is used innovatively by people with disabilities, their family and carers, to advocate for issues that are important to them and contribute to the narrative of disability group home violence, abuse and neglect. This research highlights the importance of considering other modes of information sharing that the disability community use to break their silence on issues pertaining to them.

While rapid changes are a characteristic of the social media field, men and women with disabilities gain from access, literacies and inclusion. Buchholz et al. (2020) acknowledged that accessibility is important for the safety of people with disabilities and is necessary to signal for help. Murphy and Bantry-White (2020) found that people with disabilities living in residential facilities experienced wider issues concerning denial of full citizenship and inclusion. The findings in Murphy and Bantry-White (2020) support the findings of Hall and Brabazon (2020) that service users doubt the capacity of men and women with disabilities to make choices about their own lives. The findings in Murphy and Bantry-White (2020) also emphasised the need for human rights being at the centre of service delivery for people with disabilities living in the community. This research empowers the lived experiences of

men and women with disabilities, their families and carers. This research demonstrates the importance of all individuals with disabilities having access to the internet as a safeguarding measure against violence, abuse and neglect.

An historic problem with disability research is that it excludes the voices of men and women with impairments. In 2020, scholars confirmed that disability studies research investigating people with disabilities relied on third party accounts to inform their findings (Bigby, 2020; Langen, 2020; Parley, 2020; Willott, Badger, & Evans, 2020). Langen (2020) used survey questionnaires to collect information from developmental centre employees to investigate abuse, neglect and wrongful deaths, once again relying on the reports of people other than those with disabilities. Parley (2020) explored the views of staff working within disability services to understand their views of vulnerability and abuse. Murphy and Bantry-White (2020) used inspection reports published in 2016 to understand the group home living experience for people with disabilities living separately from the community in Irish group homes. Bigby (2020) investigated disability support workers' experiences during covid-19. These studies all attempted to understand the experiences of people with disabilities by drawing on information from a third party.

Murphy and Bantry-White (2020) sought to understand challenging behaviour by observing the types of interactions men and women with disabilities have within the group home. Murphy and Bantry-White (2020) then interviewed direct care staff to explore how staff interpreted resident needs, communication abilities and relationships. The voices of men and women whom the study was about was missing from this research. It remains unknown why the voices of people with disabilities are excluded from research that is about them. Murphy and Bantry-White (2020) found that staff play a significant role in the occurrence of challenging behaviour by engaging people with disabilities. Observations and interviews with staff were the methods harnessed in their study. This research extends the findings of Murphy and Bantry-White's (2020) study to include the voices of people with disabilities into the theorization of challenging behaviour displayed in group homes.

What is missing from this recent research is the information rich, lived experience of people with disabilities themselves. Shakespeare (2014) argues that disability studies

is over-theoretical, lacking the ability to offer practical help in understanding the lives of people with disabilities. This emphasises why the social media interface is so valuable and important. Disability studies does not need more grand theories to understand and make sense of violence, abuse and neglect towards the disability community. It needs to utilize the narratives of people with disabilities that already exist on the internet.

Violence, abuse and neglect against people with disabilities is an ongoing issue. Three decades ago it became eminent that people with disabilities are more likely to experience sexual violation and these violations go underreported (Willott et al., 2020). However people with impairments are still being excluded from the most recent research undertaken to understand this problem. Willott et al. (2020) conducted a study to determine the extent that it is still underreported using safeguarding alerts compared to the number of expected abuses. The data set used was based on information gathered from the service provider's administrative system rather than information provided by people with disabilities. Three decades later, research is still trying to understand and make sense of this phenomena using source material that does not include the voices or input of those that have experienced the abuse itself. This is where social media uploaded by the victims of violence, abuse and neglect is especially useful. What this doctoral research highlighted was that social research cannot rely on the accuracy of reports from a third party. A more robust method is needed.

The unobtrusive researcher's background requires conscious and careful engagement with the self that is used in the development of new knowledge (Auriacombe & Meyer, 2020). My disability background has been foundational in the understanding and meaning making process of this unobtrusive research. As a social worker with seven years of experience in the disability and complex needs field, I have seen injustice and felt compelled to explore the lived experiences of individuals further. I wanted to inform others. I wanted to educate people and expose incorrect ways of thinking. I wanted to empower the voices of people with disabilities that were too often unbelievably and shut down. As a social worker, I ascribe to the Australian Association of Social Workers (2010) Code of Ethics. At the very core of my practice is to do no harm (Australian Association of Social Workers, 2010). I am



aware that asking people to discuss issues that are traumatic in nature can be harmful. When people are asked to revisit situations that caused them suffering, they may experience emotional flooding and re-traumatization. We live in a time where people access the internet and use social media every day. This research proves that interviewing people with disabilities was not needed to ensure they were included in the research process. The information already exists. Even as a social worker, I would like to see the benefits of the internet better utilised in the work we do. I travel to developing nations and even in the poorest villages, people have mobile phones and internet access, giving them access to the online world. So why aren't our own disability community ensured internet accessibility?

This research matters. It is founded and framed by the voices of those who matter. It provides research at the intersection of disability and social media. It transforms theory. Using YouTube as an unobtrusive research method in disability studies to explore violence, abuse and neglect is long overdue and draws attention to the importance of social media access for people living with disabilities. People with disabilities are choosing to access social media on their own terms, in their own time, and discuss such experiences. The exploration of violence, abuse and neglect is a critical issue at this time in Australia as the National Disability Insurance Scheme (NDIS) has been rolled out into existing services. The NDIS is the biggest health policy reform since Medicare in the 1970s and has received debate about whether safeguarding is going to be sufficient to protect some of the most vulnerable people in care. In May 2018, the long-awaited Quality Safeguarding Commission released the Quality and Safeguarding Rules. At the same time, they released the National Disability Insurance Scheme (Code of Conduct) Rules 2018. The rules are intended to ensure people with disabilities live free from violence, abuse and neglect. This research will compare what is presented on YouTube to the current theorization of disability group home violence, abuse and neglect.

Virtually every Australian with a disability encounters human rights violations at some point in their lives and very many experience it every day of their lives (National People with Disabilities and Carer Council, 2009, p. 4).

Regardless of culture, abuse and neglect in the lives of people living with disabilities is a major concern and occurs in systems throughout the world. Research focusing

on disability and violence has usually focused on individuals with disabilities having violent behaviours of concern, rather than people with disabilities being victims of abuse and violence (Goodley & Runswick-Cole, 2011). Most research into this area has focused on physical and sexual abuse while emotional and psychological abuse and neglect is difficult to recognize in the lives of people with disabilities (McDermott, 2012; S. Robinson & Chenoweth, 2011). Social, legal and political changes are needed throughout the world to enhance the value of people with disabilities, to show that they are worthy of respect and protection (McCarthy, 2014). Powerful and dominant modes of social and cultural operation have constructed people with disabilities as 'other', damaged, less than human and needing to be 'kept in their place' (S. Robinson, 2013; S. Robinson & Chenoweth, 2011). This includes the disability service systems in which these people live.

In more recent years, there have been some famous cases of violence, abuse and neglect that have made international headlines. In the United Kingdom, Connor Sparrowhawk was found dead in a specialist hospital unit, having had a seizure while in the bath with no staff member present to stop him from drowning. His death was entirely preventable (S. Ryan, 2017). Closer to home here in Australia, media coverage by Four Corners episodes "In Our Care" (ABC, 2014) and "Fighting the System" (ABC, 2017) have exposed the negative consequences of abuse perpetrated on people living with disabilities in group homes. ABC TV Four Corners brought this issue of violence, abuse and neglect of people with disabilities to national prominence.

In 2015, The Senate Community Affairs References Committee Secretariat (2015) recommended the Australian Government authorize and proceed with a Royal Commission into Violence Against People with Disabilities. The Committee Report recommended that a more thorough investigation of instances of violence, abuse and neglect of people with disabilities occur (The Senate Community Affairs References Committee Secretariat, 2015). With the NDIS having been implemented in Australia, this is an important time for evidence-based information to come forth giving insight into practices which reduce violence, abuse and neglect against people living with a disability. Unfortunately, the Australian Government announced in 2017 that it would not proceed with the Royal Commission. In June 2015, a range of researchers

and academics across Australia signed an open letter to the committee noting that information enabling research into violence against people with disabilities were few in numbers, especially in institutional and residential settings, for culturally and linguistically diverse people and Indigenous Australians. Many of the academic signatories had conducted research that found people with disabilities experience higher rates of violence, abuse and neglect than the rest of the community, rating it as a significant issue of social justice in Australia needing investigation. Institutional violence, abuse and neglect against people with disabilities was rife and unmanaged.

There is a relative lack of prosecutions and convictions related to violence against people with disability (Spivakovsky & Steele, 2017).

In May 2017, Disabled People's Organization coordinated with people and organizations from all over Australia, releasing a statement to Prime Minister Malcolm Turnbull calling for the immediate establishment of an Inquiry into all forms of violence, abuse and neglect of people living with a disability. The statement had wide support with endorsement from one hundred and sixty organizations and three hundred and eighty-three individuals. The Prime Minister received the statement on the 7th June 2017 and formally responded to the Civil Society statement on the 24<sup>th</sup> June, dismissing any formal inquiry and stating the new Quality and Safeguarding Rules would address the issue.

In May 2018, the NDIS Quality and Safeguarding Commission released the NDIS Rules as well as the NDIS Code of Conduct Rules 2018. Providers are measured against the NDIS Quality Indicators. Violence, abuse, neglect and discrimination within the Quality Indicators Guideline are not conceptualized but rather a procedure for managing this process by providers is given (Australian Government, 2018). The introduction of the NDIS in Australia places the principles of choice and control at the centre of disability support. Within the NDIS, men and women with disabilities and complex needs support such as challenging behaviour are already at risk of having their needs simplified (Collings, Dew, & Dowse, 2016). It is deeply discouraging that some service providers continue to doubt the capacity of men and women with disabilities to control, manage and understand their own lives (Hall & Brabazon, 2020). Such thought conflicts with years of progression in disability studies.

In South Australia in particular, the violence, abuse and neglect of people with disabilities has been at the forefront of concern with the tragically well-known Ann Marie Smith case. Ann Marie Smith was a fifty-four-year-old woman with cerebral palsy who had been receiving NDIS funding six hours care a day. Ms Smith died a horrific death on April 6, 2020 from severe septic shock, organ failure, severe pressure sores, malnutrition and issues connected with her disability. It is believed that Ms Smith may not have left the confines of her cane chair for more than a year (ABC News, 2020a). Disability Support Worker Rosa Maria Maione was charged with the manslaughter of Ms Smith. Ms Maione is also the prime suspect for over \$30,000 worth of jewellery and \$220,000 missing from Ms Smith (ABC News, 2020b). A taskforce was announced to investigate the safeguarding gaps in the disability service system (Department of Human Services, 2020). Ms Smith's body had failed her yet her mind was fully functioning. Ms Smith did not have internet accessibility and in her disabled state, was completely disconnected from the outside world.

It is clear that we have some gaps in our system for our most vulnerable people with disabilities. The case of Ann Marie Smith has just shocked everyone. There are many failings and we want to correct them. Minister Michelle Lensink 2020 (Vincent & Caudrey, 2020, p. 3).

Vincent and Caudrey (2020) stated in the Special Taskforce Report that the views of service providers and support workers are seen as more important and more credible than people with disabilities. This is a gross injustice of the system as it currently stands. The voices of people with disability must be valued and given importance in issues which are about them. Vincent and Caudrey (2020) stated that people with disabilities often remain uneducated about and unsupported to pursue their human rights. People are often inhibited from speaking about abuse because of the access barriers that exist (Vincent & Caudrey, 2020). This research highlights the importance and urgency of internet accessibility being guaranteed for vulnerable communities, including people with disabilities. People with disabilities are protected under the United Nations (2006) Convention on the Rights of People with Disabilities (UNCRPD). According to the UNCRPD, people with disabilities have the right to life (article 10), living independently and being included in the community (article 19), personal mobility (article 20), respect for privacy (article 22) and health (article 25). These human rights must be enacted in disability group homes.

Powerful information is available from the online environment that confirms the experiences of people with disabilities conveying their truths about group home violence, abuse and neglect. Using unobtrusive research methods brought attention to the value of internet accessibility for this oppressed and vulnerable group of people. This social media research empowered voices of people living with disabilities, their families and carers, and gave their experiences the attention they deserved by including their video recordings in the research process. I use an integrated literature review approach to frame and shape my findings. I combine the thematic analysis with the literature to support the claims made. Unobtrusive research methods are used to understand violence, abuse and neglect of people with disabilities living in group homes. I use information that already exists and is available on the internet by sourcing testimonies already uploaded to YouTube by people with disabilities, their families and carers, therefore valuing their lived experiences.

Chapter 1 configures the shape and scope of social media research by discussing internet accessibility for people with disabilities. The impact of the internet on society in the last twenty years and its influence on social life is presented. Social media are an interface where people with disabilities can interact in such a way that does not discriminate as their disability may not disable them in that particular online space, depending on the nature of the impairment. The impact of globalization on social media and the disability community is considered. YouTube as a research method is introduced and argued for.

Chapter 2 presents the theorization of disability in the context of this research. The medical model and social model of disability are discussed. The history of disability studies is considered and a critical realist approach to understanding disability is argued for. Ableism is conceptualized and the assumptions underlying ableism are discussed.

Chapter 3 argues for the use of social media research in the exploration of violence, abuse and neglect of people with disabilities living in group homes. The benefits of unobtrusive research methods compared to reactive methods are outlined and considered. The value of digital information summoned from the internet is presented, especially in relation to covid19 social distancing restrictions. The ethics

of this research is outlined. This leads to the development of the argument that trauma-sensitive research is particularly important for social workers who are governed by the ethical code of conduct to do no harm. This presents the social media interface as particularly attractive when exploring peoples' experience of group home violence, abuse and neglect that are traumatic in nature. Finally, YouTube as a trauma-sensitive research method is introduced.

Chapter 4 reveals the methodology of this research. The argument for social media, particularly YouTube, as an unobtrusive research method is presented. The step-by-step process of each of the six different search term strategies is detailed. Screen shots are displayed to support the discussion of the research method. The four phases of the thematic analysis are described in detail to demonstrate clearly how meaning was made from the information collected. Literature is engaged to demonstrate how social media has been used by other researchers and supports the argument for developing knowledge from social media.

Chapter 5 presents the disadvantage of the neoliberal group home as one of the four main themes that emerged from the findings. The chapter discusses how neoliberal ideologies support ableism and contribute to experiences of violence, abuse and neglect of people with disabilities living in group homes. The sub-themes identified are the injustice of individualized poverty, inadequate provision of services, impoverished and neglected facilities, and poor health and overcrowding of the group home environment. These themes were identified from residents' disclosure of group home experiences on disintermediated video and then uploaded onto the public platform, YouTube. An integrated literature review was weaved throughout the chapters and findings inserted to support the argument that neoliberalism serves to further oppress people with disabilities living within the group home structure.

Chapter 6 explores the re-institutionalization of the disability sector as the second of the four main themes to have emerged from the findings. This chapter discusses how group homes re-institutionalize people living with disabilities within the community setting. The sub-themes identified are disempowered by re-institutionalization, restricted by the principle of normalization, dehumanized through ableism, and online communities and the struggle for connection. Many of the issues which

existed under institutionalization continue to occur within the group home environment. Men and women with disabilities felt they were disempowered by re-institutionalization, restricted by the principle of normalization and were dehumanized through ableism. Men and women were unified in their view that group homes were oppressive, rigid and strict in nature. The group home environment was not described as one that fostered independence but rather one that dehumanized individuals through ableist ideals. Resident health suffered and group homes were described as being overcrowded.

Chapter 7 presents harmful interpersonal relationships, which is the third of the four main themes that emerged from the findings. This chapter considers how the group home space is shared by both residents and staff. While group homes are places that can facilitate friendships amongst people living with disabilities, they are also understood to be an environment where harmful interpersonal relationships are fostered. The sub-themes identified are dignity destroyed through relationships, broken relationships between staff and residents, resisting staff authority, and inappropriate use of staff power and control. People with disabilities find dignity through relationship, but the group home is a space where violence, abuse and neglect are commonly experienced through relationships with others sharing that space. Men and women with disabilities frequently reported experiencing conflict with staff as staff used their positions of power and authority to dominate residents. A discussion about how residents use challenging behaviour to resist staff authority is outlined. Once again, an integrated literature review is presented to support the interpretation developed.

Chapter 8 summons the necessity to break the silence of disability as the last of the four main themes that emerged from the findings. The chapter discusses how the use of social media by the disability community has been leveraged to challenge ableism. The sub-themes identified are ableism configured and perpetrated through dominant media structures, challenging ableism with social media, silence reinforced through ableism, ableism challenged by resident behaviour, restrictive practice as lawful violence, and accessibility as a safeguarding measure. Men and women with disabilities are not only silenced by their internal processes but also silenced by the dominant ableist ideologies which dominate the wider society as well as the group

home environment. An integrated review of the literature is weaved throughout the chapter and findings are presented to support the argument that people with disabilities are silenced and use social media to break silences. Restrictive practice as lawful violence is discussed. Finally, the chapter concludes with a consideration of the importance of internet accessibility as a safeguarding measure for men and women with disabilities living in group homes. An integrated literature review frames and supports the discussion.

To conclude the thesis, the findings from YouTube about violence, abuse and neglect are summarised and discussed. Recommendations are provided and the limitations of the research are considered. There were distinct and distinctive reasons why people with disabilities chose to deploy YouTube to disclose group home violence, abuse and neglect. YouTube was used as an outlet to express opinions when people with disabilities were unable to do so in their own environment. YouTube was also observed as being used as a tool to advocate and build online community connections. This investigation into disintermediated video recordings on YouTube provided insight into the reasons people with disabilities used YouTube to disclose experiences of group home violence, abuse and neglect. Using videos that were uploaded onto YouTube as a data set for my doctoral research had many advantages over using other obtrusive research methods. The analysis of body language and the observation of the group home environment available in the video format offered information that would not have been available through transcribed interviews or surveys. YouTube recordings were timely as they typically occurred immediately after the incident, which made the testimony fresh and increased accuracy of the self-reported experience. Also, comments were available for researchers to review and conversations between geographically disparate viewers was possible.

It was important to use the voices of people with disabilities in the theorization of group home violence, abuse and neglect. This research empowered and valued the self-reported, lived experiences of group home violence, abuse and neglect from people with disabilities by using data that already existed and was easily available on the internet. This research did not cause any harm because people were not asked to talk about their traumatic experiences in an interview setting.



## Research questions

The research questions were leveraged to understand why people with disabilities used YouTube to disclose experiences of group home violence, abuse and neglect. Four qualitative exploratory research questions were used to implement the YouTube video search and drive the thematic analysis of the information summoned during this research. The first question specifically implemented the YouTube search and guided the parameters of the YouTube search. I specifically searched for disintermediated YouTube videos where people with disabilities, their families and carers, discussed their group home experiences. The second research question provided a frame for understanding why people with disabilities, their families and carers, leveraged YouTube to disclose their group home living experiences. The third question was used to investigate the benefits of using unobtrusive research methods in disability studies to contribute to disability theory. The fourth question encouraged thought into how the voices of men and women with disabilities, their families and carers, support the existing theorization and understanding about group home violence, abuse and neglect. The question encouraged an extension of disability theory informed by the opinions and experiences of the disability community itself. The integrated literature review contextualized the findings within the existing knowledge and understanding of disability group home violence, abuse and neglect.

Using the World Health Organisation's understanding of violence, violence is conceptualized as,

a violation of an individual's human or civil rights through the intentional use of physical force or power (threatened or actual) which either results in injury, death, psychological harm, maldevelopment, or deprivation (World Health Organization, 2010, p. 6).

Violence is understood as being behaviour that intentionally threatens, attempts to or inflicts physical harm on others (Rosenberg & Mercy, 1991). Abuse is understood as behaviour that includes being verbally attacked, threatened, terrorized, severely ignored or rejected (Nosek, Howland, & Hughes, 2001). People with disabilities may experience emotional abuse from caregivers when those giving care shout, ridicule or ignore them (Curry, Powers, & Oswald, 2004; Oktay & Tompkins, 2004). Abuse

can also include manipulation or coercion of an individual's money or finances (Marley & Buila, 2001). Neglect is understood as being any situation where an individual's basic needs such as food, clothing, hygiene, protection or medical care are not met either temporarily or permanently (Verdugo & Bermejo, 1997). The narratives of men and women affirm, extend and contribute to the understanding of these concepts.

There is a continuum of available and supported housing arrangements for people with disabilities (Connellan, 2015). These include institutions, although they are mainly closed now, group homes, living with parents well into adulthood when others would leave home, and living individually in the community with support (Connellan, 2015). Group homes are smaller residential facilities where support is often shared amongst residents (S. Oliver, Gosden-Kaye, Winkler, & Douglas, 2020). Group housing remains the dominant accommodation option for people with disabilities where resources are limited (Beadle-Brown, Mansell, & Kozma, 2007; Bigby & Beadle-Brown, 2018). Group homes typically consist of four to eight individuals with disability living in a shared housing arrangement with direct support provided by staff supervision (Humphries, Pepper, Traci, Olson, & Seekins, 2009). Being the most common housing arrangement for people with disabilities, this research focuses on group homes. Research findings suggest that people with disabilities living in group homes are vulnerable to violence, abuse and neglect (Balandin, 2000; Carr, 2011; Marsland, Oakes, & Bright, 2015), making this research a valuable contribution to the field of disability studies.

- 1) What do people with disabilities, their families and carers, disclose on YouTube about their experiences of living in group homes?
- 2) What benefit does YouTube offer people with disabilities?
- 3) What strengths do unobtrusive research methods offer research into people with disabilities?
- 4) How does the information that is revealed on YouTube affirm and extend the existing theorization of group home violence, abuse and neglect?

Over one hundred disintermediated videos were selected with rigour and transparency to ensure repeatability of the research. The data selection of one hundred videos was determined as the saturation point, whereby no new themes and tropes emerged. The focus remained on the experiences of people with disabilities in group homes as reported by people with disabilities, their families and carers. YouTube searches that targeted men and women with disabilities, their families and carers, disclosing their group home experience were used to summon the desired qualitative information from YouTube. Disintermediated videos were transcribed and analyzed. By exploring the group home experiences disclosed by the disability community, the research questions were addressed. This thesis demonstrates that people with disabilities share their lived experiences of group home living and have utilized YouTube as a public platform to share their experiences publicly. By carefully transcribing over one hundred videos and then deploying a thematic content analysis, themes common to the disability community were identified and discussed in relation to existing literature. These themes are considered central to the discussion of group home violence, abuse and neglect of men and women with disabilities living in group homes.

The reasons why YouTube has been used to expose group home violence, abuse and neglect by individuals with disabilities, their families and carers, is considered in this research. The experiences that are disclosed publicly on YouTube and the subsequent themes that are evidenced is compared to the existing literature available in disability studies by an integrated literature review throughout the chapters. The integrated literature review enables the current theorization of group home violence, abuse and neglect to be validated and extended by discussing the findings, and interpreting the information. This thesis used the voices of people with disabilities, their families and carers, to validate existing theorizations of group home violence, abuse and neglect of people with disabilities while further contributing to knowledge.

By using YouTube as the platform and the interface for the application of an unobtrusive research method to explore the experiences of the disability community, the strengths of this method are considered. Specifically, disability group home violence, abuse and neglect were explored by summoning disintermediated videos

of people with disabilities, their families and carers, discussing their group home experiences. The thesis demonstrated the strengths that unobtrusive research methods offer research into disability studies by harnessing information rich material that is gathered from a public online space, YouTube, in disability research. As the topic is sensitive in nature, this thesis demonstrated that unobtrusive research methods are beneficial in exploring such topics as no harm was inflicted upon the vulnerable during the research process. This makes unobtrusive research methods attractive when studying topics of a sensitive nature, especially in vulnerable communities. The findings from this research method can be translated to understand the benefits of using social media to study other vulnerable communities.

This research specifically demonstrated that the voices of people with disabilities should be harnessed in the research of disability studies as the data already exists on the internet. The internet provides a global audience which findings transcend national boundaries. This thesis provides evidence that people with disabilities are finding creative ways using the internet to share their lived experiences and speak out against injustice. Unobtrusive research methods, specifically the summoning of online information, has many benefits for social research. This thesis demonstrated the value of using such methods in disability studies.

This thesis explored what different mode of information is revealed on YouTube that was absent from the theorization of group home violence, abuse and neglect by summoning the narrative from disintermediated videos and selecting quotes throughout the chapters while integrating with existing literature. Existing theories of group home violence, abuse and neglect are confirmed and extended using the voices of people with disabilities. The inclusion of people with disabilities that have group homes experiences to discuss makes this research into group home violence, abuse and neglect ethically sound.

# **CHAPTER 1**

## **DIGITIZATION AND DISABILITY: THE VIRTUAL WORLD OF DIGITAL DISABILITY**

Internet accessibility is of high importance for people with disabilities. With national boundaries being transcended, social media has the power to influence and impact. YouTube is used by men and women with disabilities to disclose experiences of group home violence, abuse and neglect. The data already exist and needs to be summoned to confirm and further inform disability theory. Both the advantages and limitations of YouTube as a tool for social research are considered.

In this chapter, I argue that the information available on social media platforms is pertinent and should be harnessed in research. This chapter situates disability research within the context of social media. I argue that the disintermediated content available on YouTube has advantages that should be leveraged to shape configurations of disability. The benefits that YouTube can offer people with disabilities is considered. This chapter lays the foundation for the adoption of a social media research design to explore disability group home violence, abuse and neglect.

### **Internet accessibility and the disability community**

The use of social media by the disability community to share information, connect and enhance learning has grown rapidly over the last ten years (Sweet et al., 2020). People living with disabilities are at risk of experiencing heightened life challenges and disadvantages, often feeling isolated from the community and lonely (National People with Disabilities and Carer Council, 2009). The internet has provided a space that many people experiencing disability can use as a means of communication and advocacy, with the ability to form strong networks that extend both online and offline (Bundon & Hurd Clarke, 2015). Men and women with disability can access the same spaces that able-bodied individual's access through social media platforms and other online spaces. The internet is an important method of communication for both people living with disabilities and people without disabilities alike.

The internet originated from military research conducted in 1969 and the World Wide Web as an internet-based platform was proposed by Tim Berners-Lee in 1989 as a

way of navigating information (Ellis & Kent, 2011). Having been created with universality in mind, it was aimed at benefitting the largest number of people possible regardless of ability or disability (Ellis & Kent, 2011). Internet accessibility for people with disabilities has complex and unique legal, technical, architectural and political dimensions, as well as being one of the most pressing civil rights challenges of the twenty-first century (Reid, 2020). High expectations of the internet to decrease divides amongst the general population and people with disabilities has been linked to digitization (Johansson, Gulliksen, & Gustavsson, 2020). Disability theorists acknowledge that the way disability is conceptualized directly impacts accessibility issues.

The public space of the web is now being conceptualized in the same way as the public space of the built environment (Ellis & Kent, 2011, p. 28).

With the pervasiveness of the online environment in everyday life, men and women with disabilities cannot be denied access to the internet anymore. With currently 2.22 billion social media users (Statistica, 2018b) and 31 percent of this group spending their time accessing social media sites (Statistica, 2018a), what happens on the internet is impacting societal structures and narratives. Social media platforms are becoming increasingly popular and are accessed daily, multiple times throughout the day because of the new portable media devices including mobile phones and tablets (Goggin, 2014). As the Internet and social media become the preferred method of communication for the mainstream, accessibility will become more important for people living with disabilities (Elcessor, 2010; Ellis & Kent, 2011). As this research demonstrates, people living with disabilities can benefit from access to the online environment. The online environment enables citizens to interact in society without having to leave their home. For men and women that are isolated or removed from the community, the online environment serves as a connection to society as Internet access drives education, employment, civil participation, cultural participation and more (Reid, 2020). Important daily activities including banking, shopping and socializing is increasingly facilitated online. The online environment needs to be accessible for people with disabilities in the same way that they need the physical world to be accessible.

Not all the world's population has the same opportunity to access the internet, and this is known as the digital divide (Iliya & Ononiwu, 2020). The digital divide acknowledges that people in developing nations do not have the same potential of accessing the online environment as a result of inequalities among countries and also inequalities within countries themselves (S. Thompson, 2018). The nature of the digital divides has been explored in research with particular focus on the biological, economic, social or organizational aspects of internet use (Johansson et al., 2020). Higher education, higher income and being employed is related to higher internet use, while age is negatively related to internet use (Scholz, Yalcin, & Priestley, 2017). Where previously there has been a gender gap in internet access, this has now closed (Dobransky & Hargittai, 2016; Hargittai & Hinnant, 2008; Perrin & Duggan, 2015; L. Robinson et al., 2015). Research shows that women value their online skills less than men (Dobransky & Hargittai, 2016; Hargittai & Shafer, 2006; L. Robinson et al., 2015). While gender impacts the digital divide, it is the people who lack support that have the most difficulty online (Helsper & Van Deursen, 2017). Studies in the past have explored potentially problematic features of the internet including navigation (Ford & Chen, 2000), orientation (Ahuja & Webster, 2001), selecting search results (Aula & Nordhausen, 2006; Pan et al., 2007) and evaluating information (Morahan-Martin, 2004). Internet accessibility in research continues to be an area of importance.

People with disabilities often face discrimination in online environments. Disability prejudice is replicated online by inaccessible digital environments (Katie Ellis & Mike Kent, 2015). The importance of the online environment being accessible by people with disabilities can be seen reflected in legislation and the formation of the World Wide Web Consortium, the main organization responsible for setting internet standards. The United Nations have recognized in their UN Convention of the Rights of People with Disabilities as cyberspace being equal to public space and advocate for media and website accessibility to be a basic human right (United Nations, 2006). Access to the internet is a basic human right for people with disabilities and able-bodied alike.

Article 9 of the United Nations (2006) Convention on the Rights of People with Disabilities (UNCRPD) states that people with disabilities have the right to access the physical environment as well as the online environment alike. Barriers to accessing

buildings and other physical environments, as well as information and communication technology, are to be identified and removed.

- 2 f) To promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
- g) To promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
- h) To promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost (United Nations, 2006).

International law recognizes and acknowledges the right that the disability community has to both online and offline spaces. Men and women with disabilities should not be denied accessibility to online spaces and online information.

While not legally enforceable, there are some famous precedents set by case law regarding accessibility, including the Sydney Olympics and Target website cases (Ellis & Kent, 2011). On the home front, Australia is a forerunner of promoting accessibility in the international community with Section 24 of the *Disability Discrimination Act* (1992) that if goods and services are available to non-disabled, they must be afforded to disabled alike (Ellis & Kent, 2011). It is important that people with disabilities are afforded the same opportunities as able-bodied people, even in the online environment.

In the fifth decade of the Internet, accessibility for all, including those with disabilities, is commonly acknowledged as central to digital inclusion (Katie Ellis & Mike Kent, 2015). The construction of online environments can exclude people with disability, therefore disabling people with impairment. If disability is seen only as a medically diagnosed impairment and thus individualized, then the community is absolved from any responsibility of removing the barriers to access (Ellis & Kent, 2011). Many researchers in the field of disability and social media have discussed accessibility issues of the online environment (Bundon & Hurd Clarke, 2015; Dobransky & Hargittai, 2016; Ellcessor, 2012; Ellis & Kent, 2011; Foley & Ferri, 2012; Goggin, 2014; Kent, 2015; Loane & D'Alessandro, 2013; Murthy, 2008). In many ways, an online environment is a place where people with disabilities can live beyond their disability (Ellis & Goggin, 2015). Computer technology, such as avatars, can enhance



people with disabilities' lives (Best & Butler, 2013). Captioning for online videos increase accessibility for deaf and hard-of-hearing people (Elcessor, 2012). Accessing online health communities is especially important to people with disabilities (Loane & D'Alessandro, 2013). Online health communities provide support to people with disabilities and has been linked with improved health outcomes and quality of life (Loane & D'Alessandro, 2013). For people that have trouble communicating, the internet provides a place where people with autism can connect without the burden of face-to-face encounters (Pinchevski & Peters, 2016). Social media access has even been important for those caught in disaster, whether of the natural world, acts of terrorism or major accidents, to communicate to the outside world (Ellis & Kent, 2011). Access to the online environment benefits users in paramount ways.

The use of internet and communication technologies to empower people with disabilities is not a new concept (S. Thompson, 2018). Internet and communication technologies have increasingly become an important artifacts for the disability community (Iliya & Ononiwu, 2020). Mobile phone use has been demonstrated to empower people with disabilities (Iliya & Ononiwu, 2020). While accessibility issues do exist, once online, men and women can utilize the space in ways that are unique as compared to people that are not challenged by accessibility. This research demonstrates the specificity of this data set by using uploaded videos that people living with disabilities have made themselves to discuss their group home living experiences which reveal instances of violence, abuse and neglect in disability group homes.

It is imperative to better understand how internet technology interacts with the life worlds and dynamics of disability (Goggin, Hollier, & Hawkins, 2017, p. 1).

The online world is a place full of rich information and provides an environment where people can hide behind the screen and choose how they present their identity, gender and embodiment (Foley & Ferri, 2012). Online, people with disabilities can imagine a life beyond their disability (Alper, Elcessor, Ellis, & Goggin, 2015). Physical attributes can be hidden online. The socially constructed ideas that lie behind disability within society are still evident in the online world (Foley & Ferri, 2012). Norms in the online environment mirror and even exaggerate the norms in real

society (Foley & Ferri, 2012). It is virtually impossible to separate technology from the larger social context.

Social platforms and online community forums like Facebook and YouTube become an extension of social life. People create a social identity in the online environment and in places like Facebook where people select photos to represent themselves, images chosen represents something about themselves (Ellis, 2010a). What is communicated online communicates something about what people want to portray about themselves socially. Everything that one does in the online world can be assigned a meaning to communicate something to others using that same space. Analyzing these representations via unobtrusive research methods enables knowledge to be built based on preexisting material. Data available through social media platforms should be leveraged in social research. More research is needed to understand how social media is used by individuals with disability (Sweet et al., 2020). Social media platforms must continue to be accessible (Sweet et al., 2020). Digital media as a source of information in social research are integral and pervasive research materials. Digital media is a pervasive aspect of social life, having transformed social environments.

The online environment provides a space where people with disabilities can be open about their opinions and views, communicating at their own discretion. People with disabilities online do not significantly trail those without disabilities in engaging in any activity online (Dobrinsky & Hargittai, 2016). Men and women with disabilities have increased odds of engaging in five activities: downloading videos, playing games online, reviewing products or services, sharing their own content, and posting to blogs (Dobrinsky & Hargittai, 2016). This demonstrates that the internet is an important aspect of daily life for individuals living with impairments. While accessing the internet may prove challenging, once online, people with disabilities have more chance of interacting with videos, sharing their own content and posting to blogs. A study by Bundon and Hurd Clarke (2015) that recruited participants online found that social media was being used strongly by people with impairments to communicate their ideas for advocacy.

Our findings suggest that individuals with disabilities are using blogs, Facebook, Twitter, and other forms of online communication to find information, engage in advocacy and outreach projects, and form strong networks that extend online and offline (Bundon & Hurd Clarke, 2015, p. 185).

While the researchers acknowledged accessibility issues for many people with disabilities, all participants recruited in Bundon and Clarke's (2015) research were using online communication and were recruited from the internet itself. This research follows Bundon and Clarke's (2015) example by using material already uploaded by individuals accessing the internet.

### The impact of globalization on disability

Social media has provided a platform for people of different places, cultures, religions, races and time zones across the globe to come together and interact socially in one space. Social media plays an important role on a global scale (Rieder, Coromina, & Matamoros-Fernandez, 2020). This digital space of interaction is accessible by internet and multimodal device. Social media has been termed an agent of globalization and has been detrimental at eliminating conventional boundaries that once restricted people and organizations (Okagbue et al., 2020). The global environment frames and shapes the local environment (Cammaerts & Audenhove, 2005). What happens at the national, state and local levels follow the global lead. The way citizenship and society are structured has radically changed over the last thirty years with the introduction of the internet and the emergence of globalization. Mobile and networked societies emerged with the introduction of the internet. Because of the influence of these online societies, what is posted online has the power to influence and effect the masses (Cammaerts & Audenhove, 2005). This reality should be acknowledged in social research.

Citizenship is connected to relationships with territory, power and one another (Siapera, 2017). The challenges imposed by neoliberal globalization involving the loss of political, social and civil rights has rendered the concept of citizenship meaningless (Siapera, 2017). With the emergence of the internet, these national boundaries have been transcended.

The grains of a new response are found in three developments: a new ontology of the citizen, brought into being through digital acts; the existence of dual

power, creating new forms of governance and social reproduction from below; and between these, the development of new procedures that directly engage state power (Siapera, 2017, p. 24).

Through digitization, new modes of citizenship have been created. Through online presence and interaction, individuals are no longer governed by states and confined by territories. Neoliberal globalization has brought about the rise of a new type of citizenship, being digital citizenship, which has emerged through digital acts (Siapera, 2017). Individuals have power to influence governance using these online spaces. The internet, global media communications and other global sensations have become a dominant global force. Strategies used by organizations to adapt what is occurring at the global level to the local is known as glocalization (Soulard, McGehee, & Stern, 2019). Glocalization takes into consideration both the local and global dialectics (Baskerville & Grossi, 2019). This new global environment impacts every aspect of society and cannot be ignored in today's cultural environment. Acknowledging the internet's impact upon cultural issues by utilizing the global environment in research is essential.

That both corporations and states have become heavily invested in harvesting, assembling, and storing data – for profits or security – about things we say and do through the Internet is practically the strongest evidence of the significance attached to our digital lives (Ruppert & Isin, 2020, p. 1).

Our digital lives have significance. The global environment has impacted the digital world. Globalization has been defined as, “the economic integration of national economies into one global market” (Dominelli, 2010). Globalization has made it harder to designate and differentiate culture, politics and other areas of society into clearly defined nations (Siapera, 2017). Societal issues have become fluid across national borders. Internet Communication Technology has enabled people from all over the world to communicate thereby eliminating time and space restrictions. Citizens that can access computer technology are able to participate in the global online environment, changing the way issues are formed and debated. Global media have facilitated the development of post national citizenship, where people become global citizens that are influenced by trends outside of their nation of residence (Siapera, 2017; Urry, 1999). Citizens of nations are aware of what is taking place in other parts of the worlds and compare their living conditions with what is occurring globally. Human rights are an example of this.

United Nations human rights extend across the globe. Because the United Nations are a centralized body governing human rights, there are processes and institutional arrangements across the world that are similar. Cross national citizenship means that national identity loses its importance due to globalization and the transcendence of national borders made possible by the internet and global media communications (Urry, 1999). People across the nations of the earth can be aware of the circumstances affecting them and measure their experiences by the centralized governing body, the United Nations. This is relevant when it comes to disability rights. The UN Convention of the rights of persons with disabilities was established by the United Nations and has global influence. What is considered harmful practice transcends national borders and is not confined to Australia. By leveraging data that are available on the internet, I am drawing from experiences that are not specific to Australia and can come from any place in the world. While these experiences may not be specific to Australia, they are still reflective of human rights laws. A data set summoned from the internet is valuable because of the effect of globalization and the internet on society today.

Social media interfaces such as YouTube allow anyone with an internet connection and digital literacies to upload material into a public space. Personal opinions and private matters can very easily be made public by sharing documents and talking about private matters in a public space. Matters of oversharing in the public domain have been considered by researchers (Dobson, Carah, & Robards, 2018). Social media are now central to where the pedagogies of intimate life are shared, contested, learned and given value (Dobson et al., 2018). The ability of assessing social media applications from anywhere in the world makes oversharing of intimate information possible and even probable. Social media platforms and interfaces such as YouTube can be accessed throughout the world enabling thoughts and opinions transcend national boundaries. Social media has enabled communities to form amongst strangers and citizens that have never met in real life (Hargreaves & Hartley, 2016). These communities are created by citizens themselves using interactive media and other social networking devices.

The distinctions between private life and private enterprise on one side, and the public sphere and public sector on the other, are neither clear nor absolute (Hargreaves & Hartley, 2016, p. 29).

Not only have national borders been transcended, but public and private life have been blurred. Social media has blurred the lines of what is considered private life and the consideration of what is public business. Interactive media activate a plethora of public data available that presents personal opinions. The potential truthfulness of such material should be leveraged in social research.

### The advantages of YouTube to shape configurations of disability

Social media and other digital multimodal technologies can potentially offer greater social inclusion for people with disabilities (Vie, 2018). Social media is an important series of platforms and interfaces that are being used both within the academic sphere and also in daily life on a global scale (Vie, 2018). Social media are increasingly being used as a tool in research. The benefits of using the internet to gather data for research are the limited costs, quick collection, access to information on sensitive issues and an absence of reactivity (Zia, De Lancey, Regan, & Burkell, 2020). Speedy data collection and low costs enabling quick dissemination of results is desirable for researchers, who usually have to win competitive grants and may become slowed down in the research process applying for ethics and organizing interviews. Summoning information quickly and at a low cost from a public social media platform is attractive to researchers.

YouTube has been used in social media research. Culshaw (2020) used YouTube as an innovative way to recruit research participants. Trevisan (2013) investigated whether internet participation makes for a more inclusive environment for people living with disabilities and whether this enhances their citizenship. Pacheco (2016) examined university transition for people with disabilities and their use of Information and Communication Technologies, observing social media, as well as individual interviews and focus group meetings, in the research method. Wollheim (2007) used YouTube to study the representation of mental illness. Ellis (2010b) used YouTube specifically to study the representation of disability (Ellis, 2010b, 2014). There are benefits of using social media in research. YouTube is an archive available on the Internet where grass roots videos can be uploaded and accessed throughout

the world, depending on Internet availability. YouTube opens up a range of opportunities for people with disability.

The video sharing site YouTube demonstrates tangible benefits to people with disability in relation to both representation and participation (Ellis, 2010b, p. 3).

The media can be used to influence people and shape opinions. The media can be deployed to change ideas or it can act to further oppress already disadvantaged groups. Ellis (2010b) brings together the work of three disciplines of study across media, disability and Internet studies to recognise the potential of Broadband and rebuilding the narrative of disability. People with disabilities have demonstrated new and innovative ways that platforms like YouTube can be used to empower them and give them a voice into issues pertaining them. Social media platforms like YouTube give the user power over what they upload or post. When control is given back to people with disability, this empowers them. Videos uploaded are grassroots videos, enabling people with disabilities freedom of speech without bias. These videos are more valuable to the disability experience than expert opinions because they are from the disability community themselves. Ellis (2010b) showed how YouTube has been used to challenge the way disability has been framed and thought about in society, making it a useful tool in disability activism. Ellis (2014) studied the representation of disability through the YouTube channel The Voice Australia (2012) and social media. King, Streeter, Herling, and Rose (2018) examined the growth of grass roots video production by underrepresented groups on the internet through YouTube. Pal, Huaita Alfaro, Ammari, Chhabra, and Lakshmanan (2015, p. 794) studied the “representation, access and contestation of Facebook and vision impairment in Jordan, India and Peru”.

YouTube certainly has an active audience with the potential to enact lasting change (Ellis, 2010b, p. 4).

YouTube as a platform invites wide uploading and viewing of content from digitally active people from around the world. What is uploaded has the potential to change perceptions and influence ideas in society. For people living with disability, their families and carers, the opportunity that platforms such as YouTube have provided is invaluable.

The Internet is an important part of society and Internet access is increasingly a necessity to access public goods and services. Vulnerable groups of people and those that are disadvantaged would benefit from accessibility including those in developing nations and older people, as well as people with disabilities. YouTube is one platform that shows how people can be empowered by having access.

YouTube, with its vibrant disability activism community is leading the way in creating a socio-political space in which to confront disability and has had a significant impact on the accessibility turn in broadband technologies (Ellis, 2010b, p. 9).

Representations of disability using YouTube have been investigated, but using YouTube to investigate personal experiences of group home violence, abuse and neglect has not yet been done. Representations on YouTube can be controlled by the person with the disability themselves. The nature of control being in the hands of the creator enables information regarding sensitive issues of violence, abuse and neglect to be shared that may not be available in person.

### The limitations of using YouTube to contribute to disability studies

A consideration of the innovative use of YouTube allows such an important discussion but importantly also reveals the potential of social exclusion via these same devices (Ellis, 2010b, p. 2)

For people with disabilities that can access YouTube, the video format can be problematic for some. The developers of YouTube have recognized the need to work on accessibility (Ellis, 2012). The importance of captioning videos on the Internet to ensure videos are accessible for the blind community has been recognized as a limitation of YouTube (Ellcessor, 2012; Ellis & Kent, 2011). YouTube announced in 2009 that all videos uploaded online would be offered video captioning (Ellis & Kent, 2011; Hamlin, 2010). Voice recognition technology embedded into YouTube have enabled the captioning feature (Hamlin, 2010). However not all videos uploaded to YouTube are captioned. These limitations can impact research by excluding the blind community and other members of the disability community that cannot interact with the video interface.

Other factors that impact on the ability to access YouTube are factors that impact the availability of the Internet itself (Chadwick, Wesson, & Fullwood, 2013). People with



disability are amongst the low income earners with low employment rates (Australian Bureau of Statistics, 2018) and experience financial and economic barriers (Chadwick et al., 2013). People with disabilities typically rely on welfare and therefore are low-income earners within the population. This may impact their ability to access the Internet. The severity of disability will impact upon the type of activity that people with impairments require assistance with (Australian Bureau of Statistics, 2018). Support through training and education is essential for people with disabilities to engage with the internet, and this is often missing (Chadwick et al., 2013). The greater the impairment, the greater the need for assistance and the greater the barrier to accessing the Internet without support. Other barriers to accessing the Internet are impairments in literacy, language and processing demands (Chadwick et al., 2013). These barriers may limit the scope of disability experiences included in this research.

The limitations of using YouTube in research for analysis has been recognized and discussed (Dubovi & Tabak, 2020; Galliah, 2018; Teng, Khong, Sharif, & Ahmed, 2020; Thelwall, 2018). Traditional means of data collection are being replaced by digital methods such as data mining (Thelwall, 2018). Thelwall (2018) critiques the problems of using YouTube comments for data gathering and analysis, including the acknowledgement that social media analytics involve human judgement and are therefore complex. Establishing the veracity of content uploaded to YouTube can be problematic (Dubovi & Tabak, 2020). YouTube has been critiqued as containing content that is invective and nonsensical (Galliah, 2018). For this reason, human judgement is required to evaluate the content relative to the topic in study. This potential limitation should be negated during the exploration of people's personal experiences because we are interested in their perceptions themselves as opposed to making judgements about the validity of the experiences.

One method of using YouTube in social research may work for one topic but may not be applicable for another (Thelwall, 2018). The popularity of YouTube as well as the broad scope of material available on YouTube makes it a plethora of information that is readily available. Limitations with particular methods may not be applicable to different topics of study using the same platform. A transparent and detailed discussion about how content from YouTube was harnessed and how meaning from

that data set was made is needed to negate any potential limitations of using this platform in social research.

There is a need for general purpose exploratory YouTube analysis methods, given the popularity of the site, and these limitations are generic to any such attempt (Thelwall, 2018, p. 306).

The limitations recognized by other researchers using YouTube for data collection may not be entirely relevant to this research because of the nature of the data collection method. Transcriptions of videos were used, where many limitations of YouTube have been based on social media data mining and the analysis of YouTube comments. The sample bias of using YouTube to explore the experiences of people with disabilities living in group homes in this study must be attributed to the people who choose YouTube to express their opinions themselves. The information collected in this study may be biased because only users able to access the Internet and use YouTube were included. In this study, men and women whom decided to express their opinions publicly were included, excluding those whom may be less inclined to share personal and vulnerable experiences in front of a camera. YouTube as a social media platform requires more effort to create content in terms of time and resources, compared to other social media platforms such as Facebook.

In this chapter, I introduced the argument that the information available on social media is pertinent and should be used in disability research. Disability research was positioned within the context of social media. I argued that the content available on social media should be leveraged to influence configurations of disability and introduced YouTube as a source of knowledge. I introduced the method underpinning my original contribution to knowledge by presenting YouTube as a social media platform to conduct research into the field of disability studies. Now that the foundation for executing a social media interface in disability studies has been established, the theoretical approach to disability will be presented.

## **CHAPTER 2**

### **THEORIZING DISABILITY: A PRACTICAL AND REPRESENTATIVE ONTOLOGY**

The mechanism through which disability is conceptualized impacts on the experiences of people with disabilities, and how those experiences are researched. Disability is more than simply an impairment, a word that connotes difference. Disability encompasses the oppression and discrimination that an individual, their families and carers, encounter on a daily basis when interacting with the system in which they live. Different approaches to disability have been employed by theorists in the past. Conceptualizations of disability have evolved as the disability experience has been understood in greater depth.

In this chapter, I will present my theoretical approach to disability firstly by providing a discussion about the history of the conceptualization of disability, outlining the medical model of disability and secondly the social model of disability. I consider the two different approaches in context to disability studies, and finally argue for a critical realist approach to disability. Adopting the quote, “nothing about us without us” (Charlton, 2000), I base my discussion on the recommendations of leading disability scholar, Shakespeare (2014), who has an impairment himself. A critical realist approach to disability is the theoretical lens through which the experiences of people with disability, their families and carers, summoned during the research process are understood. A theorization of disability would be incomplete without a discussion about ableism and the privilege given to people without disabilities. To address this, I complete the chapter by outlining the assumptions that create ableism.

#### **The under-explaining medical model of disability**

Attempting to understand and address issues surrounding disability, many different approaches have been used to advance political activism of disabled people over the last forty years. Traditionally, disability was thought about in terms of a medical diagnosis and therefore the focus was on medical intervention and rehabilitation (Shakespeare & Watson, 2002). Disabilities were treated like a sickness or disease that needed to be cured. The undergirding ideologies constituting the medical model

of disability was that impairment was a diagnosable medical condition and that the medical profession was considered the ultimate authority to cure or eliminate the condition (Falvo & Holland, 2018; Shakespeare & Watson, 2002). The medical model did not take into consideration societal factors that oppressed an individual with an impairment and acted to separate people with disabilities from society. Crude dichotomies of "normal" and "disabled" based on societal norms and values meant that anyone who could not be cured identified themselves as abnormal, dysfunctional or disabled (Falvo & Holland, 2018; M. Oliver, 1996). Being labelled as a disabled person impacted self-image and social identity (M. Oliver, 1996), creating a sense of otherness that separated the person with the disability from society. Disability was the responsibility of the individual, and society was not obligated to change any oppressive or restrictive practices that acted to further disable individuals.

The critique of the medical model emerged in psychiatry literature in the 1950's and was coined by psychiatrist Thomas Szasz, having taken many different forms since first emerging (Szasz, 1956). An increased awareness of the critiques of the medical model will enable physicians to improve care of their disabled patients, while also enhancing support for disabled colleagues or trainees (Hogan, 2019). It was psychiatrist George Engel in the 1970's who called for a shift away from reductive natural science approaches and was more in favor of the "biopsychosocial model" as an alternative (Hogan, 2019). Engel did not dismiss the biological causes of mental illness (Engel, 1977), but argued that the medicine required a more nuanced view of disease which recognized the psychosocial issues (T. Brown, 2003). The medical model of disability failed to account for societal discrimination that people with disabilities experienced.

### The over-assuming social model of disability

Engel's biopsychosocial model was widely influential with clinicians who specialized in the area of disability (Hogan, 2019). People are not only disabled by their impairment, but they are also disabled by the society and the environment in which they live (Ellis, 2016). The social model of disability is based on a structuralist augmentation (Porkertová, 2020). The social model of disability distinguishes

between impairment and disability by recognizing disability as the oppressive social structures that disadvantage an individual living with an impairment. The introduction of the social model was considered revolutionary in the disability movement, politically progressing the rights of people living with a disability (Shakespeare, 2014; Shakespeare & Watson, 2002). People living with disability were removed from their onus of responsibility and society was now responsible for their role in disabling individuals. Many different social models have emerged attempting to understand disability. While different social models of disability have been debated and discussed, at the center of each model is the distinction between impairment and disability. Impairment is defined in individual and biological terms whereas disability is defined as a socially generated system of discrimination (Shakespeare, 2014; Shakespeare & Watson, 2002; Shuttleworth & Meekosha, 2013). The social model recognizes the restrictions that society places on people living with impairment by way of accessible environments or oppressive thinking. It places responsibility on society to address any disabling or oppressive factors in an individuals' life that it is responsible for.

Disability was considered a socially constructed product of social arrangements and by addressing social conditions, the thought was that disability could be reduced and eliminated (Shakespeare, 2014; Shakespeare & Watson, 2002). The social model removed attention away from an individual's impairment and places emphasis on the way society includes or excludes the person living with the impairment. Societal structures are seen to be oppressive when they disable people living with an impairment. The binary way of thinking about disability as an impairment and as a socially constructed limitation has undergone a number of critiques from feminists, cultural studies scholars and postmodernists, leading to a number of splits within the disability studies community (Meekosha & Shuttleworth, 2009). The social model of disability intertwines with the – often – post structural theorizations of the body and gender, with the emergence of the feminist movement and researchers impacting disability studies from the 1980's (Meekosha & Shuttleworth, 2009).

The social model was used by disability activists to advance the political strategy of removing barriers in society that disadvantage and oppress people living with an impairment in a bid for social inclusion (Shakespeare, 2014; Shakespeare & Watson,

2002). For physicians to engage fully with the social model, it would require engagement in politics and a focus on societal rather than individual problems (Hogan, 2019). While the medical model of disability reinforced the sense of otherness that people with disabilities traditionally and historically experienced, the social model reinforced social inclusion. Individuals living with impairments felt liberated (Shakespeare, 2014; Shakespeare & Watson, 2002). While the social model was liberating for people living with disabilities, it did not and does not represent reality. As Shakespeare and Watson (2002, p. 5) confirmed, “the very success of the social model is now its main weakness”.

The downfall of the social model was the extreme view that disability is a result of social oppression, social relations and social barriers, while not taking into consideration the disabling factor of the impairment itself (Shakespeare, 2014; Shakespeare & Watson, 2002). This crude dichotomy was an exaggeration of truth and failed to acknowledge the daily challenges a person living with an impairment encounters because of their physical impairment itself. It failed to represent the complexities of a disabled person’s life and what was originally considered to be the social model's strength became its weakness. Disability results from both the individual’s physical impairment and their interaction with the environment in which they live.

### Critical disability studies: seeing is not believing

As the discussion moves from the social model of disability to a critical approach to disability, the approach moves from a structuralist augmentation to a post-structuralist approach (Porkertová, 2020). The field of disability studies has enfolded diverse perspectives to account for the different ways that people face oppression. Disability studies has historically focused on the oppressive nature of disability. In the 1970s and 1980s, disability studies began to focus on the role of language in creating disability and then discourse (Shakespeare, 2014). Other oppressive factors that act to disable a person with an impairment were being recognized as an important consideration in the field of disability studies. Feminist ideas linked personal to the political and addressed some of the deficits of earlier approaches by targeting gender inequality as well as some class-based oppression (Allan, Briskman,

& Pease, 2020). A focus towards deconstructing cultural representations through postmodern thought influenced by the work of authors such as Michel Foucault and Judith Butler emerged (Shakespeare, 2014). These theorists made considerable contributions to such schools of thought. Approaches like disablism enabled greater parallel to other theories understanding oppression like sexism and racism.

Feminist philosophers have contributed greatly to the research into disability as an identity and politics (Silvers, 2008). Feminist philosophers try to transcend and transform a unifying paradigm of “the disabled person” by recognizing diversity and contextual specificity (Silvers, 2008). Feminist scholars observed a parallel between women and people living with a disability. People living with disability have been denied and displaced in the same way as women as a group. Both do not comply with biological or social paradigms and are defined as something that deviates from the standard.

While poststructuralism, as a theory, reconfigures binary oppositions and the spaces between them, Shakespeare (2014) argues that the application of deconstruction will not summon justice or recalibrate the inequalities encircling impairment, because these multi-phasic inequalities cannot be reified to culture or language. He critiques the postmodern, highly theorized discursive disciplines of thought as being more concerned with speaking to academic audiences rather than activism. Disability research should be practical, rather than simply create new thought that is only useful within academia but has no practical application for people with disability themselves.

### Adopting a critical realist approach to disability

Unlike the other models of disability that focus on the structural or social barriers of oppression, a critical realist approach values the experience of the disabled person and considers factors that are intrinsic to their experience (Shakespeare, 2014). Critical realism recognizes that the evidence that can be observed may “come close to reality but is always a fallible, social and subjective account of reality” (Sturgiss & Clark, 2020, p. 143). A critical realist approach to disability also considers factors that are extrinsic to the larger context in which individuals affected live. The critical realist approach takes into consideration the whole system an individual finds themselves

in and as being affected by their interactions with the many different levels of society. It can be understood as being a relational model to understand disability. Adopting the quote, “nothing about us without us” (Charlton, 2000), this understanding of disability has been selected because of the recommendations of leading disability theorist with an impairment himself, Tom Shakespeare. The critical realist approach sees disability as always being an interaction that occurs between an individual and the wider context in which they live (Shakespeare, 2014). It factors in the individual's lived experiences and also their interactions with other people and their environment in which they occur, acknowledging that people are disabled by both their biology and by society.

An interactional approach allows for the different levels of experience, ranging from the medical, through the psychological, to the environmental, economic and political (Shakespeare, 2014, p. 678).

Even if all social barriers were removed, some people with disabilities would still continue to be disadvantaged because of their physical or cognitive impairment and the inability of the environment to manage this diversity. For example, some individuals may not be able to work the full day due to fatigue. Others may be limited in the work they can do because of differential understandings and cognitive ability. Some impairments require assistive technology which generates extra costs to purchase equipment (Smith et al., 2004). The complex reality of disability is more difficult than equalizing social opportunities. People are disabled by both society and their bodies (Shakespeare, 2014). Using an interactional approach to disability, Shakespeare (2014) re-conceptualized impairments as a predicament. Where the medical model understood the impairment as being a tragedy and the social model neglected the experience of impairment, the interactional model is flexible and accounts for the complexities of impairment. Predicaments involve challenges and difficulties, and therefore this approach offers a more realistic insight into the disability experience than other approaches.

Disability always includes an aspect of pain and frailty that comes from the limitation associated with a biological dimension (Shakespeare & Watson, 2002). Shakespeare is a leading disability academic and activist in the disability field, who has a personal lived experience of severe and enduring physical disability. His work at the World



Health Organization and contribution to the World Report on Disability makes him a leading expert in the field of disability studies. Because of his expertise combined with his lived experience of disability, I place a high value on his contribution to knowledge and recommendations into the field of disability. When conceptualizing disability, Shakespeare (2014) calls for a realist approach to the world that is grounded in empirical research.

People living with impairments experience factors that disable at different levels. Intrinsic factors refer to factors internal to the individual including but not limited to the impairment itself, personality characteristics and personal motivation (Shakespeare, 2014). Extrinsic factors refer to factors of a wider context that the individual may find themselves in, including but not limited to living environments, support systems, policy and societal oppression (Shakespeare, 2014). All impact upon the individual and contribute to disability. By researching disability as interactional and relational, disability is not seen as necessarily always an oppressive factor (Shakespeare, 2014). A person with a disability may experience help and support from family and friends which adds positive value to their life, and the critical realist approach allows for this experience to be acknowledged, where the other models do not. A benefit of using a critical realist approach to disability is that flexibility of choosing a research methodology (Ton, Gaillard, Adamson, Akgungor, & Ho, 2020). The critical realist approach allows for a qualitative, thematic analysis of information to be conducted. Critical realism allows for outcomes and events to be understood in their natural setting, particularly the how and why things happen (Sturgiss & Clark, 2020). People with disability are often missing from research that involves them and this is a problem. Many difficulties exist in including people with disabilities in research, including communication difficulties and understanding. To empower people living with disabilities, I believe that research that is about them should include them. A relational understanding of disability enables individuals to understand and make sense of their predicaments. An impairment is something the individual themselves comes into an understanding of how to deal with, as well as society and the community around them. Disability is very much experienced by the person living with the impairment and is compounded by the environment in which they find themselves in. Individuals are not only affected by their direct

surroundings; they are also impacted by the wider sociopolitical environment that they live. What is happening at an international level will have a flow on effect to the individual themselves.

Guided by these concepts from a critical realist approach to disability, a research method will be applied that acknowledges, seeks and explores the complexities of disability group home violence, abuse and neglect. This research will contribute to a firmer conceptual framework and empirical footing by using disintermediated information produced by people living with disabilities themselves. A theorization of disability would be incomplete without an understanding of the assumptions that create ableism. Next, I will outline the assumptions that create ableism and advantage for people without disabilities.

### The underpinning ableism problem

People without disabilities are advantaged within structures and systems that are created for them. Preference is given to dominant norms about communication, ability, knowledge, capacity and norms of social interactions (Reynolds & Timpe, 2020). These assumptions about ability oppress and marginalise people living with disabilities. Such socially constructed ideas place value on people's bodies and minds based on preferences of normalcy, intelligence, excellence and productivity (Lewis, 2020). These inherent ideas place value on who is deemed worthy and who is not based on ability and appearance (Lewis, 2020). Ableism creates obstacles for people and stops them not only from flourishing but also from surviving (Wieseler, 2020). Such preferences are ignored and are taken for granted in an ableist world, damaging the disability community by creating oppression and disadvantage that impacts daily living. Ableism is the theoretical lens that enables these assumptions to be highlighted and recognised. Assumptions about abilities and capacities when left uninvestigated are at risk of being ableist and therefore discriminatory to people with disabilities (Reynolds & Timpe, 2020).

Language choices perpetuate the system of oppression created by ableism (Bottema-Beutel, Kapp, Lester, Sasson, & Hand, 2020). Research into disability is often conducted by able-bodied researchers who may be unaware of their language and the impact that it has. Bottema-Beutel et al. (2020) recommends that researchers

understand what ableism is and reflect on their language to ensure that their research does not perpetuate discrimination against people with disabilities and contribute to the ableist problem. Unemployment, mental health and victimization are some of the effects of ableism (Botha & Frost, 2020; Bottema-Beutel, Cuda, Kim, Crowley, & Scanlon, 2019; Cage, Di Monaco, & Newell, 2018; Johnson & Joshi, 2016; Sarrett, 2017). Language used by able-bodied people about the disability community can further decrease their value and undermine their contribution to economic life. It is imperative that the assumptions underlying ableism be understood and fully developed in the conceptualisation of disability to ensure that this research does not contribute to the problem. For this reason, those being studied are referred to as people with disabilities rather than the disabled, aiming to put the person before the disability.

The way in which disability is understood impacts the analysis of research findings when analysing the data set. In this chapter, I have argued for a critical realist approach to disability in this research. This is based on the recommendation of Shakespeare (2014), a leading scholar in the field of disability research and theory who is living with a disability himself. Any discussion about the theorization of disability would be truncated and inappropriate without the consideration of the epistemology of disability. For this reason, I outlined the medical model of disability and the social model of disability before discussing the field of disability studies in context with the two approaches. I presented the critical realist approach to disability as the theoretical lens through which the experiences of group home violence, abuse and neglect will be understood. Lastly, I acknowledged the assumptions underlying ableism and presented the argument for placing the person before their disability. In the next chapter, I will offer an argument for the deployment of unobtrusive research methods to explore experiences of disability group home violence, abuse and neglect.

### **CHAPTER 3**

## **OFFERING AN ARGUMENT FOR UNOBTRUSIVE RESEARCH METHODS:**

### **SAFE RESEARCH METHODS FOR VULNERABLE COMMUNITIES**

Research has relied heavily upon reactive research methods including interviews and surveys to inform theory. The downfall with reactive methods is the information collected contains bias. Bias affects the reliability and validity of data sets, results and how they are interpreted. Unobtrusive research methods use information that already exists without research bias. Data observed through unobtrusive research methods offer strengths to researchers and should be selected over other reactive methods where possible. The advantages of unobtrusive research methods are considerable.

In this chapter, I argue for the deployment of unobtrusive research methods to explore group home violence, abuse and neglect as experienced by citizens with disabilities. This chapter situates the significance of the research method within the field of disability studies. The argument for the selection of unobtrusive research methods highlights the authenticity of data collection made available by the internet. The authenticity of people's experiences is protected by using unobtrusive research methods and this emphasizes the gravity of the research method. The argument for the deployment of unobtrusive research methods enables the exploration of what people with disabilities, their families and carers, disclose on YouTube their experiences of group home living. This chapter highlights the benefits of social media research, in particular leveraging YouTube for data collection. It is argued that the social media data collection method chosen is trauma-sensitive. The need for trauma-sensitive research is especially favorable within human service professions including social work where social workers are bound by the ethical code to do no harm. This thesis was written during the covid-19 world pandemic and therefore appropriately includes a discussion about the advantages of social media research during times of crisis.

## The bias of reactive methods

Reactive research methods gather 'new' information but are systematically influenced by the presence of the interviewer and the dynamics of the situation itself (Raymond M Lee, 2000). Reactivity occurs when the subject of study is affected by either the instruments of study or the researcher themselves (Fielding, Lee, & Blank, 2008; Raymond M Lee, 2000). Part of the challenge of reactive research methods in capturing the truth is also known as the Hawthorne effect. The Hawthorne effect impacts the validity and reliability of research findings.

Interviews and questionnaires intrude as a foreign element into the social setting they would describe, they create as well as measure attitudes, they elicit atypical roles and responses, they are limited to those who are accessible and will cooperate, and the responses obtained are produced in part by dimensions of individual differences irrelevant to the topic at hand (Webb, Campbell, Schwartz, & Sechrest, 1999, p. 26).

Interviews and surveys are a foreign element into the social setting and have been relied upon heavily in the social sciences for data collection (Webb et al., 1999). While interviews and surveys have provided insight into a number of important issues, they are not without bias (Auriacombe, 2016). Reactivity limits the accuracy of information obtained through interviews and surveys. Interview and survey respondents are aware of the interviewer's presence and their involvement in research. They are also aware that their responses are being collected and analyzed. When a respondent is aware of being studied, the probability of bias is high (Webb et al., 1999). The reactive bias present during the interview and survey process is therefore high.

Many factors produce research bias and affect the quality of information obtained through reactive methods. One of the major errors in interviews is believing that what respondents have reported is the truth (Kellehear, 1993). Bias impacts truth. The interviewee is aware that they are being tested and observed. Those being interviewed could try to maintain their standing in the eyes of the interviewer and report information that favors them rather than be explicitly accurate in their disclosures (Raymond M Lee, 2000; Webb et al., 1999). This is regardless of how the questions are structured. Even variations in the way questions are worded can affect how the interviewed person responds (Raymond M Lee, 2000). Interviewees will

respond to visible cues produced by the interviewer including the age and gender of the interviewer (Webb et al., 1999). These factors all effect the reliability and validity of the information obtained through reactive methods.

Sourcing valid and reliable information when researching sensitive topics can be especially problematic when information is subject to reactivity (Raymond M Lee, 2000). Sensitive topics as defined by Raymond M Lee (1993, p. 4) is “research which potentially poses a substantial threat, to those who are or have been part of it”. Interviews can cause old traumas to transpire (Halicka & Halicki, 2020). Asking individuals to revisit and discuss scenarios that were abusive in nature may invoke feelings of shame and cause respondents to alter their responses. This potentially harmful experience during the research process is not desirable. Most people regard research that is likely to harm participants as unacceptable (Bryman, 2016). Research ethics policies are designed to intervene to reduce harm to participants. If there is a way to collect information that does not ask people revisit and discuss harmful situations but rather uses existing information and therefore do no harm, this should be preferred.

The exploration of experiences of violence, abuse and neglect of the disability community is a sensitive topic. Interviews and questionnaires have been relied heavily upon in the social sciences and therefore it is important that other nonreactive methods of social research be used to contribute to knowledge (Webb et al., 1999). Information collected by the means of interviews and questionnaires is reported behavior rather than actual observed behavior and thus the validity of findings can be questioned (Kellehear, 1993). Errors in research can be reduced by preferring methods that do not contain the reactive risk (Webb et al., 1999). Individuals may react to being asked to discuss experiences that have been harmful in the presence of an interviewer, with the knowledge that the information will be used for research. In such cases, nonreactive research methods are preferred.

### **Preferring nonreactive methods**

Obtrusive research methods such as interviews and surveys are subject to reactivity. Reactivity is considered a methodological weakness of obtrusive research methods and often cited as a justification for unobtrusive research methods (Raymond M Lee,

2000). Observation of research participants in their natural environment is an unobtrusive research method that can be very useful for collecting information rich material (Babbie, 2001). Observation can be a useful method to gather information about how participants behave in their natural setting (Starks & Brown Trinidad, 2007). The main difference between unobtrusive research methods and reactive methods is that all other modes of observation, with the exception of qualitative field research, require the researcher to intrude on the subject of study to some degree (Auriacombe, 2016). The information collected by observation can be used to make meaning out of the observed experiences. A major benefit of unobtrusive research is that it is non-reactive and people express their views on their own terms (Kellehear, 1993). Those under investigation are not harmed by the research process itself (Kellehear, 1993). Unobtrusive research methods are nonreactive in nature and look beyond the limited accounts that people provide themselves to examine society at a deeper level.

Unobtrusive use of "found" data can expose biases in data collected via reactive methods, or allow an otherwise hidden population or practice to be explored (Hine, 2011, p. 1)

Unobtrusive research methods can be used to affirm or extend knowledge created through reactive methods. Nonreactive research methods are activated through an investigative process that deploys already existing sources, texts and materials. Data sets are collected from naturally occurring responses. Unobtrusive researchers observe actual behavior of people in society, ensuring data sets are free from the Hawthorne effect and free from research bias associated with interview dynamics. An advantage of using secondary data sets is the replication opportunities that are available (Auriacombe & Meyer, 2020).

Physical traces, simple observations and archival records are three kinds of nonreactive information that Webb et al. (1999) distinguished in their classic work on nonreactive methods. Auriacombe (2016) stated that unobtrusive research techniques gather information about the respondent through public documents and can include published articles, books and archival records. Adding nonreactive methods to reactive methods, called methodological triangulation, further strengthens confidence in findings (Janetzko, 2008). Observation and analysis can be

easily repeated by rechecking findings and ethics is not required because people are not interviewed (Kellehear, 1993). The non-disruptive aspect to unobtrusive research methods means that it is inexpensive, accessible, safe and ideal for longitudinal studies (Kellehear, 1993).

Transparent, repeatable and verifiable research is concerned with how robust findings are based on valid empirical information, careful sampling and good ethical work (Kellehear, 1993). Ethical researchers operate in the most socially responsible way possible relating to issues of privacy, consent, confidentiality of participant, protection from harm of the participants. It minimizes cheating and the negative use of research while researchers themselves have a wider moral and social responsibility (Kellehear, 1993). Coupled with the fact that I am a social worker and attribute to the Australian Association of Social Workers (2010) ethical code to do no harm, I am highly motivated to adopt a research method that is trauma-sensitive, making unobtrusive research methods highly attractive.

### The Internet and unobtrusive research methods

Kellehear (1993) discussed different types of unobtrusive research including written records, audio-visual records, materials and observational work. Raymond M Lee (2000) built upon Kellehear's (1993) work by including the internet as platform to activate unobtrusive research methods. Lee (2000) argued that computer technology has provided the tools for improved acquisition, storage and management of information, enabling world-wide communication and the ability to access widely dispersed information.

These methods have a small but extended history. C Wright Mills (1959) argued that there is more than enough information in the world to research and investigate a whole range of issues. Now with the World Wide Web and social media, even more data sets are available. The internet has become so popular and has revolutionized culture. Prior to the advent of 2.0 platforms, the online and offline world were distinctly different. With the introduction of social media platforms including Facebook, YouTube, LinkedIn, Instagram and Twitter in the first decade of 2000, the online and offline environment became blurred (Niero, 2014). These new social media platforms enable an intertwining of on and offline relationships. Therefore,



there is no separation or distinction. Instead, the on and offline interfaces and platforms align and dialogue. This has many advantages for social researchers that can go online to access information to study what is occurring in the world in real life. For the unobtrusive researcher, this means that an abundance of "found" data sets is available on the internet at the click of the finger without leaving home. Online research methods have been gaining ground as a more popular research method over traditional data collection tools over the last two decades (Niero, 2014).

There is a wealth of information available on the internet for unobtrusive research into issues relevant to scholars and citizens. This material can be both contributed and accessed from anywhere in the world that has access to the online environment. Niero (2014) investigated the changing nature of the role of the interviewer in the rising popularity of the rise of online sociological research studies, in particular the researchers' invisibility. He acknowledged that in real life, the interviewer has control over the interview. With the rise of computer technology and collecting information over the internet through online surveys and other online research methods, the interviewer is not present and therefore loses the ability to control the interview process. Using the Internet for unobtrusive research methods mean that evidence is free from reactive bias. Another benefit of unobtrusive research methods and the internet is that large amounts of content is available to the researcher at a low cost (R.M. Lee, 2004). Using the internet for unobtrusive research is convenient for researchers.

Hine (2011) listed social research that had utilized data off the internet in the research process. Hine (2011) made the point that the internet created an opportunity for an aspect of social behavior to be researched that was not available through reactive methods. Many researchers have tapped into the benefits of using online information in their social research. The challenge in the Internet for unobtrusive research is that this type of archive lies in the ability to sort through the massive amounts of information available and choose a specific and relevant sample that is manageable (Raymond M Lee, 2000). YouTube is a valuable source of evidence for health research.

Health is an area that has been researched using unobtrusive methods via the Internet in different ways in recent times. YouTube has been used to investigate health information made available by digital media. The Internet has been used to study how the use of the Fitbit has created an online community that manages their health and shares information (Vesnic-Alujevic, Breitegger, & Pereira, 2018). Narratives within online communities on eating disorders have been explored through online social media forums (Cinquegrani & Brown, 2018). Approaches to internet research ethics, ethical considerations in digital research context have been considered (Giaxoglou, 2017). The Internet has been used for economic research into citizen's Internet activity and how the use of the Internet has revolutionized life (Rewera, 2013). The power of the internet through the use of social networking campaigns has been studied (Spears et al., 2016). The validity of fundamental methodological principles within political communication research in the online world has been investigated (Cerri, Fisher, & Taheri, 2012; Vowe & Henn, 2016). This research shows the influence that the Internet can have over health and other disciplines also.

Digital sources housed online are appropriate for the use of unobtrusive research methods. A range of fields have transformed through the online environment: Family Studies (Wynia, 2017), Early Childhood Education (Uwins, 2015), School of Education (French, 2016), Gender Studies (Attwood & Isupova, 2018), Faculty of Medical and Human Sciences (Brady, 2015), School of Hospitality and Tourism from the Faculty of Culture and Society (Jia, Luck, & Schänzel, 2016) and School of Public Health (Adanri, 2017). A social media method in the field of disability studies, specifically investigating experiences of violence, abuse and neglect, is culturally appropriate and an important exploration of work.

### Covid 19 and internet research methods

This research was conducted during the covid-19 world health pandemic. It is apt that consideration of the global pandemic be mentioned in a discussion of methodology. Social distancing measures and lockdowns may restrict information gathering methods such as interviews and focus groups. Unobtrusive research methods actioned on social media platforms are particularly attractive during crisis,

including the covid-19 pandemic. Social research can be conducted by researchers in solitude and via multimodal devices.

During an epidemic, an overabundance of information spreading between humans via digital and physical information systems occurs (Tangcharoensathien et al., 2020). Some of this information is accurate and some is not (Tangcharoensathien et al., 2020). Managing this influx of information to manage misinformation is conducted at a national and international level (Tangcharoensathien et al., 2020). Research into the spreading of this misinformation during the covid-19 global health pandemic has been studied by researchers (Liu, Caputi, Dredze, Kesselheim, & Ayers, 2020; Rovetta & Bhagavathula, 2020). During covid-19, individual activity on social media platforms including Facebook, YouTube and Twitter increased (Abd-Alrazaq, Alhuwail, Househ, Hamdi, & Shah, 2020). The opportunity for social media to be leveraged to communicate health information to the public was apparent (Abd-Alrazaq et al., 2020). The potential of social media to influence the public was particularly evident. Research showed that the extent of receiving covid-19 information online impacted risk awareness and engagement in various protective behaviors, including testing (Li, Feng, Liao, & Pan, 2020).

The internet was leveraged for research during the covid-19 pandemic. A google internet search was used to carry out research into the number of front line doctors who had died from coronavirus (Ing, Xu, Salimi, & Torun, 2020). An application to a research ethics board was required to source this publicly available information (Ing et al., 2020). A modified research method was trialed during covid-19 pandemic, with online group interviewing methods with vulnerable people and their support group being deployed (Dodds & Hess, 2020). Internet research has become increasingly popular since the covid-19 health pandemic outbreak as researchers seek other methods of collecting information. Information has been used creatively to investigate different phenomenon during this period. The potential impact of social media on the population has been recognized during the pandemic. Even during this covid-19 outbreak and the strict social distancing measures that were enforced, this research continued uninterrupted.

## The ethics of online data

The ethics of social research is concerned with the most socially acceptable way of collecting information (Kellehear, 1993). Ethics is ensuring the safety and welfare of research participants are maintained (Kellehear, 1993). Confidentiality of participants and voluntary consent are ethical principles that need to be considered during the research process to ensure ethical research is carried out (Kellehear, 1993). The internet is often used by vulnerable population groups for health information, communication with friends, and creating and continuing support systems (Sharkey et al., 2011). Conducting research with vulnerable population groups has been a complex and challenging process for researchers (Neville, Adams, & Cook, 2016). Ethical difficulties arise when seeking to source information from groups that have been deemed vulnerable. Issues surrounding informed consent and voluntary participation are complex to manage.

The principle of voluntary consent is that participants should not participate in research unless they fully and explicitly agree to participate (Neuman, 2014). Participants should know that they are participating in research. The principle of confidentiality holds that the identify of participants should be kept secret from the public (Neuman, 2014). By participants having anonymity, their identity remains unknown to the public. Obtaining informed consent and ensuring confidentiality is generally considered sufficient by review boards to fulfil the ethical principle of ensuring no harm is done in the research process (Tiidenberg, 2020). The fulfilment of these principles is contextual in an online environment and has associated complexities.

Informed consent is a difficult principle to fulfil when using information that is available online (Ess, 2020). Individuals uploading content to social media would not be aware when sharing that their contribution may be used for research purposes. Social media platforms however are public domains and often the material is shared publicly. Social media have been exploited by marketing campaigns and this has raised questions about the ethics of the use of online data by third parties (A. Thompson, Stringfellow, Maclean, & Nazzal, 2020). The issue of privacy and privacy protections is one of the biggest concerns in the online research ethics debate at

present (Ess, 2020). The internet changes how researchers identify research participants (Kaufmann & Tzanetakis, 2020). The matter is clear cut when social media sites are private and material is not shared for the public domain. This is clearly when data sets are not available to be shared. Conversely, those that upload material have personal control over privacy – and public – settings. They select the size of their audience.

Questions surrounding deontology are unclear in an online environment because of the public nature of the internet platform. Yet the private nature of the content being shared, which normally would not be shared publicly in a non-digital environment, is available to be read (Ess, 2020). This ethical matter has been raised, particularly with regard to content analysis and using direct quotes from individuals (Ess, 2020). The concern is that by entering the quote into a search engine, the individual would be easily found (Ess, 2020). Using direct quotes from YouTube would not have this same effect as video narratives have been transcribed rather than pulled directly from the social media platform. Once again, the tension lies between what is public material and for observation in contrast to what is considered private material. While debate has arisen over the concepts of informed consent and confidentiality being fulfilled by using public material from social media in research, there is no confusion or grey areas when it comes to material sourced by hackers. Using material sourced by hacking for research is clearly unethical and should not be used by researchers (Ess, 2020). The question about sensitivity lays with vulnerable groups of people.

Vulnerable people are individuals that are incapable of protecting their own interests (Tiidenberg, 2020). Classifying vulnerable populations has been found to have an impact upon the study conducted as researcher may feel gaining ethical permission to research such groups, include minorities such as groups based on sexuality, race, gender, or mentally or physically impaired for example, would potentially be too difficult (Tiidenberg, 2020). Vulnerability in the online environment is conceptualized differently than in real life and is therefore contextual. Vulnerability online may be classified as children or adults who share naked pictures of themselves, for example (Tiidenberg, 2020). Determining vulnerability in an online environment is debatable. Online research into issues which are illegal are considered sensitive (Tiidenberg,

2020). This encapsulates the research topic of disclosure by people with disabilities about experiences of violence, abuse and neglect. Because the population group is vulnerable and the research topic is sensitive, this research is very sensitive in nature. However, this information needs to be considered against the public sharing laws of YouTube. The opportunity to include the voices of the disability community in disability research needs to take preeminence in the decision to leverage YouTube in this study and weighed against the public nature of YouTube.

Using online information in social research is often considered part of public observation and therefore exempt from ethical review (Zia et al., 2020). Not everything available on the internet can be used for research purposes (Hine, 2011). It still needs to be considered ethically.

The online environment is a tricky one to negotiate in terms of deciding how to apply the principle to do no harm (Snee, 2013, p. 55).

Snee (2013) reflected on his own research where he used personal travel blogs that contained personal information and yet were available online. He raised the argument that ethical standards for internet research are subject to debate. The principle of doing no harm to a research participant was central to ethical considerations. The blurring of boundaries as to what was considered public and private information was questioned. With social media's format and evolving nature, there is a blur about what is online and offline.

YouTube is a public platform and videos summoned are public material. With the amount of information available on the internet, internet research is increasingly possible and increasingly attractive. The men and women with disabilities, their families and carers, in this research were empowered in their representations to ensure that the material data were interpreted ethically. Ethical considerations arise when engaging adults with severe disability in social research. To engage adults that are severely cognitively impaired in research, researchers may need to draw upon persuasive techniques (Bircanin, Sitbon, Favre, & Brereton, 2020). Without understanding the research or consenting to being part of the study, other measures are needed to engage them. Developing trust and engaging in the participant's terms are needed (Bircanin et al., 2020). This includes carefully reading the participant's

signs of tiredness to allow participants to take a break from engagement as needed (Bircanin et al., 2020). The tension between including participants in research and conducting ethically sound research methods can be challenging. These ethical issues are not a consideration when using unobtrusive research methods to investigate disintermediated videos created by people with disability uploaded onto YouTube.

As this is unobtrusive research, the researcher did not have any contact with the contributors of content. Following Harris, Kelly, and Wyatt (2014), consent was not sought from the authors of the videos uploaded to YouTube due to the public accessibility of YouTube and also taking into consideration the considerable size of the online community. The authors of the channels where videos have been summoned were not contacted or advised that their material was being used in research. Following Gardner, Warren, Addison, and Samuel (2019), the videos were treated as online public resources. Because of the public nature of the internet, informed consent to include the content in this research was not required.

### Social Workers and trauma-sensitive research

Unobtrusive research methods are often associated with historical research or sociology. Unobtrusive research methods have much to offer in the field of social work. Violence prevention is a significant area of study for the social work profession with its focus on human rights and social justice (Araten-Bergman & Bigby, 2020). Violence traumatizes people and social workers are interested in helping vulnerable groups of people that have experienced trauma. People that have experienced trauma have had their physical, psychological and/or moral safety threatened (Bloom, 2013). Caregivers are in a position of power and have the responsibility of ensuring a safe space for the people they are caring for (Bloom, 2013). When caregivers become perpetrators of violence, abuse and neglect, the people in their care have had their ability to self-protect shattered and the impacts on victims can be long lasting (Bloom, 2013). With the prevalence of trauma in society, social workers are frequently providing intervention for clients that have a history of experiencing trauma. They need to ensure that their practice does not re-traumatize the people that they are meant to be helping.

Social workers are responsible for ensuring that their practice is culturally competent, safe and sensitive (AASW 2010 p.5).

Sensitive practice is trauma-informed. It is logical to assume that people who have experienced trauma will present to social workers in the diverse settings of practice (Knight, 2015). Ascribing to the Australian Association of Social Workers (2010) Code of Ethics, social workers in Australia must ensure their practice is sensitive to the needs of the people that they care, support and advocate for. It is through an understanding and knowledge about the impacts of trauma that social workers can be informed, and in doing so, ensure their practice is safe and effective (Knight, 2015). Trauma-informed practice is a framework that enables social workers to conceptualize their practice (Alessi & Kahn, 2019). A lack of understanding and knowledge about trauma can result in the re-traumatization of clients simply by being involved with the client.

Trauma-informed social workers appreciate how common trauma is, and that violence and victimization can affect psychological development and lifelong coping strategies; they emphasize client strengths instead of focusing on pathology, and they work on building healthy skills rather than simply addressing symptoms (Levenson 2017, p.106).

Trauma-informed social workers understand the complexities of trauma and the lifelong impact it has on victims and develop skills to ensure best practice principles and minimize any negative impacts of intervention (Alessi & Kahn, 2019; Knight, 2015; Levenson, 2017). Research investigating personal experiences of trauma is needed to further develop trauma-informed practice.

Our clients who have suffered extraordinary violence, at the hands of others, have much to teach us about both individual and social healing, about how to change our institutions to reflect actual human needs rather than the distortion of unresolved trauma (The Source: The National Abandoned Infants Assistance Resource Centre p.16).

People that have lived through traumatic experiences have invaluable knowledge that needs to be shared so that trauma-informed practice can be improved. Trauma is prevalent in society and research into this area is important to further develop understanding and improve practice. Research into the area of trauma has grown in interest (Legerski & Bunnell 2010, Jaffe et al 2015, Allfleck 2017, Jain et al 2011). Research into the effect of trauma has considered the challenges of researching sensitive topics where participants are asked to speak about their traumatic



experiences (Clark 2017, Edwards & Sylashaka 2016, Nielsen et al 2016). While research into sensitive issues have grown in interest, so too has the concern that such research may harm participants involved.

To obtain information about traumatic events, research has required participants to discuss and revisit times in their life that were painful for them (Legerski & Bunnell, 2010). Trauma researchers have required participants to revisit and recount events that were traumatic to them in great detail by using data collection methods including interviews, written narratives or questionnaires (Legerski & Bunnell, 2010). Revisiting traumatic topics and talking through painful memories was once considered therapeutic in the clinical arena of trauma-related disorders (McClinton Appollis, Lund, de Vries, & Mathews, 2015). In more recent years, this kind of therapy and data collection method is believed to be harmful to patients and may lead to re-traumatization.

The disclosure and discussion of traumatic events can be overwhelming and distressing for participants, causing long lasting harm. Recounting traumatic events occurs when trauma researchers ask participants to discuss their traumatic experiences for research purposes during interviews, written narratives or questionnaires, for example. This process can impact negatively on research participants and ethics committees usually require distress-related symptoms to be monitored and immediate therapy offered to participants, as well as and follow-up therapy (Jaffe, DiLillo, Hoffman, Haikalis, & Dykstra, 2015). There is growing awareness in the field of research that trauma related research causes participants harm (Affleck, 2017; Jaffe et al., 2015; Jain, Nazarian, Weitlauf, & Lindley, 2011; Legerski & Bunnell, 2010). There is also growing concern from ethics committees and review boards about the appropriateness of interviewing participants about experiences that caused them trauma (Jaffe et al., 2015; Nielsen, Hansen, Elklit, & Bramsen, 2016). It is concerning that questions that trigger negative emotions could cause severe psychological harm, even leading to participants becoming suicidal (Jaffe et al., 2015). For research to be approved by ethics committees, research must be shown to be ethical.

Institutional Review Boards understand that asking participants to recount traumatic experiences will induce extreme distress and can be hesitant to approve trauma-related research (Jaffe et al., 2015). Lawyers, board members of ethical committees and mental health professions have been concerned that researchers are re-traumatizing research participants and harming groups that the research is ultimately designed to help (Nielsen et al., 2016). For fear of research that causes harm to participants, ethics committees raise concerns when approving research that requires participants to recount and discuss experiences where they experienced trauma (Jaffe et al., 2015; Nielsen et al., 2016). The need to conduct research into sensitive topics is recognized, as well as the potential harm that can be caused. There is a tension that exists between the need to do such research and the necessity to protect participants of research from harm (Jain et al., 2011). Social workers often conduct research with people that are vulnerable about sensitive issues and it is important that research is sensitive to the trauma that participants have suffered. This I call trauma-sensitive research.

Trauma-informed perspectives seek to help, empower and promote safety in scholarship that seeks to address unjust systems (Day, 2018; Levenson, 2017). Trauma-informed social workers opt for trauma-sensitive research methods, where possible. Research has found that participants were willing to communicate the depths of their pain and suffering using multimedia as a data gathering tool. Murthy (2008) used digital media as a source of data collection in their social research project where handheld video cameras were given to asthmatic patients in order for children to teach others about their illness.

What struck me was not just the respondents' deeply felt desire to communicate, but also their eagerness to communicate even intimate details (Murthy, 2008, p. 843).

The findings from Murphy (2008) demonstrated that vulnerable communities may feel more comfortable communicating their truths using multimedia rather than being probed with intrusive questions through an interview process. Multimedia as a data gathering tool was demonstrated to collect rich and information. The use of digital technology in social research proved here to provide information that was not available from other forms of data collection. Sourcing information that already

exists from the internet in research is emphasizing the client strengths that enable someone that is vulnerable and oppressed to finding and utilizing a method that empowers their voice in a safe way that they have control and power over. Referred to as the Hawthorne effect, power imbalances exist between the interviewer and interviewee during the interview process.

Where research focuses on sensitive areas, or particularly vulnerable groups, it can be a considerable imposition to ask respondents to recite their situation for the researchers' benefit (Hine, 2011, p. 3).

When interviewing vulnerable people and asking them to revisit experiences of abuse, this would exasperate feelings of vulnerabilities and resistance. This can be negated by using information that already exists. Information provided voluntarily and at the discretion of the vulnerable person themselves can be used to ensure trauma-informed scholarship. Such research methods are trauma-sensitive.

When researching violence and abuse, self-reports are the most efficient data collection method in research (McClinton Appollis et al., 2015). While other unobtrusive research methods, such as observation and reading of client files, exists for researching sensitive topics, such methods are not as effective data collecting methods as self-reports from survivors of violence, abuse and neglect themselves.

Since almost every conceivable aspect of daily life is reflected somewhere online, and since the cloak of anonymity can lead people to a frankness they rarely show in face-to-face encounters, the Internet offers rich data for almost any social researcher and particularly those working in sensitive areas (Hine, 2011, pp. 2-3)

This makes YouTube particularly attractive as a platform to enact this research method. Data sets summoned from YouTube are unobtrusive and therefore not causing harm through re-traumatization of participants. YouTube videos contain self-reported narratives of experiences of violence, abuse and neglect. Researchers and especially social workers should be careful that in their attempt to help those who have suffered, they do not do any further harm to these vulnerable communities. Not only that, but research design must be ethically sound to be approved by an ethics board and be conducted.

Using unobtrusive research methods to collect information that already exists should be preferred over intrusive research methods which have the potential to harm.

Living in the era of the information age, extensive amount of data exists on the internet which can be summoned in research about sensitive topics that would otherwise have the potential to harm participants. This makes unobtrusive research using data summoned from social media platforms into sensitive topics very attractive and of great value.

## YouTube as a trauma-sensitive research method

To achieve psychological safety, victims must regain the power of speech, a narrative of memory, and the symphony of modulated feelings that constitutes full humanness (Bloom 2013, p.133).

The use of disintermediated videos to recount experiences of violence, abuse and neglect create a safe space for victims of abuse to tell their story as they have power and control of what they say and when they post. The effect of psychological traumatic experiences is fragmenting in both memory and speech, the brain requiring that memories are integrated for healing to occur (Bloom, 2013). When people talk about their experiences to a video camera, they may feel as though they have a safe space to voice their experience and this can serve as a healing process.

Trauma-informed social work incorporates core principles of safety, trust, collaboration, choice, and empowerment and delivers services in a manner that avoids inadvertently repeating unhealthy interpersonal dynamics in the helping relationship (Levenson 2017, p.105).

By watching the videos, we become bystanders. Bystanders have two choices. They can either remain silent and therefore by remaining silent, are accepting the violence. Or they can do something about it by acting. Social workers know about the impact and adversity that trauma has on individuals. We need a new research technique that does not further traumatize the individuals that we should be advocating for. The information that we require is available on the internet and needs to be collected. This investigation, using data summoned from social media, is a trauma sensitive research method.

Other research methods can further traumatize an already traumatized and vulnerable group of people, when you are asking them to talk about experiences of violence, abuse and neglect. We have a social responsibility to act upon the stories that are disclosed via disintermediated videos. The benefit of using videos that are

uploaded onto YouTube by clients themselves is that the videos are made completely by the choice of the individual themselves. They have spoken about their sensitive issues in a manner that is self-paced. This self-paced disclosure is based on understanding of trust within trauma-informed care and practice principles (Levenson 2017, p.108). YouTube as an environment is a space that the creators of content choose to trust. These are characteristics recognized as needed to ensure people that have experienced trauma can thrive in an environment that facilitates healing. YouTube is a space where people are speaking on their own terms and in their own time about experiences of violence, abuse and neglect.

The benefits of using YouTube as the interface and platform for a trauma-sensitive research method extend beyond simply efficient data collection that is free from the Hawthorne effect. YouTube as a data collection method empowers the voices of people living with a disability that have used film at their discretion to recount experiences that may have been traumatic in nature. It is unnecessary to ask vulnerable communities to recount experiences that were traumatic in nature if the information already exists. Researchers, and especially social workers, are bound by the ethical code to “do no harm” (Australian Association of Social Workers, 2010) and should leverage the information that already exists on social media. This pre-existing data collection method empowers people with disabilities rather than asking people to revisit traumatic experiences, potentially triggering life-threatening responses.

Empowerment in the context of research is an important concept for vulnerable communities. It is the individuals and communities that are able to exercise influence and control over resources, events, and outcomes that Block et al. (2011) understands as being empowered (Block et al., 2011). This idea of empowerment is closely linked to self-advocacy and self-determination (Block et al., 2011; Clifford, 2013). For vulnerable communities that are being researched, empowerment is desirable. Researchers are in a position of power because of their expertise and position within the research process. Empowerment in research goes beyond establishing informed consent (Cascio, Weiss, & Racine, 2020), and can equalize the power imbalance. Empowerment in research can be demonstrated where the participants decide themselves how they will be involved (Cascio et al., 2020). When people with disabilities use YouTube to discuss their group home experiences of

violence, abuse and neglect, empowerment is being exercised. Individuals are exercising influence and control over their content, channel and postings. They are using their channel for self-advocacy and self-determination.

The intersection of empowerment and research is complex, especially when researching vulnerable communities that have experienced trauma. An agent is someone who acts, rather than someone who only consents (Cascio et al., 2020). The individuals who used YouTube to document their experiences of group home violence, abuse and neglect are demonstrating their sense of agency. This is an empowering technique of data collection. It is one thing to have informed consent in a study. The research is extended and the intersection of empowerment and research is strengthened ethically when individuals themselves are displaying agency. This is especially true for vulnerable people groups when the topic of research is sensitive and has been traumatic.

Adverse life events that are traumatic in nature and have a stressful character are considered adverse events (Karr et al., 2020). This search term strategies of this research did not specify people with intellectual disabilities and could have included other impairments. I am refining this discussion to people with intellectual disabilities now because of the increased risk that people with intellectual disabilities have experiencing adverse effects and also their impaired functioning to process such life events. People with intellectual disabilities are at increased risk of exposure to traumatic and adverse events, and especially interpersonal violence, as demonstrated by research into this area (Mevisen, Didden, & De Jongh, 2016). The difficulties associated with processing these traumatic and adverse events may be impaired due to impaired cognitive and adaptive skills (Mevisen et al., 2016). The conceptual, social and practical domain are areas in life that evidence symptoms of impairment in people that are intellectually disabled (Schalock et al., 2010). Deficits in language, communication skills, memory, reasoning and social judgements begin during developmental periods and continue in life (Schalock et al., 2010). Self-management is impaired in areas of money management, personal care, school and work tasks (Schalock et al., 2010). A trauma-sensitive research method is particularly important for people with intellectual disabilities that have experienced adverse events.

In this chapter, I have argued for the adoption of unobtrusive research methods to explore the topic of disability group home violence, abuse and neglect. I have compared and contrasted the benefits of deploying a nonreactive method rather than reactive methods. I have revealed that the data available on public social media platforms should be utilized in disability research and that unobtrusive research methods should be preferred over other more intrusive methods especially for investigating traumatic experiences. The ethics of using information summoned from the online environment was considered. Unobtrusive research methods were argued as vitally important in the field of social work where social workers are bound by the ethical code to do no harm. Information summoned from social media and analyzed using unobtrusive research methods was positioned within the social work discipline as a trauma-sensitive research method. This chapter presented an argument which underpins the deployment of public information summoned from social media within disability studies, which is my original contribution to knowledge. In the next chapter, I will outline the method deployed in the research process and how meaning was made from the data set.

## **CHAPTER 4**

### **WHY INFORMATION LITERACY MATTERS: SUMMONING MEANINGFUL DATA SETS FROM THE DIVERSITY OF INFORMATION AVAILABLE ON SOCIAL MEDIA**

Social media are public interfaces and platforms where information is shared between users online. The boundaries between the online environment and the offline environment have disappeared with the prominence of social media use. What is available online is an accurate reflection of the offline world. Social media platforms are spaces that are rich in information. The way that data sets are collected and interpreted informs the epistemology of social research. A step-by-step description of the data gathering process and consideration of the methods that other researchers have deployed when using social media research supports the creation of knowledge in this thesis. From internet search strategies to the way meaning is made, the methodology is crucial in positioning the research in the field of disability theory.

In this chapter, I present the method deployed during the research process and explain how meaning was made from the information. YouTube was used as a data source. Complete disclosure of the data collection method enables transparency and for the research to be replicated. This chapter is essential for positioning the social media research as a valid and reliable research method. The importance of an integrated literature review is presented in the context of unobtrusive research methods. This situates the analysis of data within existing disability theories and provide the basis for which theory validated and then extended by the findings of this research.

I begin this chapter by presenting a forensic exploration of the six specific YouTube searches that were summoned during data collection. The key search terms deployed in the research are operationalized and parameters of the research defined. This methods section demonstrates how different search terms entered into the YouTube search bar enabled access to many disintermediated videos that were summoned for analysis. The strategies used by the researcher to assess whether the videos returned during searches fit the parameters of the research questions are



described throughout the process. I present the thematic analysis that was used to analyze qualitative data summoned from YouTube. Finally, the process in which the information transcribed from disintermediated YouTube videos was used to make meaning of the information is discussed. As is common with qualitative unobtrusive research methods, a process of contextualizing the information in existing disability theory enabled the information to translate into knowledge. The imperative of this chapter is to ensure that the research presented in this doctorate is transparent, rigorous and repeatable.

### Establishing trustworthiness in qualitative research

It is important that this research using data collected from social media be recognised as a legitimate creation of knowledge that contributes to disability theory about group home violence, abuse and neglect for people with disabilities. Establishing trustworthiness is a way that researchers can persuade themselves and readers that their findings are worthy of attention (Lincoln & Guba, 1985). This research uses the concept of trustworthiness refined by Lincoln and Guba (1985) that extends the conventional qualitative assessment criteria of validity and reliability by including the criteria of credibility, transferability, dependability and confirmability. These trustworthiness criteria will be interwoven throughout the detailed, step-by-step description about how this research conducted a thematic analysis that was trustworthy and worthy of attention.

In 2018, I deployed unobtrusive research methods to understand group home violence, abuse and neglect of people living with disabilities in group homes. Disability was conceptualised broadly and included all types of physical, emotional and mental impairments. These may have included mental ill health, psychosocial disabilities, mild to moderate learning disabilities, mild to moderate intellectual disabilities and physical disabilities. Group home accommodation provides extra support for people that experience impaired functioning. Group home accommodation is available in different types of settings and available for different groups of people. Group homes can house children, teenagers or adults. The decision was made to exclude group home accommodation for children or foster children. The focus of this research exploring violence, abuse and neglect was adult

accommodation for people with disabilities. Because of the unobtrusive research method deployed to summon publicly available information from the social media platform, YouTube, ethics approval was not required. There were five phases of this thematic analysis, which I will outline.

I specifically sought disintermediated videos, directly produced from group housing. Based on the understanding of disintermediated platforms by Brabazon (2020), the content of disintermediated videos uploaded on YouTube is determined and defined by the audience of the platform itself. I desired a trauma-sensitive research method that utilized the internet. Reactive data collection can impact upon the information obtained. Through YouTube, public videos are available that present the narrative and life experiences of these men and women, on their own terms. YouTube, and other similar digital platforms, allow for the sourcing of an abundance of easily and readily assessable information (Gardner et al., 2019). I used information already in existence and was available on the internet by sourcing testimonies already uploaded to YouTube. Individual testimonies did not have to be rich of words as even observing what people decided to record and post enabled me to understand why people with disabilities living in group homes were using YouTube to disclose their experiences of violence, abuse and neglect. Exclusion criteria included media uploaded by News Channels or documentaries. I included disintermediated videos uploaded by disability advocates and individuals themselves as this was considered part of the disability community. Data were available on YouTube. To reduce the influence of a user's history to search results, only one YouTube account was used to search for videos. How this information was interpreted and analyzed remained the key area for discussion.

### Conceptualizing the disability search term strategy

The potential for a wide range and scope of disabilities to be included in this research is acknowledged. From the outset, it was understood that the meaning and experience of the term 'learning disability' is constantly changing and inconsistently defined (Cluley, Fyson, & Pilnick, 2020). Other terms that refer to the same group of people include 'intellectual disability' and 'developmental delay' (Higgins, 2014). To ensure that voices of disenfranchised groups are not excluded from research, existing

information available on the internet, specifically YouTube, was summoned and considered in relation to existing disability theory. The strength that unobtrusive research methods offer research into people with disabilities is that members of this group share interests and viewpoints. It also shows that these views can be expressed by representatives conveying the authentic voice of people with disabilities. Intellectual disability was not specified in the search terms because authors of channels did not typically disclose the nature of their disability, however much of the literature has an intellectual disability focus. This is because group homes typically house those with impaired cognitive function. Group home accommodation has become a main form of accommodation for adults with disabilities since deinstitutionalization of the disability sector in Australia and other countries such as England, Sweden and the United States (Larson, Ryan, Salmi, Smith, & Wuorio, 2012; Jim Mansell & Beadle-Brown, 2010; Tøssebro et al., 2012). Living in the group home environment, it was expected that most of the creators of content about group homes experienced mild to moderate intellectual or learning disabilities. The nature of the impairment was often times discovered upon watching the video and analysing the content.

I'm also disabled. I have PTSD. Chronic post-traumatic stress disorder. I also have depression. I also have anxiety. So, I mean I don't have bipolar and all the rest of it. All the residents have it, like schizophrenic and all that (Latrice Allen latriceallen@live.com, 2015b).

Life would be a lot easier if I didn't have cerebral palsy like I do (Rebel Fighter, 2018d).

A group home is for mental health (Angus Rudd, 2014).

My glasses here are completely bent out of whack because I ran them over with my power wheel chair (Rebel Fighter, 2017).

I've been diagnosed as having social anxiety (Rebel Fighter, 2018c).

The content from the various videos captured and disseminated the mode and form of disability and its meaning for the speaker. Disabilities ranged in scope and nature

including intellectual, psychosocial and physical. Discussion of assistive technology revealed a physical impairment. Discussion of mental health conditions revealed mental illness. A range of disabilities was evidenced in the data set summoned by the search term strategies. Also, the grouping together of people with disabilities can be arbitrary and random, with people of differing nature of disability grouped together.

People with higher levels of, like people that have more severe disabilities will get priority over you. For example, Luigi and somebody else in my building, I cannot say his name, gets priority over me because their disability is more severe and while I understand that, I also feel that my care was being overlooked here and in some cases, it was being rushed to accommodate the other clients (Rebel Fighter, 2018d).

Hello my name is Kyle Demichael and I live in a group home and I thought group homes were supposed to be let's say nice or great or something but it's somewhat nice but not really. See it's about people with disabilities and people that need help. There's all kinds. There's bed resting ones, there's non-talkative ones, violent ones, disability. Some people don't talk. There's good hearted ones, there's misunderstood ones, people without families or with families. But I'm really talking about the group home itself (Kyle demichael, 2019).

This illustrates that people with disabilities are othered as a unifying group. Some individuals appeared neurodiverse, perhaps with an attendant cognitive impairment or learning disability. These terms however were not used or deployed by the presenters. What is revealed in their testimony is that the contributors to YouTube are also active in the community by viewing and browsing the videos created by others (Bircanin et al., 2020). There is the possibility of people with severe disabilities contributing to this research. People with severe disabilities would be sharing homes with people whose impairments are not as severe and disabling.

Yeah house mates' suck. Yeah. My house mate that I had to put up with winds up on the floor and his name's Devon. He's like all retarded and he's in a group homes (Mark Cinque, 2018).

What is evident from the mode of information revealed on YouTube and currently absent from the theorization of group home violence, abuse and neglect is that the voices included in this research have digital capacity. They are able to use media to participate in this research. People with disabilities that do not possess digital capacity or have the support to participate in the digital space have been excluded from this research as a result of collecting information from a public social media platform. The support of social networks that a person with disabilities has access to living in group homes is another impacting factor upon the participation in this research. Support of social networks in accessing the internet to ask for help from family, friends, colleagues or support people is an important factor in accessing how the internet is used and the advantages gained from it (Ragnedda, 2017). Parents of individuals with disabilities using their channel for advocacy were observed specifying the nature of their child's disability upon whom they were sharing their group home living experience. Some videos specified "autism" in the video title. What appeared to be a mother of an autistic son, included the nature of the impairment within her channel's title, being "Autismwarriormama".

You can't believe the money that parents and families with autistic people spend on things that get broken, smashed (Autismwarriormama, 2017).

Considered and diverse representation of people with disabilities in research and policy development is necessary to fight marginalisation and stigma (Altermark, 2017). Some people with disabilities that did not have internet access or lacked the capacity to use YouTube were excluded from this research. The exclusion of people due to digital capacity or internet accessibility does not make this research any less valid. It is important and necessary that the voices of people with disabilities that can access the internet be listened to and understood in context of disability theory to validate and contribute to understandings of disability group home violence, abuse and neglect. As expressed by Charlton's (2000) slogan "nothing about us without us",

unobtrusive research through observation and analysis of YouTube provides insight into the strengths of this mode of data collection and information theorization.

Socially just research questions the terms, concepts and assumptions that render the disability community as othered. This is accomplished by “unlearning” privileged modes of knowledge production and finding strategies to summon alternatives (Altermark, 2017). By including disintermediated videos in social research, knowledge production is including a mode of information that is able to be shared online by people with disabilities. This allows for members of the group to exceed their categorization of oppressed and disadvantaged, rather recognising them as contributors of the disability debate. Letting people speak is not enough. We must value the contribution of people with disabilities and what they have to say.

The unobtrusive research methods applied in this research enables learning from people with disabilities and conditions that allow for their communications to be unstrained from discourses that marginalised them. This is a major advantage of a social media research. It forces us to reconsider the place of social media and accessibility for the disability community. Providing a space for marginalised groups to speak from and unlearning our modes of knowledge production to include the voices of people with disabilities can be achieved through this unobtrusive research method. It is imperative that people with disabilities can contribute to the knowledge production of theory (Altermark, 2017).

### Phase 1: Familiarizing myself with the data set

Thematic analysis was chosen in preference to other approaches. The exploratory nature of this YouTube study could be classified as inductive, as questions and theories were deduced in conversation with the data (Rieder et al., 2020). Qualitative research must be conducted in a rigorous and methodical manner to ensure methods create useful results (Nowell, Norris, White, & Moules, 2017). The research commenced by summoning disintermediated videos produced by self-identified people with a disability, living in community housing, and sharing their testimony consciously and publicly from YouTube. Using social media as a data collection method is complex because it involves human judgement (Thelwall, 2018). I specifically searched for videos created by men and women with disabilities

discussing their group home experiences. In qualitative research, the researcher is the instrument for analysis and therefore qualitative research is inherently subjective (Starks & Brown Trinidad, 2007). For this reason, it is imperative that the researcher be honest and vigilant about their own perspectives, pre-existing thoughts and beliefs, and how it impacts the research process (Starks & Brown Trinidad, 2007). I expected that discussion about group home experiences would include the disclosure of violence, abuse and neglect based upon my experience of disability group homes and also my review of the literature prior to starting the research. I began the search for a data set using the search term strategy, “the truth about group homes”. This first search term strategy was inspired by my desire to locate videos that exposed group home lived experiences that may be controversial. I expected that the search term “truth” would locate videos containing people’s individual experiences. As I transcribed the videos that returned from the first search term strategy, I observed the language used by the disability community themselves to describe their group home experiences. This process resulted in the deployment of six specific search term strategies: “the truth about group homes”, “group home experience”, “My life in a group home”, “Don’t go to group homes”, “Inside my group home” and “I hate group homes”.

Table 1 - Summary of YouTube data set

Search Term	Number of new channels	Number of Videos
The truth about group homes	7	34
Group home experience	4	8
My life in a group home	4	5
Don’t go to group homes	4	7
Inside my group home	9	21
I hate group homes	5	30
Total	33	105

When a useful video was found that fit the parameters of the research, I drilled into the author's YouTube channel by clicking into the channel and accessing their videos. Thematic analysis is a relevant qualitative research method that requires a detailed description and pragmatic approach to ensure data analysis is conducted in a trustworthy way (Nowell et al., 2017). A complete forensic step-by-step process of each search strategy was recorded throughout the data collection process and is provided below. Once a channel that had uploaded videos discussing experiences of the group home had been located, the video was transcribed and other videos of a similar nature uploaded onto the channel was investigated. I investigated each channel further and searched for other disintermediated videos about the group home experience from the same author of the channel. The constitution of group home violence, abuse and neglect became apparent as I searched and listened to the lived experiences of the disability community. Channels can further be categorised by authors into one or more topics, and these YouTube topics selected by authors have been problematized, with topics being misallocated and unrepresentative of content (Rieder et al., 2020). In this research, an exploration of topics was not deployed. This research sought to explore content specifically that captured the narrative of the disability community regardless of categories or topics attributed to channels by authors. What disturbs a person is unique and individual to them. This is the unique contribution of this social media research. The voices of men and women with disabilities, their families and carers, are understood and valued as being the experts in this issue that affects them. I transcribed the selected videos into a Word document. To do this while I was typing, I used the YouTube application on an iPad to view and observe the video, pausing and then playing the footage as I typed the narrative.

Two main units of information architecture, being videos and channels, structure the YouTube platform (Rieder et al., 2020). YouTube does not provide a straight forward and easy way of creating data sets, however most authors focus on channels as entry points (Rieder et al., 2020). This research used the search tool to locate channels and researcher discretion selected content which fit the parameters of the research. The channels were then drilled into to investigate whether other videos of a similar



nature which fit the parameters of the research were available. The assumption was that creators of content would make more than one video documenting their group home living experience. To demonstrate how multiple videos were transcribed by locating one author, I use the example from “Latrice Allen latriceallen@live.com”. This illustrates how an author was located through a search term strategy. A network of videos was located from drilling into the author’s channel. Latrice Allen latriceallen@live.com was found during search term strategy 1. The initial search was using YouTube on the computer and I used the iPad to find Latrice Allen latriceallen@live.com’s channel to view during the transcription process.

I opened YouTube on the iPad and searched for “Latrice Allen latriceallen@live.com”. Having located the channel, I touched the video on the iPad, which took me into Latrice Allen latriceallen@live.com’s video (refer to figure 1).

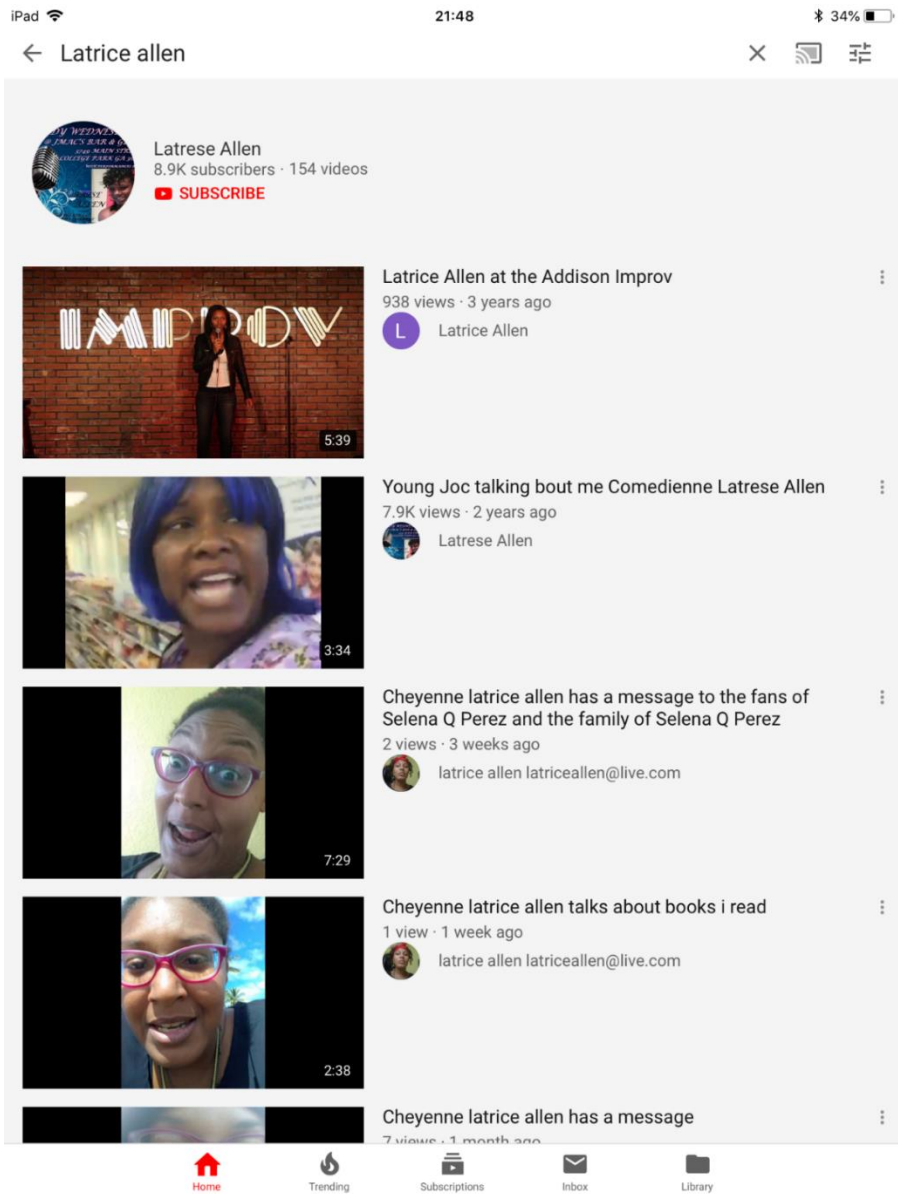


Figure 1

I entered into Latrice Allen latriceallen@live.com’s channel by clicking the small circle icon next to the name of her channel under the video. This transported me into her channel where I could then access all of the videos (refer to figure 2).

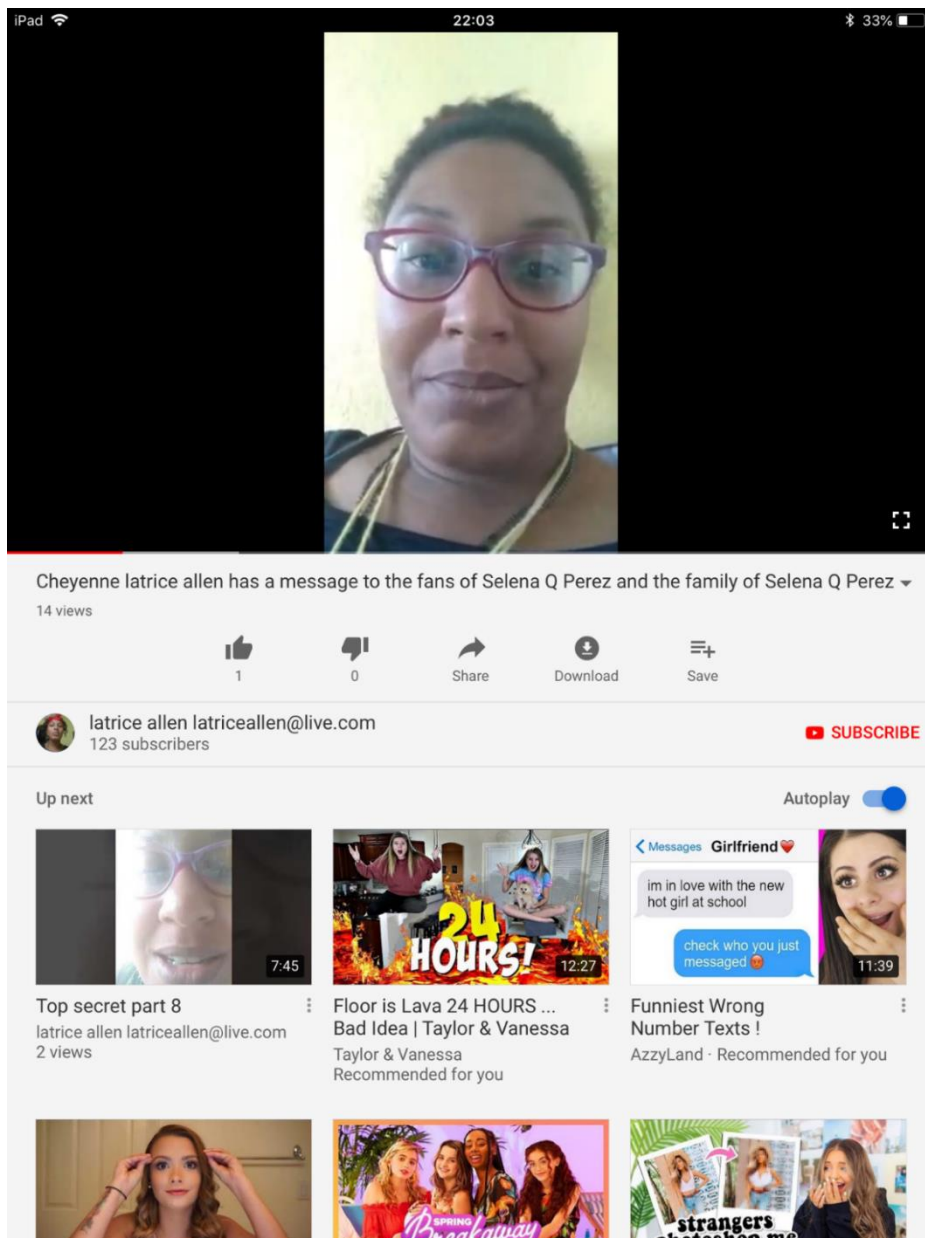


Figure 2

This visual gateway transported me to the home page of her channel. The video from the previous page had minimised and appeared in the bottom left-hand corner (refer to figure 3).

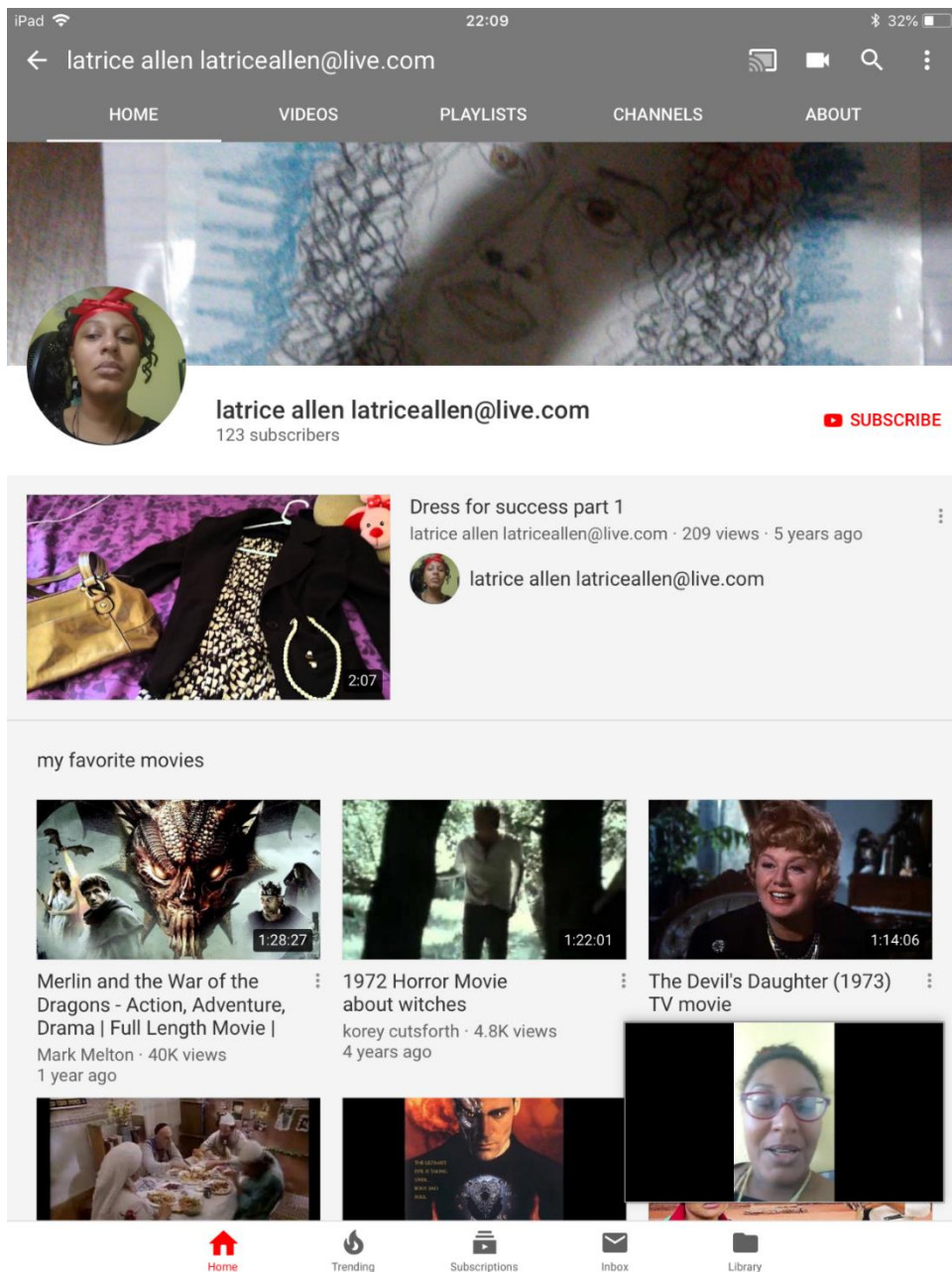


Figure 3

By touching the screen and swiping right on the video, the video disappeared, and I was left with the home page. I clicked “videos” at the top of the page to locate all the selection of videos Latrice Allen latriceallen@live.com had posted (refer to figure 4).

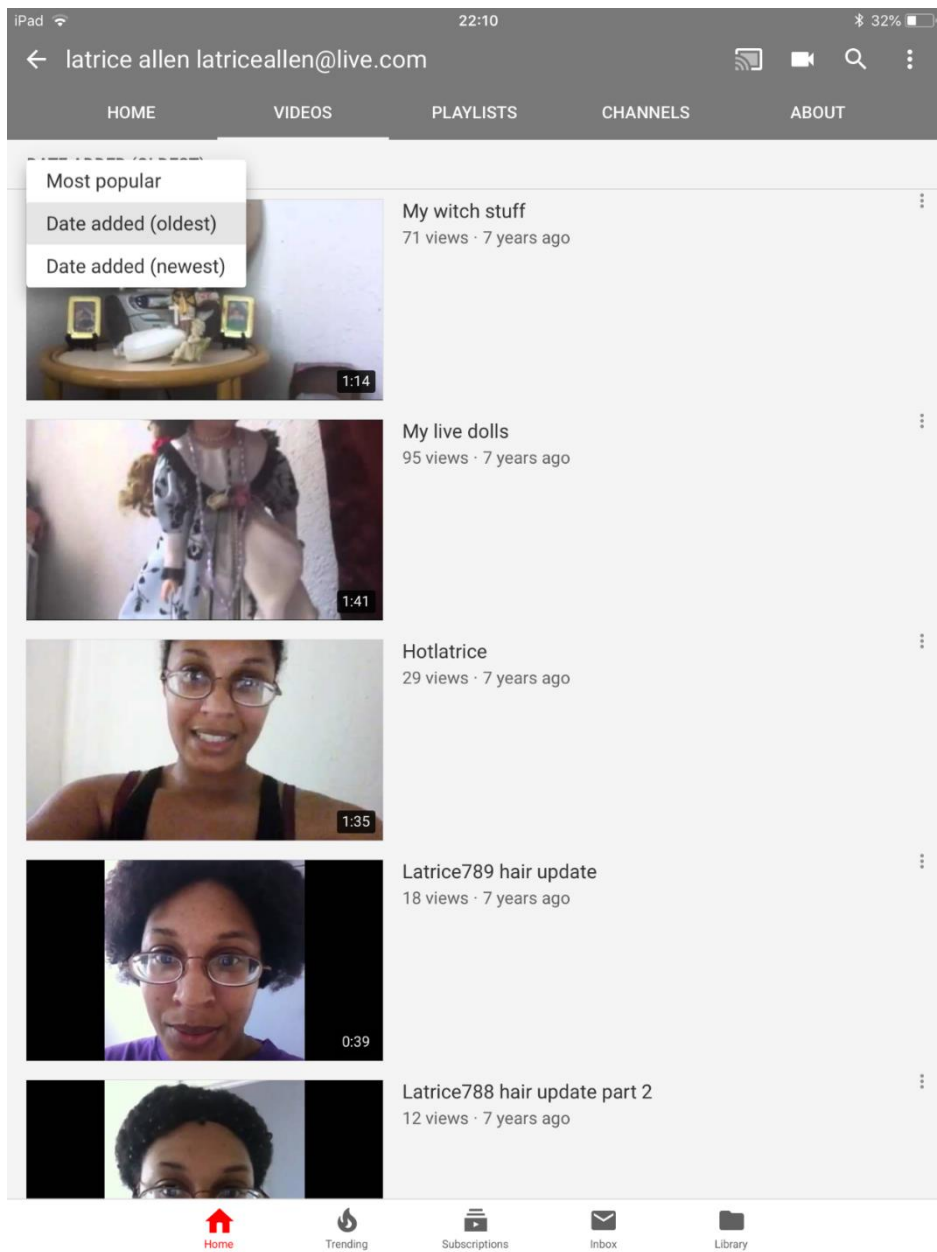


Figure 4

I sorted Latrice Allen latriceallen@live.com's videos by age, with the oldest posted seven years ago. Browsing through each of the video titles, I searched for videos related to housing. Each of these I watched to ascertain whether they contained content regarding the lived experience of group homes. I chose to sort by oldest video first because I wanted to transcribe the author's story in chronological order to aid insight into the group home experience. The oldest video I located about Latrice Allen latriceallen@live.com's group home experience was titled, "Bad things happen in group homes" (refer to figure 5).

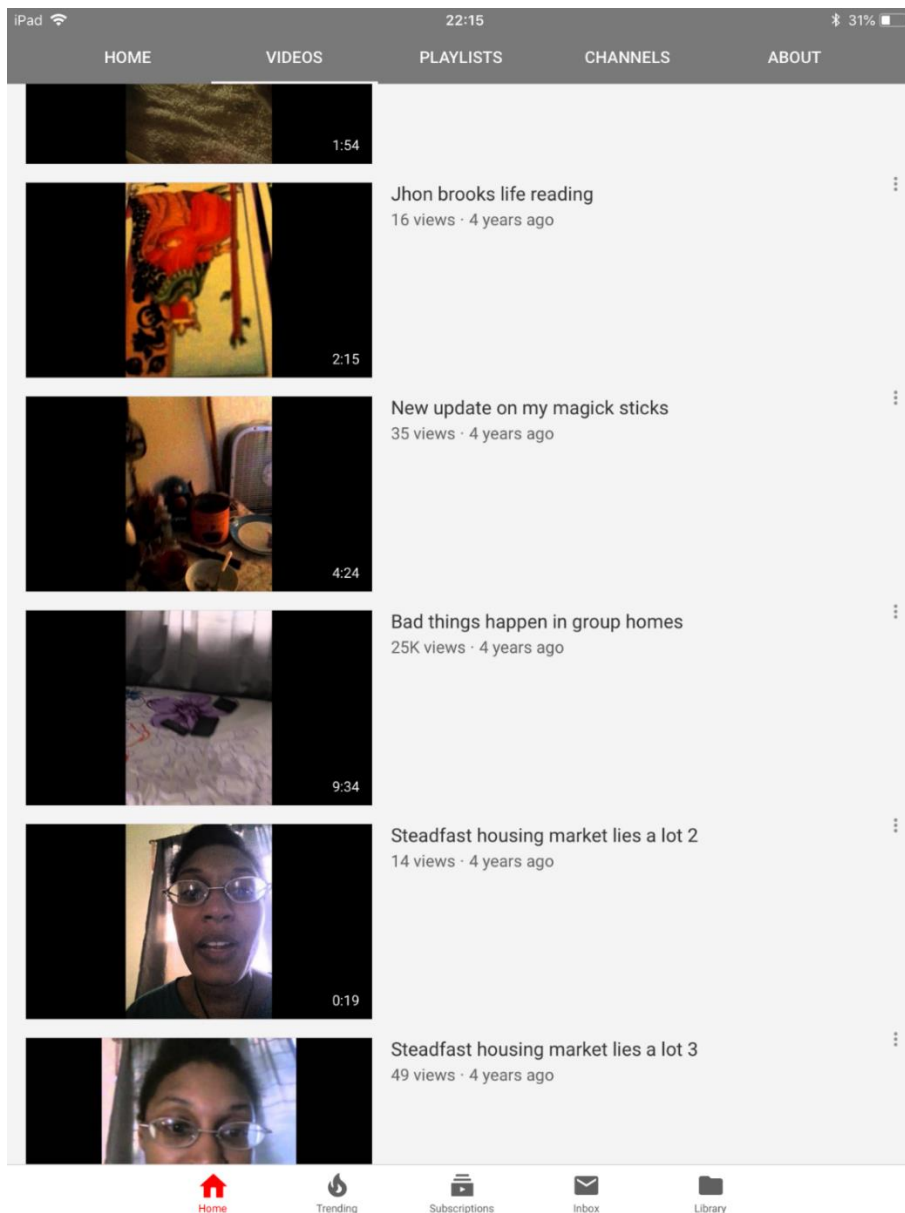


Figure 5

I used my iPad to play the video on YouTube while I transcribed the commentary into a Word Document on my computer. I created a folder called Data Set and transcribed all YouTube videos into one Word document. I played each video and paused regularly (refer to figure 6). In accordance with research by Lloyd, Osborne, and Reed (2019) that also transcribed YouTube videos, videos were replayed several times to ensure accuracy of the transcription. I would replay the video if I missed what was being said because of difficulty understanding or making sense of the narrative.

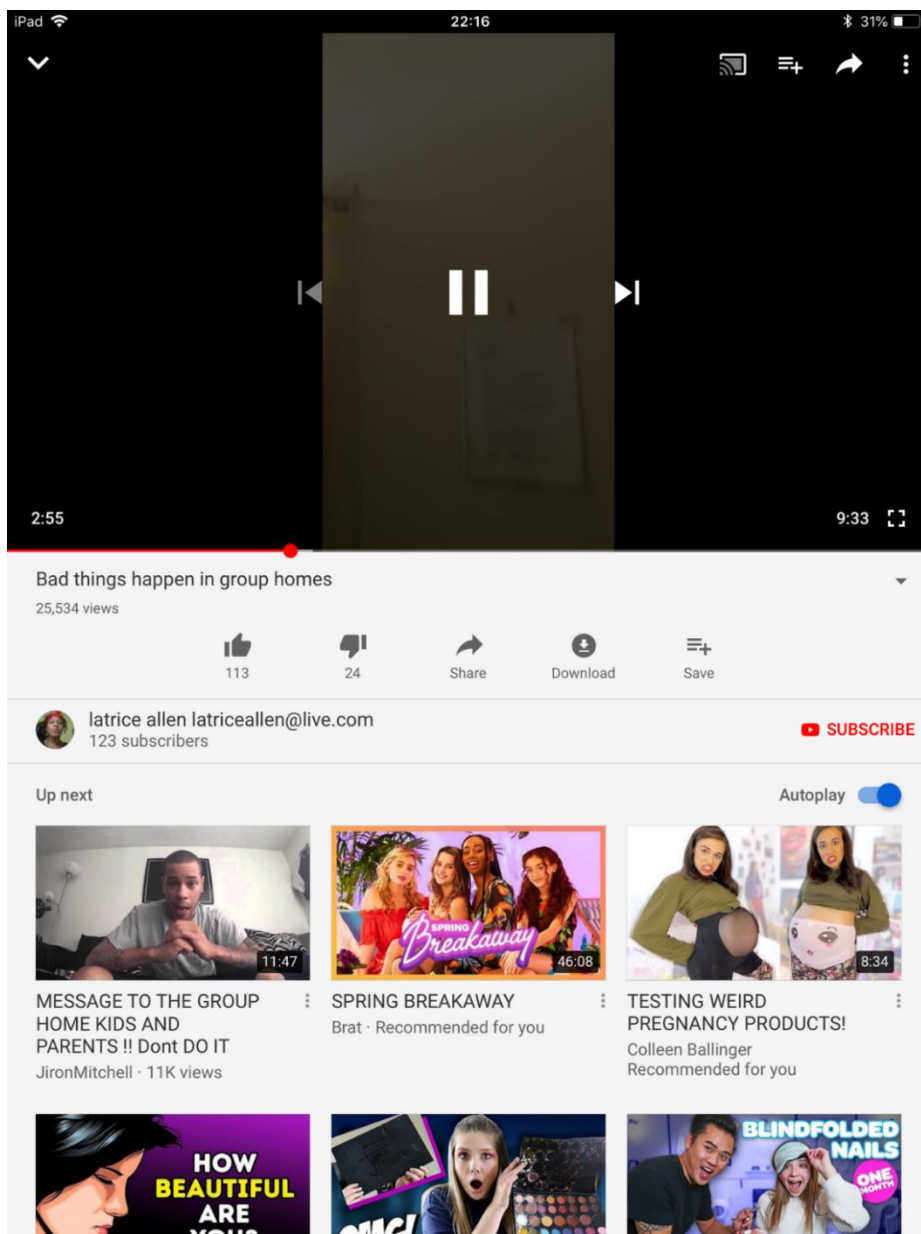


Figure 6

I transcribed the videos to collect the data in hard copy. To ensure each video was transcribed accurately, I replayed each video after it had been transcribed while reading the data I had just transcribed. If during the second replaying of the video there were any discrepancies that needed correcting, I replayed the video a third time. I replayed the video while reading the transcription carefully until the video could be played in totality without needing to be paused to be corrected. This process ensured the data collection was reliable.

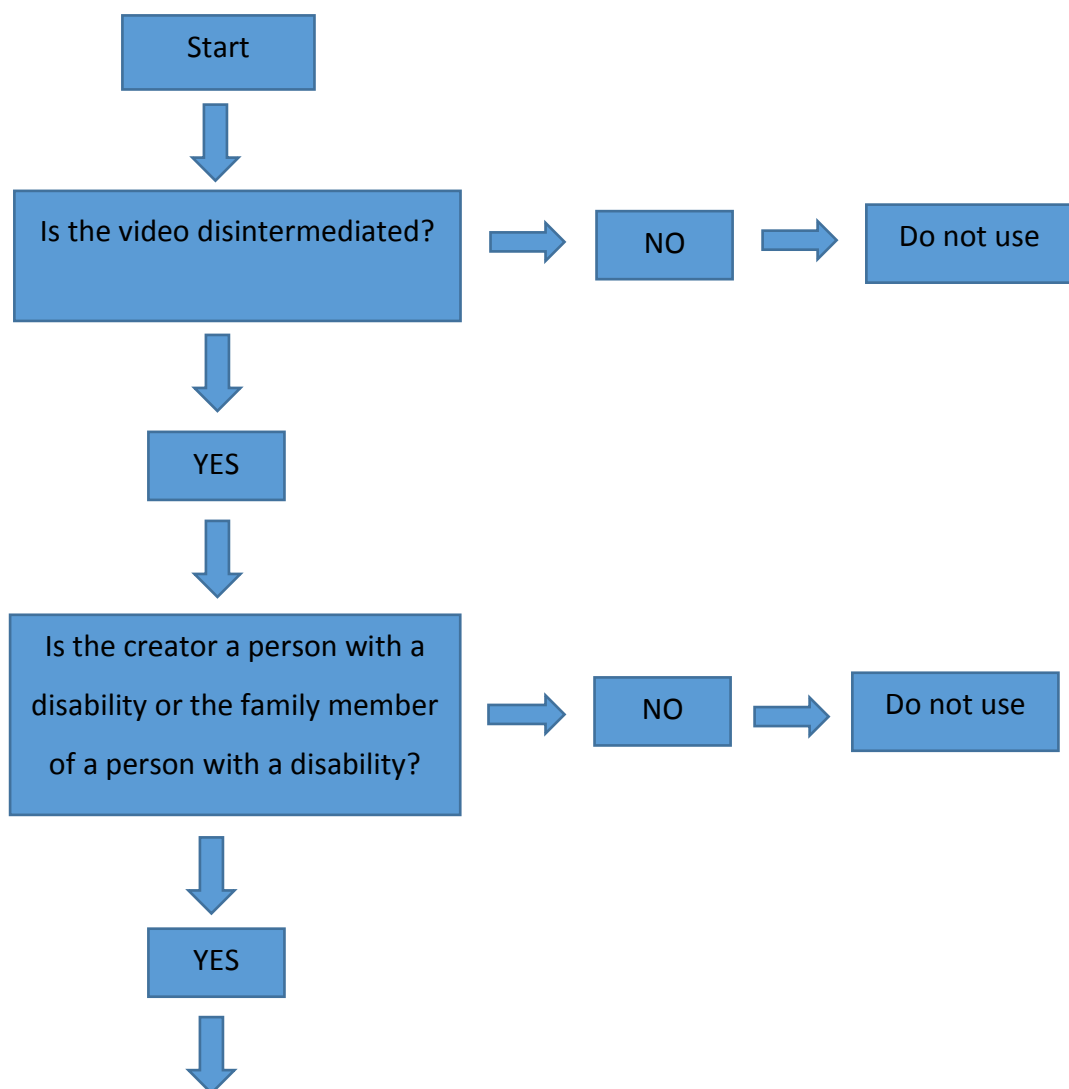
The next video in chronological order from oldest to newest was called, “Steadfast housing market lies a lot 2”. I used the transcribing method to transcribe the data from YouTube into the data set Word document. The next video in chronological order was, “Steadfast housing market lies a lot 3”. In Latrice Allen latriceallen@live.com’s “Steadfast housing market lies a lot 3” video, other terms were used by the author to describe the group homes where people with disabilities lived. The next video in chronological order was, “Steadfast housing lies a lot”. By listening to the content, this appeared to be the first in the three videos that Latrice Allen latriceallen@live.com had recorded. Videos were in chronological order of when they are posted by the user, but not necessarily of when they were recorded by the user. I used the transcription process to transcribe the next video. I continued using this method until all videos that were to be included in the data set were summoned and transcribed. This method demonstrates how each search term strategy was used by summoning one relevant video. One video was used to access the author’s channel and explore the content of other videos created by the same author. What was important was that the author had experienced the group home environment. The data set demonstrated that people with disabilities commonly posted more than one video about their group home experiences of violence, abuse and neglect.

The target population were videos recorded by people with disabilities and their families, whereby the videos had been uploaded directly onto the public YouTube interface. These videos disclosed experiences of group home violence, abuse and neglect. I accessed the sample population by using YouTube searches using search terms and then using personal judgement to select videos that fit the research criteria. The researcher assessed video titles, descriptions under videos and narratives within videos to determine the suitability of content. Purposive sampling that used the judgment of the researcher in locating cases with the specific criteria in mind was used to find authors of relevant content (Neuman, 2014). Once purposive sampling was used to locate an author, a snowballing technique was used to access the sample population. Snowballing describes a method for selecting cases in a network (Neuman, 2014). Search terms became apparent once the research process had begun. I started with the first search term being, “the truth about group homes”.



The second search was, “group home experience”. The third search was, “my life in a group home”. My fourth search was, “don’t go to group homes”. My fifth search was, “inside my group home” and the sixth and final search was, “I hate group homes”. I started by brainstorming search terms and then used terms based on the words that became highlighted to me as I researched that people with disabilities and their families were using to describe their situation. I will now provide a decision making flow chart (refer to figure 7) to ensure the methodology is easily reproducible, and then a forensic exploratory step-by-step description of each search term strategy that was deployed during the data collection phase of the research.

### Decision making flow chart



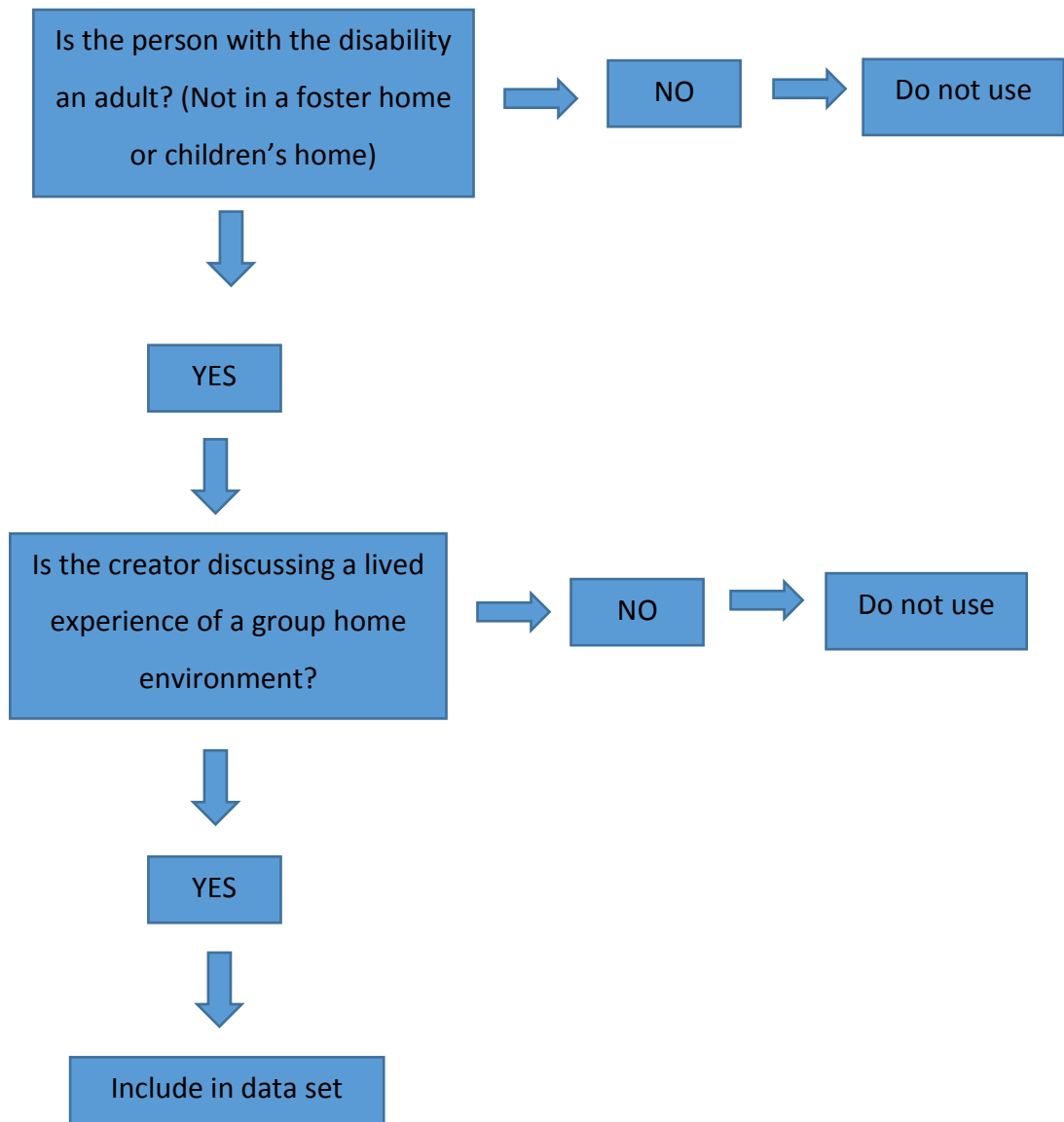


Figure 7 - Decision making flow chart

### Search term strategy 1

In the YouTube search bar, I typed, "the truth about group homes". I chose not to filter my search as I wanted to explore what was available in response to this conversational phrasing. Using the scroll bar on the right-hand side of the screen, I scrolled down through the videos. The first few videos that were on the top of the list did not look relevant (refer to figure 8). I will explain how I decided this.

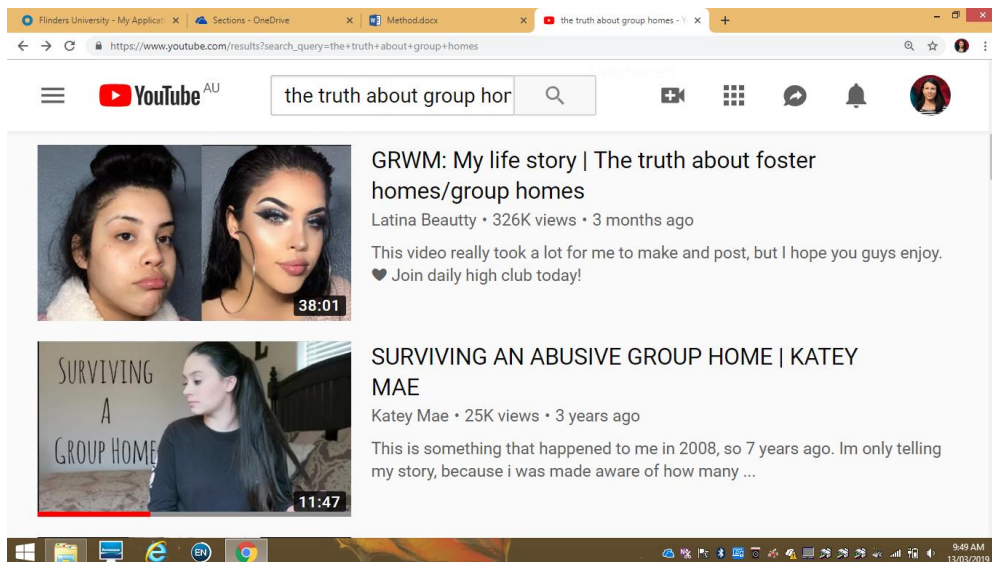


Figure 8

The title of the first video clearly indicated that the content was about foster homes, which was outside the parameters of my research. I continued to scroll past this video. The title of the second video suggested the content was about an individual's experience because of the description. I double clicked the video and viewed the video partially to observe whether the content fit the parameters of my research and was appropriate to include in the data set.

The author, Katey Mae, disclosed that she was unable to leave the group home because she was under the age of 18. From the outset of watching the video, I was able to determine that this video did not fit the parameters of my research. By observing the comments below the video, I assessed that the author was reporting on her lived experience in a children's home (refer to figure 9). This video was evidently outside the parameters of the research.

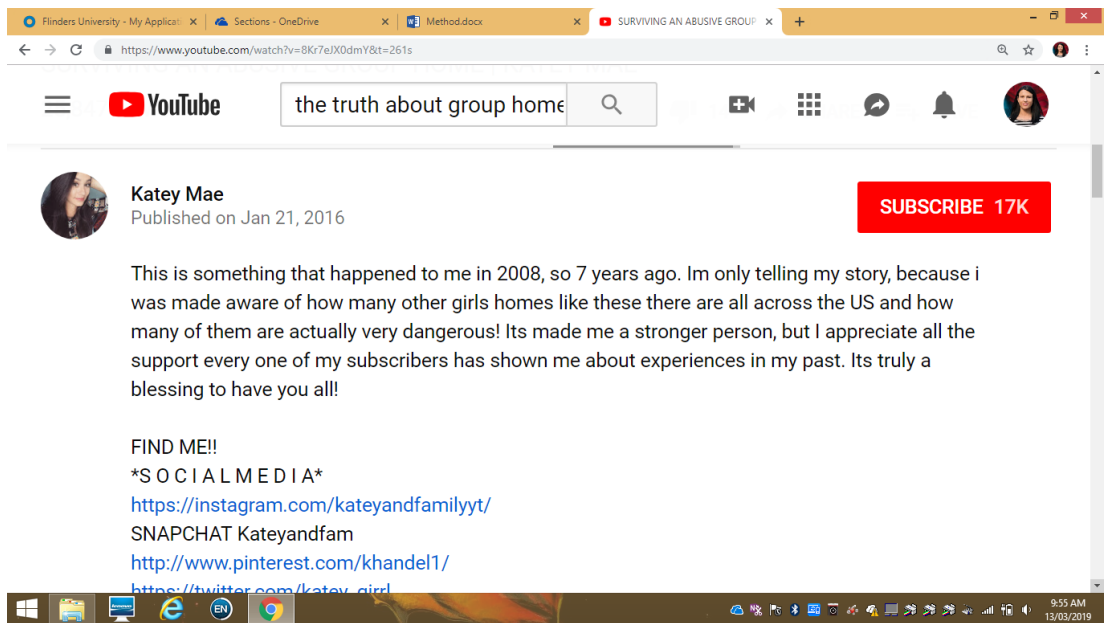


Figure 9

I used the backwards arrow in the top left-hand corner of the screen to return to the list and continued my search through the returned items. I continued to scroll down the page by using the scroll on the right-hand side of the screen. To assess the suitability of the following two videos, I firstly observed the videos and their descriptive titles. I assessed the top video as appearing suitable because the video was disintermediated and was supported by the description, “bad things happen in group homes” (refer to figure 10). I needed to ensure the author, Latrice Allen [latriceallen@live.com](mailto:latriceallen@live.com), fitted the scope of my research and this could only be confirmed by listening to the content of the video itself.

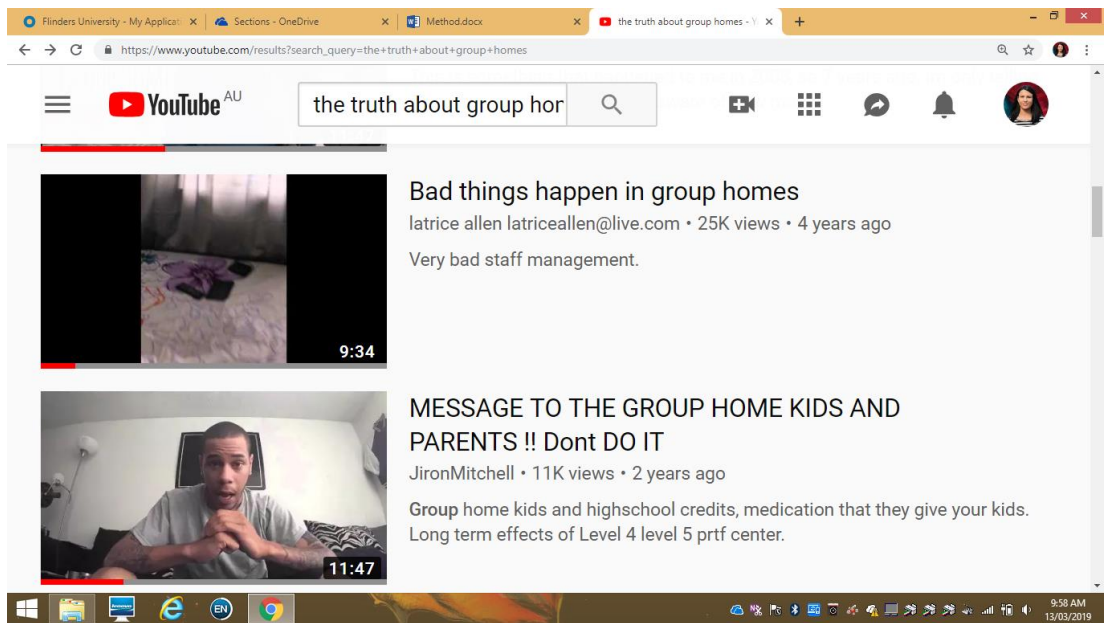


Figure 10

While viewing Latrice Allen latriceallen@live.com’s “Bad things happen in group homes” video, I determined that the author’s group home experience fit the parameters of my research as she disclosed living in adult group housing. She recorded herself discussing her group home living experience and uploaded the video to her own YouTube channel. I clicked into her channel and viewed the other videos that she had posted. As I scrolled down through Latrice Allen latriceallen@live.com’s videos, I observed that she was reporting regularly on her disability group home lived experience. There were other disintermediated videos with titles that obviously fit the parameters of my research because of the use of the words “group home” in the video title (refer to figure 11).

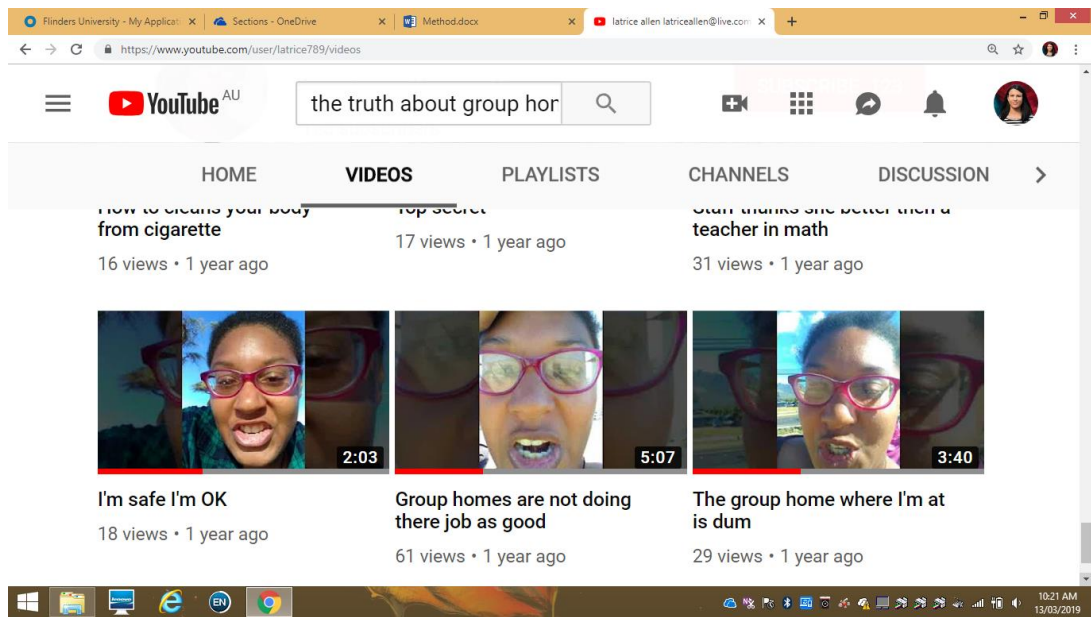


Figure 11

By finding Latrice Allen latriceallen@live.com’s channel, I located an internet platform that contained many videos that were information-rich about the group home experience. I included many of Latrice Allen latriceallen@live.com’s videos in the data set and transcribed many videos from her channel. After I finished transcribing videos from Latrice Allen latriceallen@live.com’s channel, I entered the search terms, “the truth about group homes” into the search field in YouTube to return more videos. I scrolled down the pages until I came across another video that appeared appropriately titled, “the dark side of group homes” (refer to figure 12).

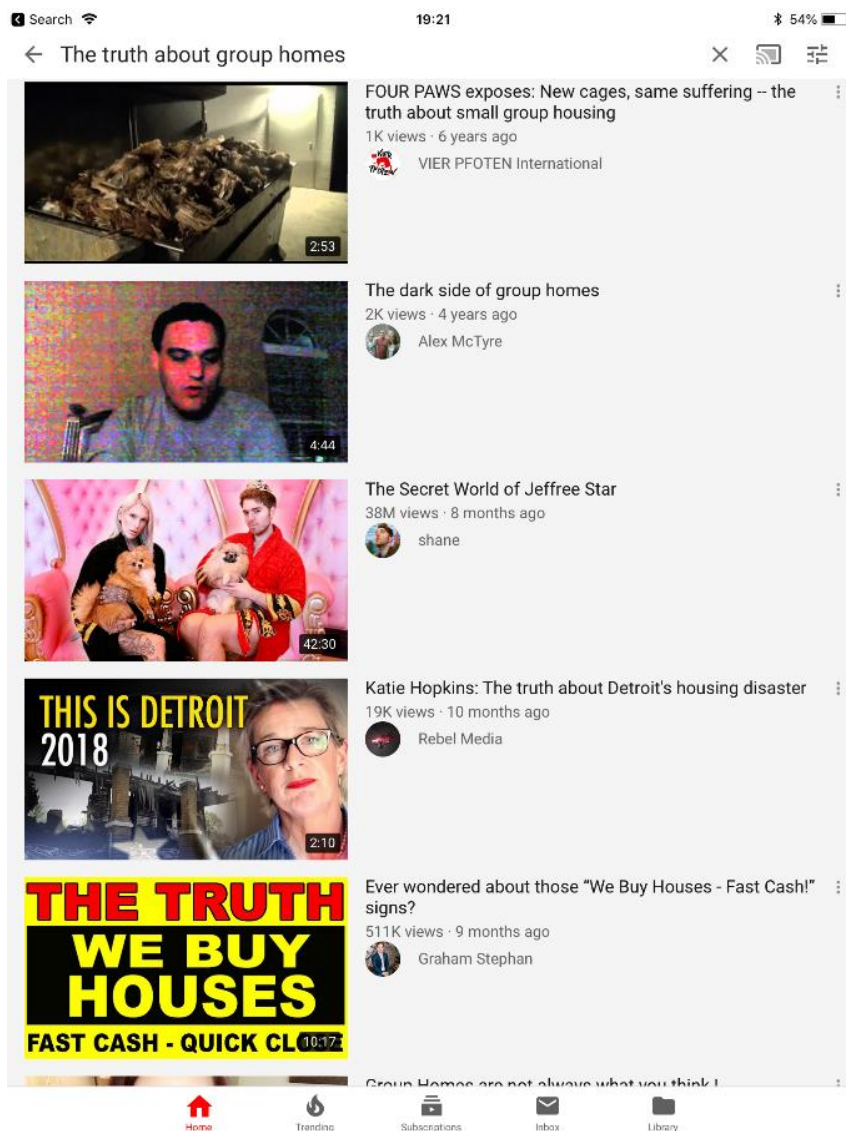


Figure 12

By drilling down into Alex McTyre’s channel and observing the descriptions of the video titles, I discovered that Alex McTyre had a diagnosis of autism and described himself as a disability activist. By listening to his video, I established that the video was not appropriate and did not fit the parameters of my research as Alex McTyre was not discussing his lived experience of a group home. Alex McTyre spoke generally about the topic group homes rather than speaking of his own personal lived experience. This content did not fit the parameters of my research and therefore was not included in the research. I continued searching for videos that fit the parameters of my research.

By scrolling down the list of videos that returned from the original search, I located another channel of a mother discussing her experiences of the group home environment in which her autistic son was living. By scrolling through the titles of the videos posted on her channel, I concluded that there was only one video that was suitable called, "Creative Housing Solutions for Young Adults with Autism". It was evident that at the beginning of the video, a disability carer was speaking. The mother of the individual with disability included the carer in the video by asking the carer questions about her son's care. I executed judgement and summoned this video because the son was non-verbal and the mother had included the carer in her video's content to speak and report about the group home environment on behalf of her son. By searching and investigating through the mother's channel, I discovered that this was the only video discussing the group home lived experience.

I returned to the search and continued scrolling down the list until I came across the channel, "It's So Cassey TV" with the video titled, "What Really happens at group homes... Disability Part 2". I scrolled into this channel to discover that there were two videos to be transcribed about the group homes experience. I returned to the main search and continued scrolling until I came to, "Group Home and Abuse" disintermediated video uploaded by "Mental Health and Support" disability advocate channel. I used judgement to assess the uploaded video as a disintermediated video featuring a resident speaking about his group home experience, and therefore included it in the research. I continued to scroll down the list and come across, "I hate group homes" in the channel "Kedrick LaCaze" (refer to figure 13). While this video implied in the description that the author disliked group homes, I needed to ensure that what was being discussed was disability group homes as opposed to foster homes or other demographics of group housing.



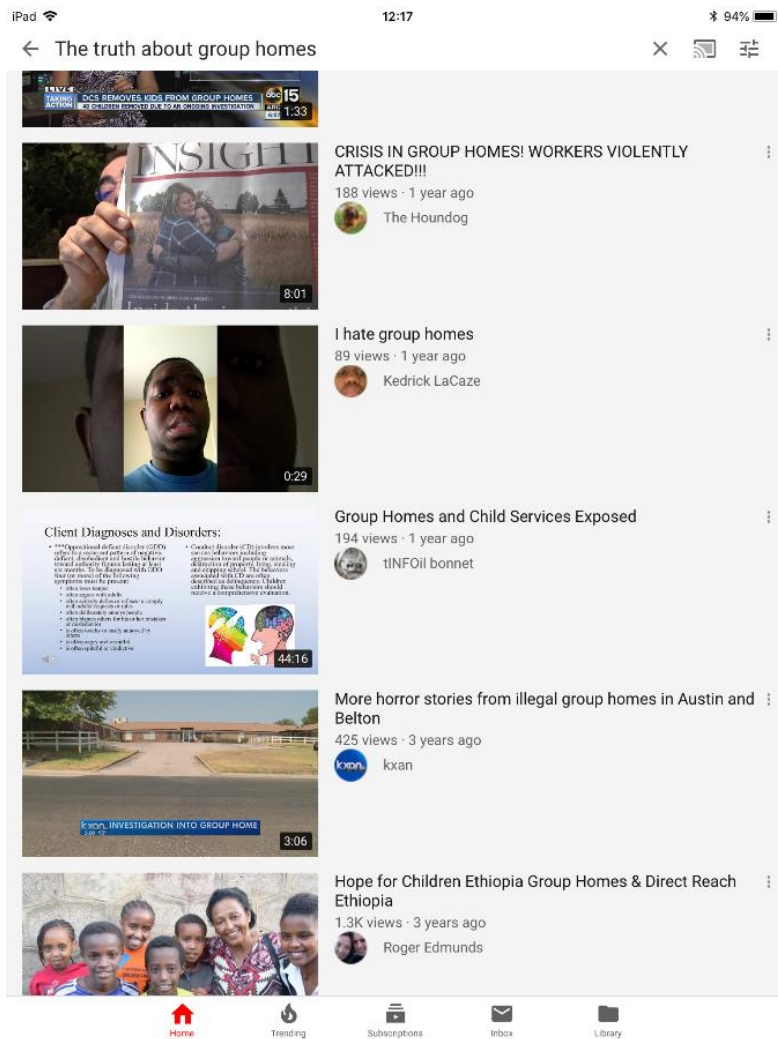


Figure 13

When scrolling through the videos, I observed that there were only five videos uploaded onto this channel. By watching and investigating further into the videos, I established that there were no disclosures of disability. One of author’s videos filmed a group of children jumping around in the home together. This indicated that the content of the video could be about a children’s group home or foster group home and therefore I did not include this video in my data set because of the uncertainty surrounding the type of housing situation. I carefully used my judgement to establish that the videos did not fit the parameters of my research and decided not to include the videos in the data set.

I continued to scroll down the list. I passed more videos that were children speaking about their group home experience in children or foster homes. Then I came to “Joshua Weidemann’s” channel and his disintermediated video, “This is what

happens in group homes is some of the living things that have ever happened to me". By observing and viewing the video, I established that this video fit the parameters of my research. The individual disclosed that he was born with cerebral palsy. After transcribing, I returned to the search. Scrolling down the list I found the channel by "Vanessa Thomas". To assess the content of the video, I played and listened to the author's narrative. Vanessa Thomas stated that the recording was her second video. I drilled into her Channel to find the first video uploaded. I located, "Group Home the Final" (refer to figure 14). The videos were about the disability group home lived experience and therefore were included in the research.

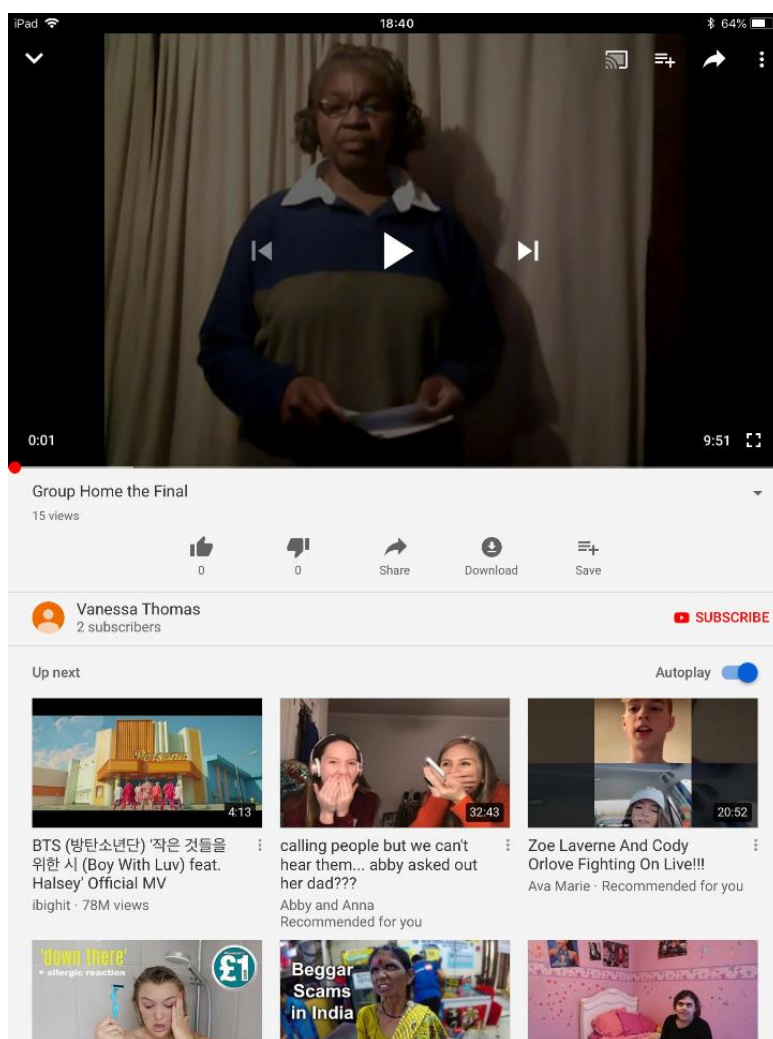


Figure 14

After transcribing the two videos, I returned to the search results and continued scrolling down the list. I found "Trenton Lopez" channel, "Don't live in group homes part 2". I drilled into the channel. From looking at the titles, nothing was indicative

of another video about group homes which meant that I had to play and observe each video to assess their relevance. After scrolling down, I acknowledged that I had reached the point of saturation as no more videos contained evidence of being about group homes. It was necessary to summon a different series of terms for a new search.

### **Search term strategy 2**

From this first deployment of a search parameter, I typed in the top search bar, “group home experience”. I scrolled down until I found a video titled, “Group home life ahahahah”. I selected the video to transcribe. While playing and observing the video, I assessed the content as inappropriate as the author discussed a children’s home. The description under the video read, “Staff almost fight kid”. When investigating further into the channel, other videos posted included teenagers. I established this channel not to fit the parameters of the research and therefore not to be included in the data collection. I returned to the search list and located a channel called, “A-k-Amy Knight” (refer to figure 15). This channel contained numerous videos that documented the author’s lived group home experiences.

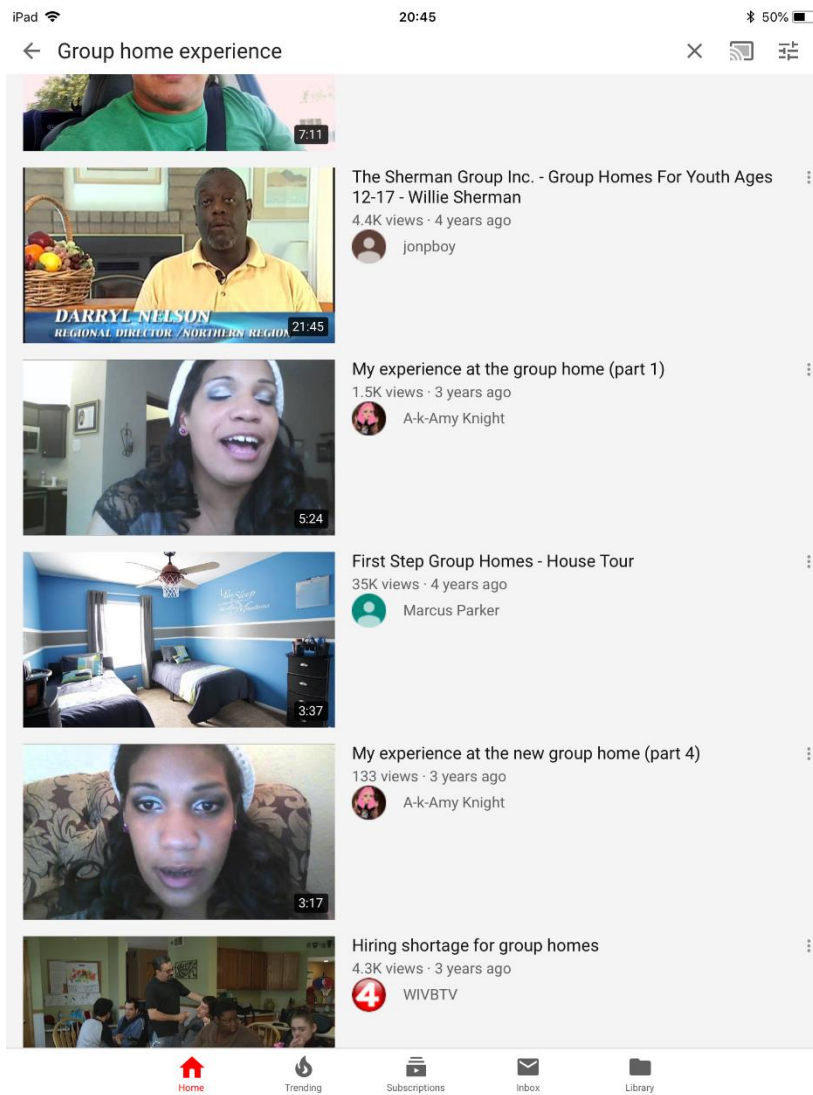


Figure 15

To establish if the content on A-k-Amy Knight’s channel was suitable, I drilled into her channel. By observing the other videos uploaded, I began investigating whether the channel fit the parameters of the research. I clicked on “videos” to see her list of videos and scrolled down. The description of the videos revealed to me that she was living in a group home because she was impaired due to her mental ill health (refer to figure 16). I established that these disintermediated videos fit the parameters of the research as the author was evidently an adult. The title of many videos indicated that the author had many stays in hospital because of her disabling mental ill health.

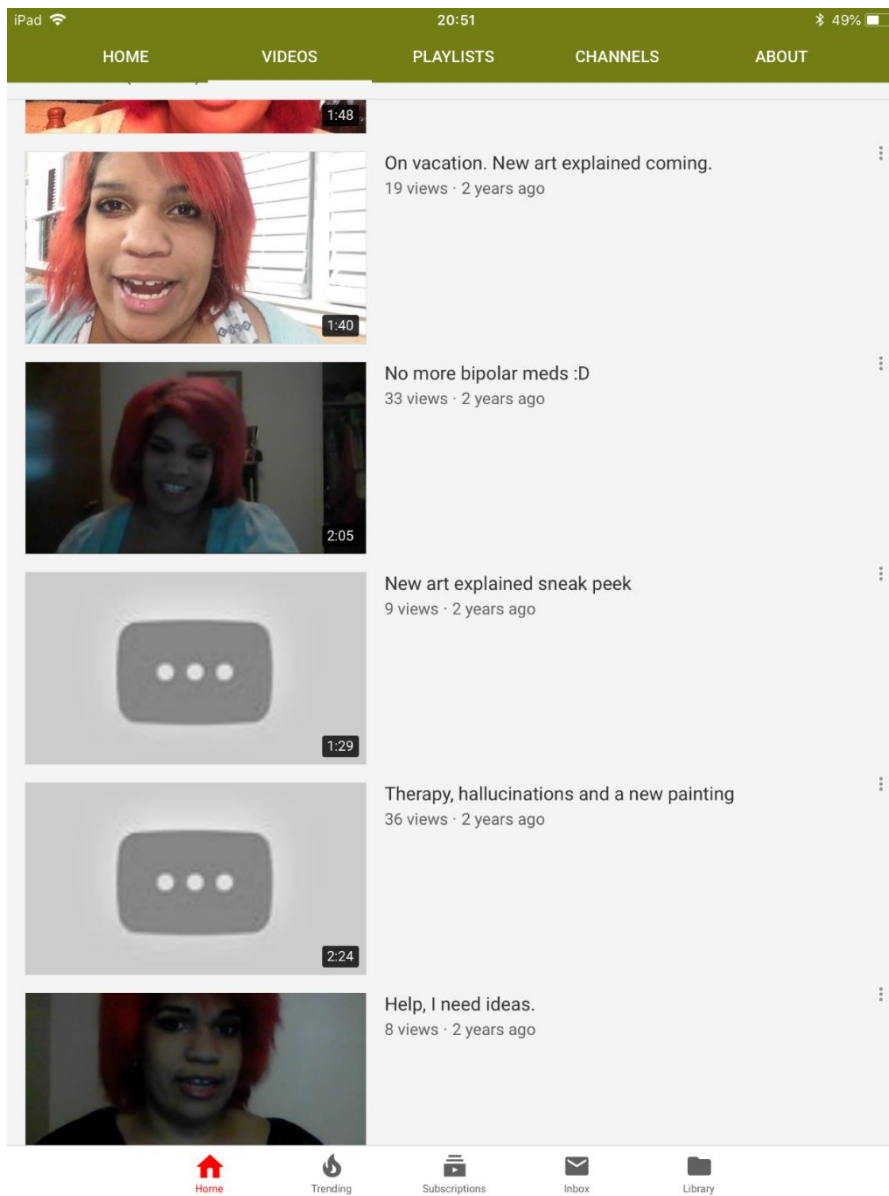


Figure 16

I used the drop-down box top left of screen to sort A-k-Amy Knight's videos in chronological date order with the oldest first through to the newest (refer to figure 17). This enabled me to gain insight about the author's life story.

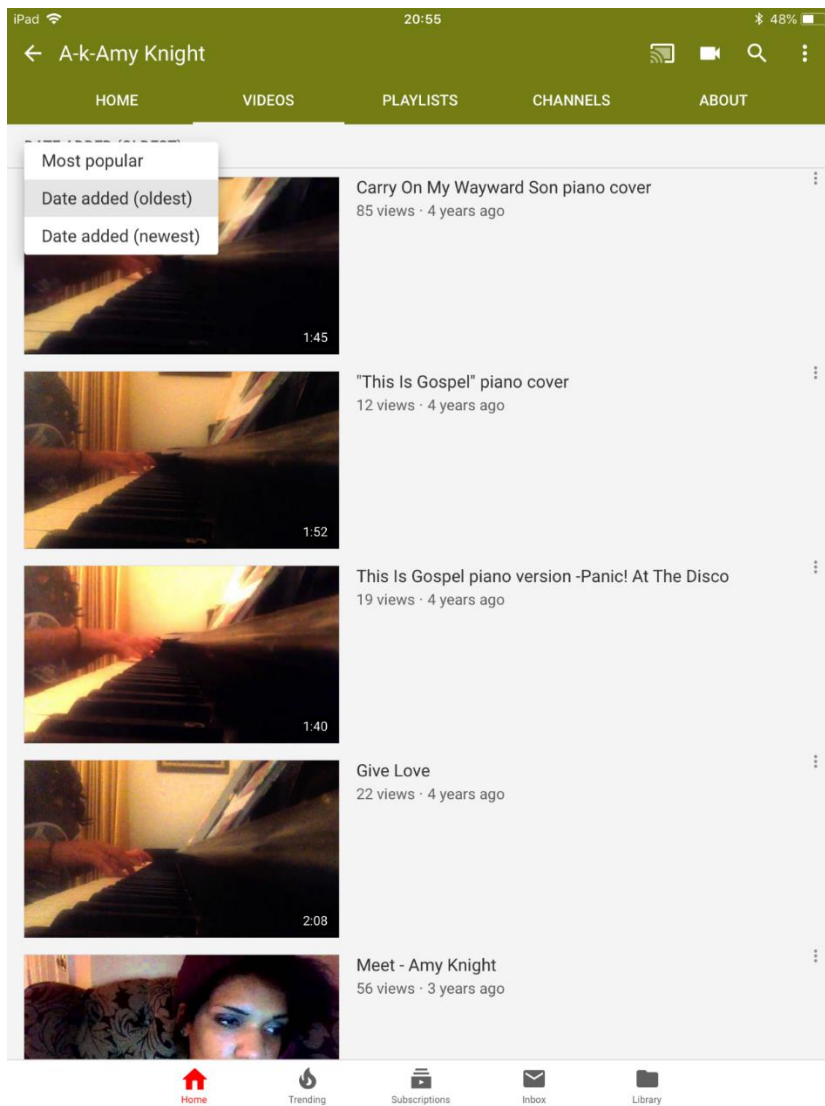


Figure 17

Two video titles on A-k-Amy Knight’s channel indicated her condition. One video was titled, “What is schizoaffective disorder?” and another, “Bipolar Disorder – Types and Complications” (refer to figure 18). I assessed the channel as fitting the parameters of my research.

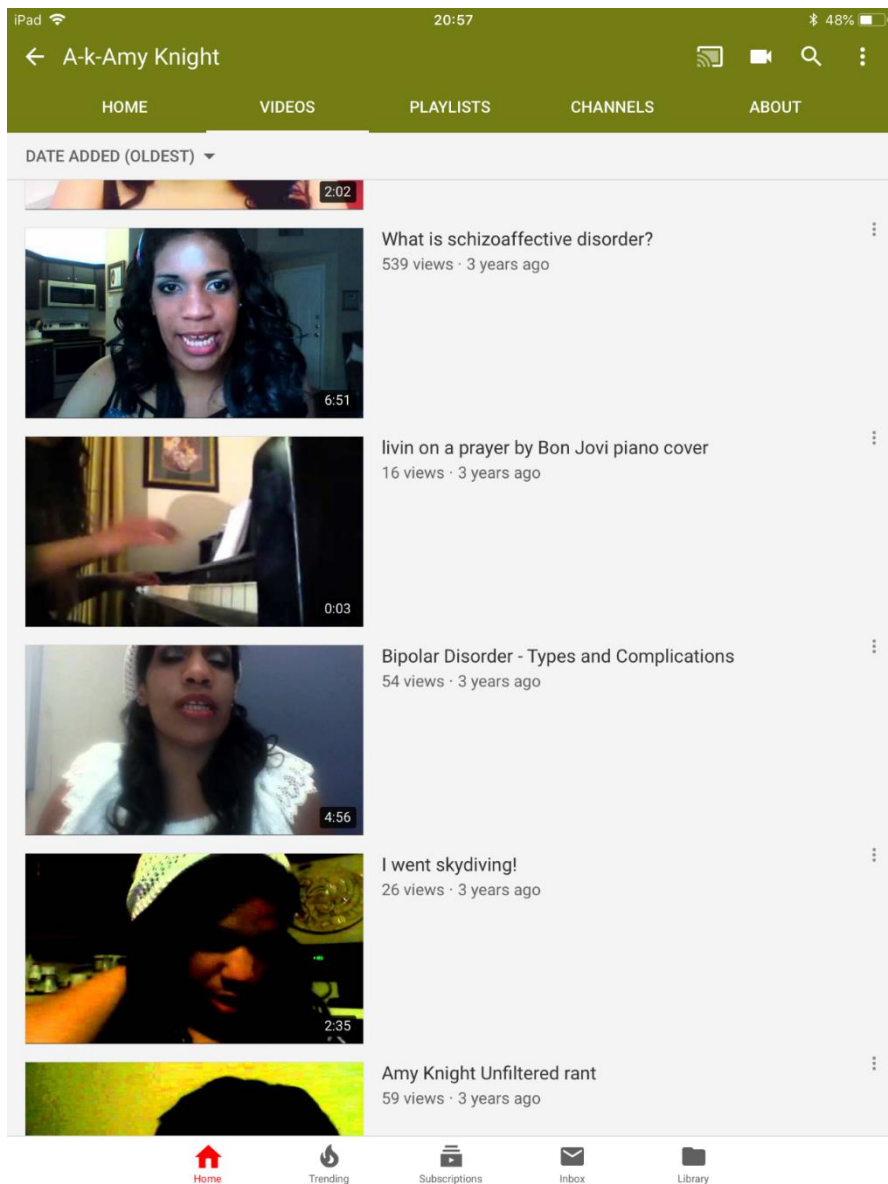


Figure 18

Scrolling further down, I observed that Amy had uploaded four videos to her channel that may have contained content about the group home living experience (refer to figure 19).

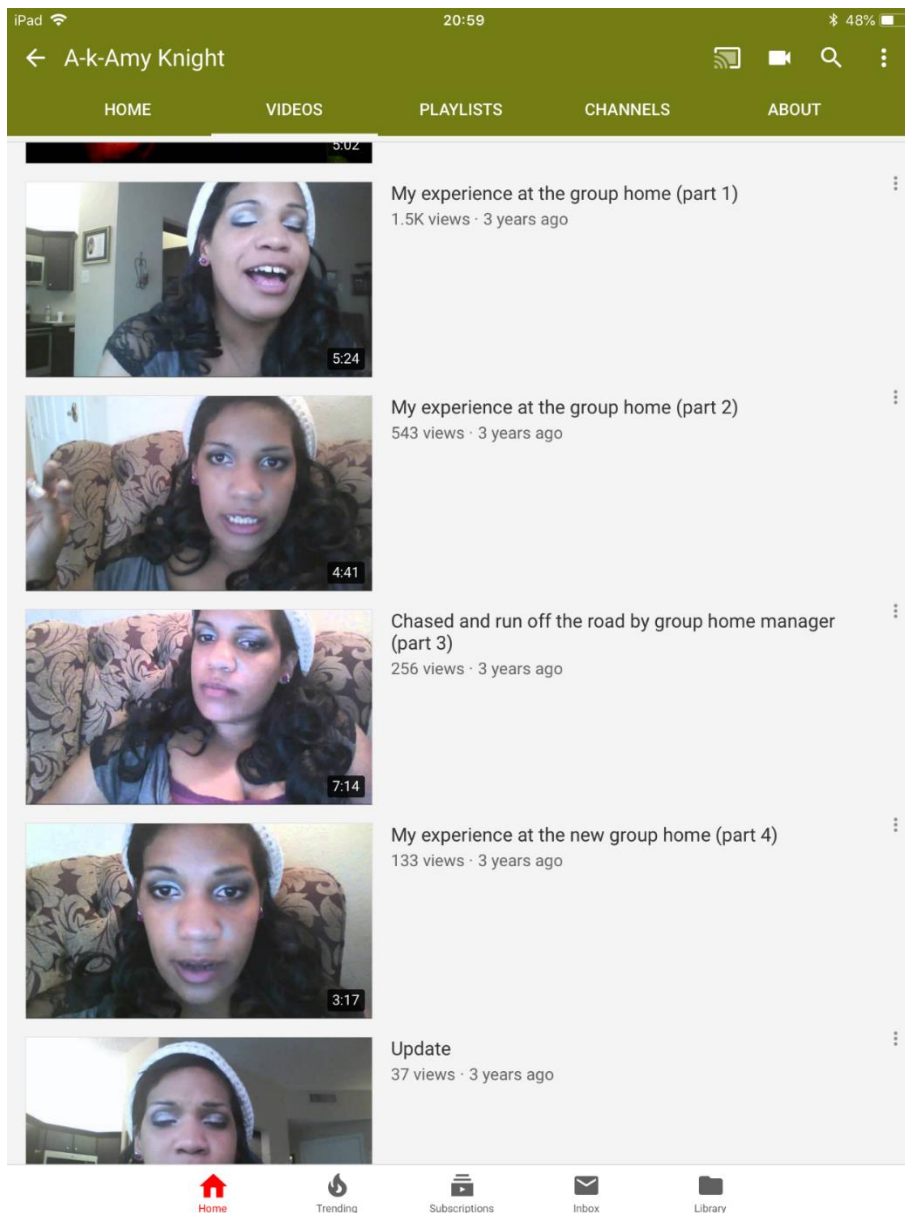


Figure 19

I returned to my search, “group home experience” and kept scrolling down until I found another disintermediated video that I established as being suitable. The video was titled, “Group home” and the Channel was titled, “Rapheal Hardwick”. I scrolled into Rapheal Hardwick’s channel in search of other videos containing content about the group home experience. By observing the descriptions of video titles, it did not appear that any more videos contained content of Rapheal Hardwick discussing his group home living experience. I played and observed Rapheal Hardwick’s video titled “Group home” on my iPad while transcribing his narrative. After the transcription process, I returned to the search and continued to scroll down the list. Some videos



I needed to play and observe to establish whether they fit the parameters of the research. I continued with this process until I found, “I am stuck living in my group home! October 2018 life update” on “Rebel Fighter” channel. After transcribing this video, I drilled down into Rebel Fighter’s channel and observed that none of the other video titles suggested being about the group home experience. I returned to the search list.

I continued looking down the list until I found, “Group homes and host homes” on a channel titled, “callie31701”. I established this as a suitable video to be included in the research because the author discussed her group home experience. I observed the individual to be an adult with a moderate speech impairment. This showed that difficulty communicating verbally did not deter people with disabilities from recording and uploading content to YouTube. After transcribing callie31701’s first video, I drilled into the channel to search for more suitable videos to summon for the data set. I observed callie31701 to have taken footage of the group home. The video did not include any narrative and therefore was not included in the research as thematic analysis of the content was to be deployed. When returning to the search, I assessed that saturation point had been reached as the other videos on the list had already been included in the first search term strategy data collection or were not about group homes.

### **Search term strategy 3**

I entered into the YouTube search field the new search term strategy, “My life in a group home”. This search returned videos that had already been summoned and also new ones that I had not yet been included in the data set. I clicked on, “What it’s like to live in a group home” on the channel “KobyWhite”. The video began with a tour of the group home and had been edited with music. When listening to the video, I observed that the individual appearing in the film was young. Further upon observation, the individual was discussing experiences of a group home for children. I exercised judgement to conclude that the content did not fit the parameters of my research and therefore was not included in the data set.

I continued to scroll down the list until I located, “What my life is like at my group home these past few days” on the channel “Daimos Z”. The film captured a fight

taking place between a group home resident and a staff member. The video description stated, "Fuck my roommates". The authors and resident were evidently an adult, and fit the parameters of the research. This channel was summoned to be included in the research as it fit the research parameters. I found a disintermediated video where the author's face appeared in the video, "Re: Tagged by Shocker Rider Five". As I watched the video, I transcribed only the first minute because the author discussed his group home experience and then spent the remaining eighteen minutes discussing a video game.

I kept scrolling down the search list and found "HIDDEN SECRETS OF (Adult residential group home)" by the Channel "Voices4 allneeds!" The disintermediated video was a tour through her home played to music. I transcribed all Voices4 allneeds' videos as the content of each video disclosed the group home experience. All videos fit the parameters of my research. I returned to the search and kept scrolling down until I found, "A day in the life of Jose living in a group home" on the channel "Jose Baez". I transcribed two of Joes Baez's videos. I needed to begin a new search as after scrolling for some time, I could not locate any new videos which fit the parameters of the research. The point of saturation had been achieved and a new search term strategy was deployed to locate new content.

#### **Search term strategy 4**

I typed in the YouTube search bar, "Don't go to group homes" and scrolled down the list that returned. The first video that returned was, "Don't go to group home. And an update on me" by Andrew Passino. This video was included in the data set and transcribed because I established it as fitting the research parameters. I continued to search for videos to be included in the data set. When I returned to the search list, I located, "the truth about maryhaven and other group homes #AutismAwareness" on a channel called "Desiree Duckett". This video appeared disintermediated and so I played it. After listening to the first twenty seconds, I realised this video fit the parameters of the research as a family member was talking about her autistic brother and his experiences of group home violence, abuse and neglect. After transcribing the video, I continued to search and found a disintermediated video, "Man gets upset about his group home type shit" on the Channel "ace". The descriptions said, "My

videos about life and a fucked-up group home call Progressive Care in which they don't care about me fuck them". I drilled into his channel and transcribed all videos that included "group homes" in the title.

I returned to the search results and found it more difficult to find disintermediated videos about group homes. I located a video that had already been transcribed and drilled into the channel to search for more videos to include in the data set. I located more suitable videos about individual's lived group home experiences. The channel was called, "Voices4 allneeds!" The video was called, "Seriously more? (1)" and included an explicit description under the video that I decided to include in my data set because of its length and transparency. I transcribed two more videos within that channel called, "Why?" and, "Abused and neglected (part 1). These videos included a lengthy and informative description which I included in the data set, as they provided information about the group home experience.

I returned to the search results and continued scrolling until I found a video called, "Group homes" on a channel called "Khat Skellington". I drilled into the channel and observed that the author had uploaded other disintermediated videos. Upon observation I established that this was the only video that this was the only video to discuss the individual's group home experience. Other video titles indicated that they were about other topics that were not associated with group homes. As I summoned and watched each video, I observed that the individual disclosed information about attending court and being put on placement. It became evident that this video contained content describing the foster home experience and therefore did not fit the research parameters. I decided not to include this video or channel in the data set. I returned to the search results and continued to scroll down the list of videos that returned from the search term strategy. Many of the videos had already been transcribed from previous searches. I had reached saturation point. A new search was needed to locate new content that had not yet been included in the data set.

### **Search term strategy 5**

I typed in the YouTube search bar the search term strategy, "Inside my group home". As saturation point was being achieved, it was becoming increasingly difficult

to locate new content. Data saturation provides the conceptual yardstick for the size of data collection in qualitative research (Guest, Namey, & Chen, 2020). Data saturation has been reached when information threshold has been achieved and no new incoming data or information is being produced or collected (Guest et al., 2020). The searches were now returning many videos that had already been included in the data set (refer to figure 20). It was becoming evident that saturation point for the data set was being achieved.

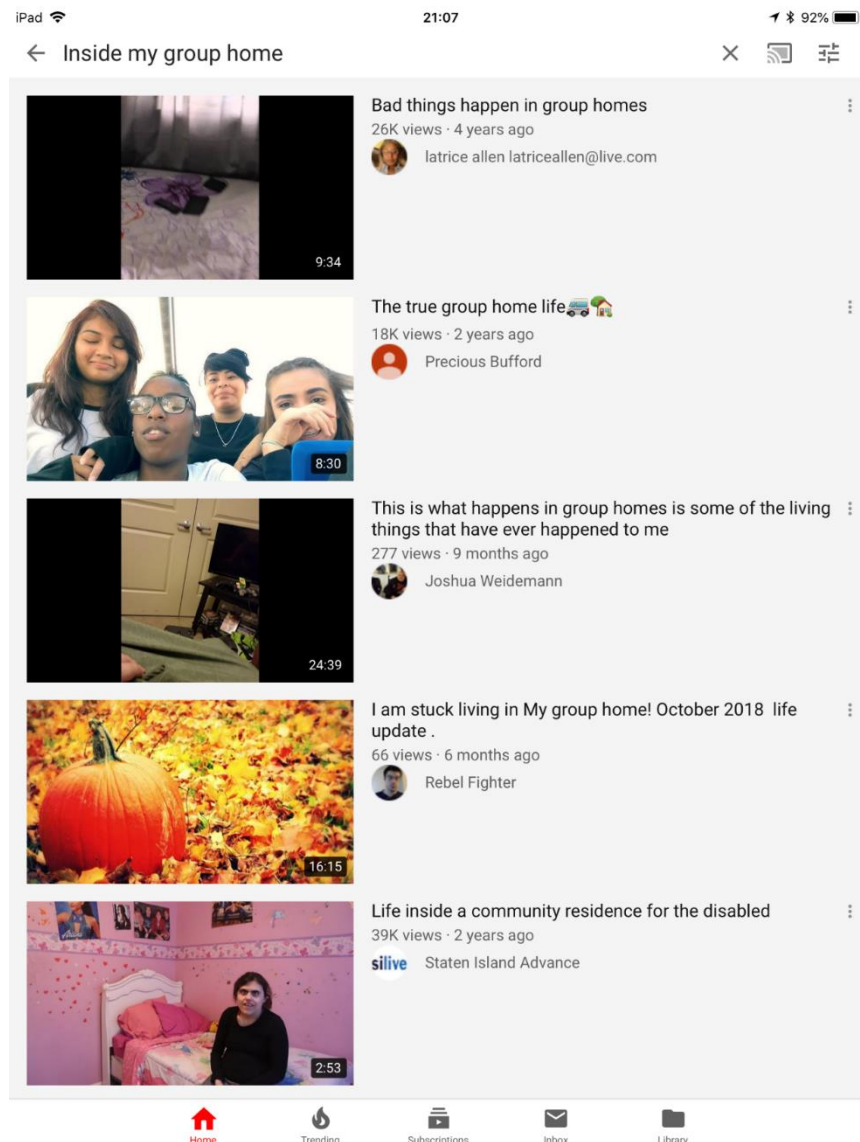


Figure 20

I located a new video titled, "I am stuck living in my group home! October 2018 life update" on the channel "Rebel Fighter". The author referred to previous videos that he had posted when speaking of his group home experience. After transcribing the

first of Rebel Fighter’s videos, I drilled into his channel and summoned other videos that fit the parameters of my research. I sorted Rebel Fighter’s videos in chronological order by clicking “date added” and selecting “date added (oldest)”. I summoned and transcribed all videos that included content regarding group housing. After transcribing all appropriate videos from Rebel Fighter’s channel, I returned to the search results list.

I continued to scroll down the list until I located, “Opinion on group homes in the state government with group homes” on the channel called “Nada Saue”. I assessed this video as fitting the research parameters. After transcribing the video, I drilled into the individual’s channel to search for more group home content but did not locate any. I returned to the search results. I observed that the searches on the YouTube application open on my computer and my search results on my iPad application differed. The search terms were exactly the same but they had returned videos in a different order (refer to figure 21 and figure 22).

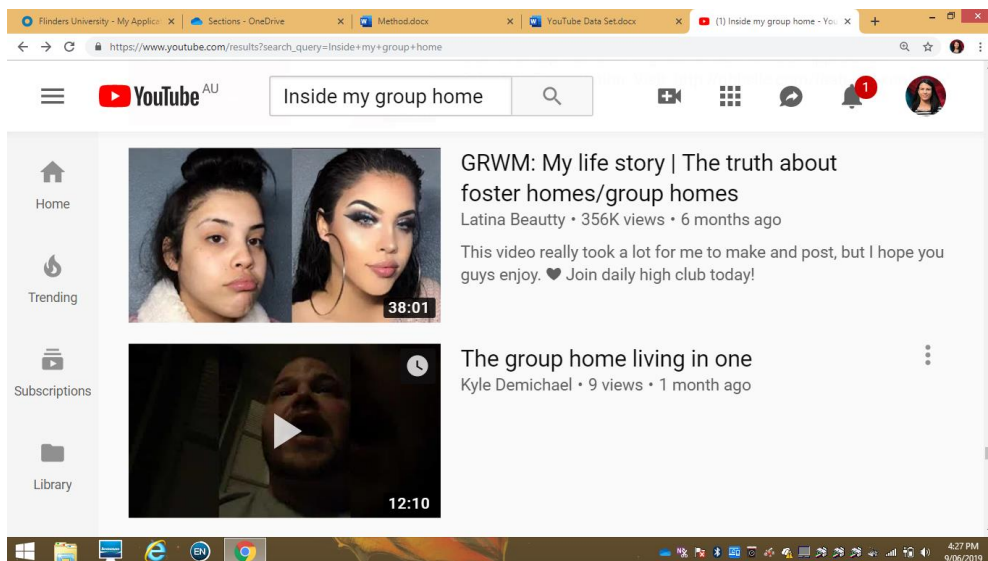


Figure 21

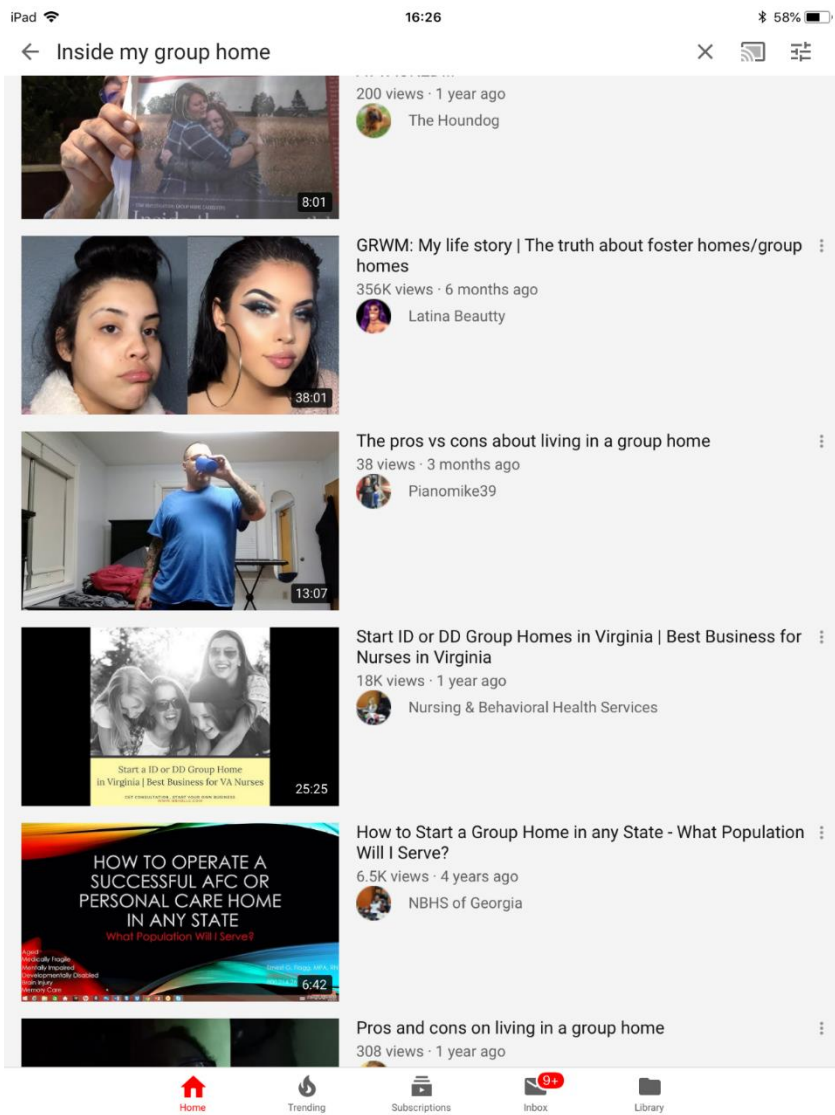


Figure 22

My aim was to locate the disintermediated video called, “The group home living in one” uploaded to the channel “Kyle Demichael”. I used the computer list and searched for the video I desired to transcribe by typing the name of the channel and video into the search terms on my iPad (refer to figure 23).

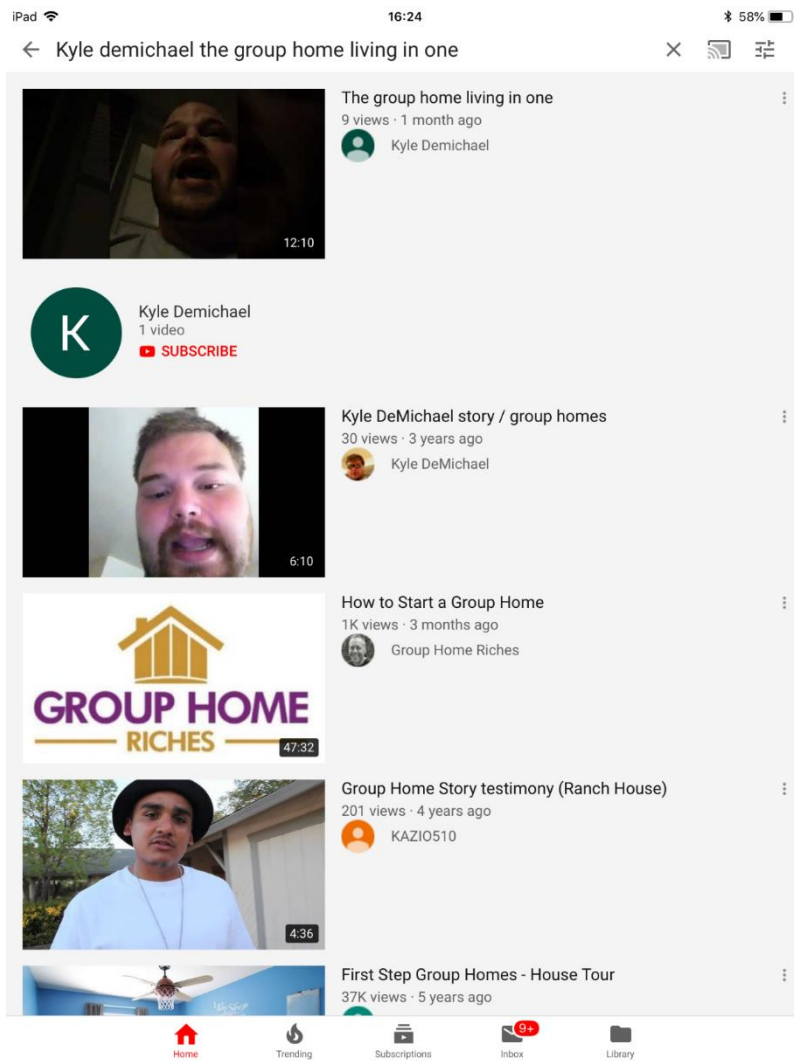


Figure 23

After transcribing that video and listening back to ensure that I did not miss any words, I returned to the list and continued down. Once again, the search on the iPad and computer differed. I made the decision to use the computer's search list as the driving search engine. This revealed to me that searches were random in nature and were not guaranteed to return the same. I copied the name of the channel "Ceserio the autistic kid" into my iPad and found the disintermediated video to transcribe. The channel name indicated that the author experienced disability and fit the parameters of the research.

The next video I transcribed was called, "Moving out of my group home less than 2 years!!!! 5/1/16" located on "Official DeerFire". After transcribing the video, I drilled into the author's channel and found another appropriate video I deemed as

suitable called, "Tour of group home 5/7/17". After investigating the videos, I assessed that there were no other videos about Official DeerFire's group home experience that fit the parameters of the research. I returned to the search list. The next video was titled, "Staff at group home illegally films me after dragging me out on van ride against my mom's wishes" on the channel, "David Graycat". After summoning David Graycat's video and including it in the data set, I drilled into the channel to check for other videos. I assessed the other content on David Graycat's channel to not be relevant and therefore excluded from the data set. I returned back to the search list.

I located a video on the channel, "Autismwariormama" that did not return during previous searches. It was called, "Dangerous Group Homes for Autistic People" and fit the research parameters. After summoning and transcribing the video, I returned to the search results list and continued down until I found, "Autism group homes in Indiana and all 51 states and cuts to autism care the next 20 years" on the channel, "Jake thorne". I drilled into Jake Thorne's channel and located other suitable videos that fit the research parameters. I observed Jake Thorne as having a speech impairment which made his videos more difficult to understand. I was not able to use his entire narrative but rather included only parts of his story that I could clearly make sense of. This was to ensure reliability and accuracy of information. I drilled into Jake Thorne's channel, sorted his videos by chronological order, and then searched through the list. I only summoned videos which included the term, "group home" in the title, as this content fit the research parameters. The next video on the list was, "Autism living In Group homes". The author had a speech impairment and the content was difficult to understand. This video could not be included in the data set as I could not ensure accuracy of data transcription to ensure reliability of content. A new search strategy was needed as the point of saturation had been achieved.

### **Search term strategy 6**

I entered in the search field, "I hate group homes" and pressed enter. I found, "I hate group homes" by "Kedrick LaCase". After transcribing the video, I investigated the channel to assess whether more suitable videos that fit the research parameters



were available, finding none. I continued to search down the list for videos to include in the data set. I located, "5 Fuckin Things I hate about house mates in the Group home and Co-workers at work" on the channel, "Mark Cinque". After transcribing Mark Cinque's video, I drilled further into the channel. I sorted videos in chronological order. I observed that Mark Cinque's channel contained other videos with relevant content being about group homes. The oldest video on his playlist titled, "Retarded Housemates" was summoned for the data set and transcribed. The next disintermediated video that I assessed as being suitable was called, "This place sucks" and then, "I Fuckin hate being wokein up in the Morning!" Mark Cinque's video titles were indicative about his group home experience. I played and observed the videos to establish that the content fit the research parameters. For example, there was one video titled, "Rules suck! Suck! Suck!" By playing and observing the video, I discovered that the content was about work rather than the group home experience. This video did not fit the parameters of the research. By exploring further, I located another disintermediated video called, "Why the Fuck!" which was about Mark Cinque's group home experience. To assess the suitability of this video, it required that I play and observe the narrative. After searching through Mark Cinque's channel and failing to locate any other relevant content, I returned to the search results. I found, "Moving into a Mental Health Group Home?" by Aaron Stark. This was deemed unsuitable upon listening to the narrative, as the author disclosed that he lived at home with his parents and desired one day to move into a group home. The channel did not fit the parameters of the research as Aaron Stark had not experienced the group home environment yet. I returned to search results and continued scrolling.

I located a video called "Group homes in Texas" by Angus Rudd and established that the video fit the research parameters. I transcribed the video and searched the remainder of Angus Rudd's channel, unable to locate other material which fit the parameters of the research. I returned to the search list and found, "Group home fight" by Pianomike39. After transcribing the first video, I drilled into Pianomike39's channel and observed that there were several videos with relevant content about the author's group home experience. I sorted his videos in chronological order and summoned any videos that included the description, "group home" in the title. I

then summoned two videos called, “Group home update” and, “Psycho series group home McJuggerNuggets”. To assess whether they were relevant, I would play and observe the content of each video, and transcribed any videos with “group home” appearing in the title. Videos transcribed in order included, “Group home Mcjuggernuggets psyco (sic) series appointment”, “Missing another appointment” and “Still haven’t moved yet”. After transcribing all of Pianomike39’s videos that fit the parameters of the research, I deployed the search term strategy again, as time had lapsed between sessions.

During the next session of locating information using the search term strategy, “I hate group homes”, a new video appeared near the top of the list which had not returned during the search term strategy the session prior. This confirmed again that YouTube searches can change order. The date that this video was posted was one week earlier yet the previous search was one day earlier. The channel was titled, “Ceseriyo Few” and the video was titled, “I hate the group home workers I’m going to dad’s house”. I drilled into Ceseriyo Few’s channel and sorted videos in chronological order. This indicated that the author had been posting for eight months and I observed that he had other videos with the description, “group home” in the title. Many of Ceseriyo Few’s videos contained “autism” and “schizophrenia” in the title. I summoned, “About my life and what I think I Will never do” because the young man provided information about his life and care workers. I included all other videos with “group home” in the title. Some videos contained the description in the video title but no words in the video itself, just a boy screaming and hitting his head.

Theoretical saturation (Willis, 2013) of this research was determined when this search was completed, after transcribing approximately one hundred videos. Theoretical saturation was established because it was becoming increasingly challenging to locate new videos that had not been previously transcribed. I transcribed the videos myself and this provided the opportunity for me to become well acquainted with the data set as I transcribed. It is imperative that researchers immerse themselves in the information to ensure the breadth and depth of the content is thoroughly understood (Braun & Clarke, 2006). The process of data transcription facilitated a thorough understanding of the data set and themes began to emerge during data transcription and before the coding process itself. Thematic

analysis is not a linear process but rather involves the moving back and forth between different phases of working with the data (Nowell et al., 2017). Therefore, meaning of the data started being established from the moment the data were first transcribed. To manage this, a reflective journal was kept during the data transcription process and I journaled my ideas as they arose. Writing memos in a reflective journal and consulting with colleagues during the research process as ideas evolved enabled a deeper engagement with the data (Cutcliffe, 2003; Finlay, 2002). The ideas that emerged from my transcription process and documented as memos in my reflective journal were shared with my supervisor during the transcription process, acting as researcher triangulation (Nowell et al., 2017). My supervisor assisted in the meaning making of the themes and directed me to particular disability theory. This was a significant part of the meaning-making process and knowledge creation of the thesis. The following excerpt is a memo from my reflective journal kept during the data transcription process.

Staff power is used to reinforce rules, regulations, routine (rigid) which makes the environment institutionalized. Rebellious against the staff power for desire for freedom leads to violence/challenging behavior. Lonely, isolated, grouped together, missing family. Rigid rules. These group homes are like institutions.

This memo captured the evolving idea that led to one of the major themes revealed through this doctoral research: of re-institutionalization. This memo was written while I was transcribing the videos. I consulted with my supervisor and read literature about deinstitutionalization of the disability sector following the recording of this memo. I located literature about the re-institutionalization of the disability sector. This led to the emergence of the major theme. Following is another memo that contributed to another major theme to emerge from the data set.

Staff/client relationships – boundaries within the home environment make for a dehumanizing environment. It is natural for care with the home to be personalized and a friendship to develop. When a client is not allowed to have a friendship with someone providing care to them such as personal care – this is very unnatural.

This memo contributed to the evolving thought about relationships between staff and clients. It informed another major theme of the thesis: of harmful interpersonal relationships. Idea emerged and I discussed my thoughts with my supervisor. Consulting with my supervisor acted as triangulation during the thematic analysis of the information by contributing to discussions about emerging themes. Potential codes were also noted in the reflective journal during transcription, as I became well acquainted with the data set. These included, “power, facilities, online community, institutionalized, moving/instability, evidence, voice/break silence, reason for posting, environment, staff power, rules, poverty, money, human rights, boredom”.

## Phase 2: Generating initial codes

Having been familiar with the data set, the second phase of the thematic analysis process began after the data set had been read and I had an understanding of what information was interesting (Braun & Clarke, 2006). After the videos were transcribed in completion and the full data set collected, the data set was printed on paper. The data set was read by the researcher and analyzed further using codes. The coding phase was validated by my supervisor throughout the coding process. Thematic analysis allows the consideration of process and meaning (Savage, 2000). During the coding phase, the production of codes was created from theorizing data (Nowell et al., 2017). Coding in qualitative research is a process of interacting with the data through reflection (Savage, 2000). The transcription was broken into analytical units or units of meaning, to keep the data manageable (Savage, 2000). Each analytical unit was read line by line with care and meaning ascribed to each unit through the allocation of a code. The data were considered in the context of the individual video and then segments of data were marked with coloured highlighters. Describing words and notes were written beside each analytical unit. Segments of data were assigned codes. Coding was the process by which data were organised to develop relationships between codes, and organise themes by interpreting the data.

Hello this is me, Latrice Allen. Just wanted to show how you the group home where I'm at. This is the kitchen. Room. Hallway. Ok. Wow she must have did something to the phone. So anyway, ok back to my room. Back to my room everybody (Latrice Allen latriceallen@live.com, 2014a).

This piece of data were broken down into a manageable analytical unit for coding. The codes ascribed to this analytical unit were “reason for posting”, “group home facilities”, and “online community”. After the data set had been coded, the codes between analytical units were compared and meaning was made.

Hello there. Patrick here with you again. Today I just wanted to tell you about a little more in detail I guess about why I decided to leave supported housing and why I would probably never do it again and the purpose behind this video is I guess to educate people on what supportive housing is really like and yeah to show what supportive housing is really like and to see if that’s something you really want because it’s not for everybody. However some people don’t have a choice and they have to live in supportive housing because of their disability (Rebel Fighter, 2018d).

This analytical unit was given the codes “reason for posting” and “exposing the truth”. When linking the two codes amongst analytical units, the theme “breaking the silence of disability” emerged. Analytical units of data were given as many different codes as deemed relevant. Memos were recorded to capture any interesting impressions that emerged from the data as it was read thoroughly. This formed for discussion about themes with my supervisor weekly. Once coded, the relationship between codes were explored and codes were linked between transcripts. By constantly comparing the interpretation of results to the transcripts, I ensured the veracity of the claims about data. Themes are more than categories (Green et al., 2007). Themes provide an explanation to what is occurring and how codes fit together into categories (Green et al., 2007). The themes emerged after this coding process. The themes were compared to the literature. The data were used to affirm and extend the literature, creating new knowledge. To ensure that all videos were included in the thesis and all material used to inform the findings, I printed the bibliography and marked the information included in the thesis. Any remaining videos were then compared to the findings and inserted in the chapters where possible.

### Phase 3: Searching for themes

The third phase of the thematic analysis began once all the data had been coded. The coded data were then sorted and collated into groups. These groups were identified as themes.

A theme is an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole (DeSantis & Ugarriza, 2000, p. 362)

The identified themes brought meaning to data set and to the experiences of men and women with disabilities, their families and carers. The analysis and interpretation of the themes developed in richness when integrating existing disability literature with the findings whilst writing the chapters. The integrated literature review was leveraged to make meaning of the data set. Four overarching themes were found; the impact of neoliberalism, the consequences of re-institutionalization, harmful interpersonal relationships, and breaking the silence of disability. Important insights into the challenges and needs of people with disabilities living in group homes were highlighted. The table below details the themes that were identified and the codes that informed the themes.

Table 2 - Categories that informed themes

Themes	Impact of neoliberalism	Consequences of re-institutionalization	Harmful interpersonal relationships	Breaking the silence of disability
Category (number of videos )	Facilities (42)	Rules (22)	Online community (31)	Reason for posting (9)
	Fear of homelessness (9)	Chores (9)	New staff (6)	Unheard (11)
	Poverty (16)	Staff agenda (6)	Fear of retribution (12)	Silenced (43)
	Lack of funds (18)	Resident roles and responsibilities (16)	Misplaced residents (14)	Staff negligence (61)
	Funding (10)	Institutional (18)	Inexperienced staff (13)	Speak out (18)
	Group home finances (3)	Controlled environment (18)	Staff roles (22)	Expose (31)
	Overcrowding (14)	Disempowered (11)	Dishonesty (6)	Debrief experience (23)
	Instability (24)	Powerlessness (14)	High staff turnover (8)	Seeking help (12)

Staff quality (25)	Lack of freedom (8)	Theft (14)	Evidence (13)
Under resourced (10)	Resident rights (33)	Resident behaviour (43)	Disclosure (23)
Inadequate staffing (15)	Boredom (23)	Friendship (21)	Opinion (9)
Questionable spending of funds (9)	Staff as experts (4)	Moving (28)	Voice her problem (4)
Profit (9)	Maintain order (8)	Crime (23)	Update (19)
Unmet needs (25)	Lack of privacy (29)	Sexual assault (8)	Advocacy (7)
Quality of service (8)	Staff power (51)	Mental illness of other residents (18)	Dissatisfied (18)
Unhygienic (11)	Dehumanizing (18)	Unsafe environment (21)	Empowered voice (17)
Occupational Health & Safety (10)	Dominance (12)	Drugs (14)	Informative (6)
Lack of vacancies (8)	Quality of food (7)	Staff harassment/abuse (54)	Diary of events (19)
Unresponsive (16)	Denied medical treatment (3)	Conflict (41)	Disability community (18)
Waiting list for housing (5)	Rigid schedule (19)	Hostility in environment (17)	Unethical practice (6)
	Loss of independence (10)	Miscommunication (4)	Raising awareness (19)
	Wants activities (7)	House dynamics (10)	What people want (12)
	Isolated (13)	Resident staff conflict (21)	
	Inflexible (7)	Self-harm (13)	
	Authoritarian (5)	Discrimination (7)	
	Activity (10)	Verbal abuse (18)	
	Weight gain (3)	Harassment (19)	
	Loss of control (8)	Lack of communication (9)	
	Unsupported (11)	Disrespect (13)	
	Cover ups (19)	Anger (33)	

When conducting unobtrusive research, the unobtrusive researcher's background requires consciousness, transparency and presentation, ensuring that the researcher enters a critically reflective process that is used in the development of new

knowledge (Auriacombe & Meyer, 2020). During the thematic analysis, my experience working in the disability sector, and my understanding the disability theory conducted through my initial literature review, influenced the development of the four main themes. I also regularly debriefed with my supervisor regarding the coding system and the themes that were emerging. This acted as researcher triangulation and strengthened the credibility of this study (Nowell et al., 2017). My supervisor would discuss themes with me and direct me to relevant existing disability literature. As I analyzed each quote and what people were saying, the understanding and interpretation developed.

#### Phase 4: Meaning making in unobtrusive research methods

Being hard-to-reach offline is different from being hard-to-reach online (Kaufmann & Tzanetakis, 2020). Men and women with disabilities living in group homes may be hard for researchers to access. Service providers may not allow researchers into a group home environment, especially if there is violence, abuse and neglect of residents occurring. People with disabilities may have difficulty leaving the group home and are often segregated from the community. The internet enables men and women with disability to engage with the wider community in the global, online space. The advantage of YouTube as a data source is that it gives access to a range of individuals that may be hard-to-reach and offer replication across studies (Lloyd et al., 2019). This social media platform, and the use of unobtrusive research methods, confirms that access into the group home is possible. YouTube has made the difference to this mode of research, ensuring that the domestic environment can be rendered public, but on the terms of the individual uploader.

Kaufmann and Tzanetakis (2020) reflected on the challenges of using a public social media platform to reach hard-to-reach hackers that preferred to remain anonymous and hidden in the online environment. This research studies a group that is the opposite. The men and women with disabilities, their families and carers, do not try to remain hidden online. They have created an online presence. In reality, this group may be hard-to-reach and the group home difficult to gain access into. The internet has made reaching this group possible. Unobtrusive research methods need to be interpreted to understand meaning and representation.



Unobtrusive research methodologies underpin the importance of existing knowledge, the ontological and epistemological foundations upon which the researcher's worldview is based and, the critical reflexive process by which new knowledge and direction are contextualised to the individual context of the researcher (Auriacombe & Meyer, 2020, p. 648).

The method in which the data were translated into knowledge informs the methodology. The internet does not just facilitate the investigation of issues between researchers and participants, but the internet itself produces knowledge (Kaufmann & Tzanetakis, 2020). Valuable insight can be gained through observing the lives of people with disability through the mode of YouTube, systematically and with care. Men and women that live in group homes do not need to be disturbed to investigate their lives and the human rights abuses that restrict them. By summoning disintermediated videos from YouTube, the knowledge created from observation and analysis was used to inform disability theory about group home violence, abuse and neglect.

Videos encased in YouTube provided an opportunity for observation of information to be conducted that may have been missing or overlooked from the research project that used interviews or surveys. Rather than the need for the researcher to request interviews, YouTube was sourced directly from the internet. The evidence within YouTube videos provided demonstrated that men and women with disabilities disclosed their experiences of violence, abuse and neglect on their own terms, according to their own will. A great sense of agency in the men and women uploading the videos was observed through this data collection method.

Using unobtrusive research methods in social research may eliminate certain bias, promoting conceptual and contextual analysis (Auriacombe & Meyer, 2020). An interrelationship exists between unobtrusive research methods and theory during the process of meaning making in qualitative research (Auriacombe & Meyer, 2020). The researcher transcribed the disintermediated videos summoned from YouTube. During the transcription process, the researcher was constantly reflecting, interpreting and comparing new information to what was already known, with major themes becoming evident (Auriacombe & Schurink, 2012). To make meaning from data, disability theory was consulted and read. The integrated literature review

assisted in meaning making. The findings were contextualized within existing disability theory.

My interpretation of findings was based on common themes that emerged from conducting my data collection and thematic analysis. These findings were then contextualized by existing disability literature. By combining the observed data collected unobtrusively with disability theory, empirical research was combined with theoretical research. This is a particular strength of this methodology informing disability theory. The knowledge created is based upon empirical evidence that includes the voices of men and women with disabilities. The relationship between disability and digital technologies is complex (Trevisan, 2020). By using the literature to position the findings, the relationship between disability and YouTube was analyzed and understood. Each video was evaluated for its reliability. Reliability of information uploaded on YouTube has been questioned in research (Saffi et al., 2020). Validity of information was ensured by observation and investigation. I drilled into YouTube channels to investigate whether the channel was owned by an individual. The investigation process involved listening to each video, if necessary. Specifically, indicators of adult, disability and group home living needed to be evidenced. To replicate this study, the researcher would have to do the same.

While YouTube is the most widely used video hosting website in the world, the quality and reliability of information has been questioned (Saffi et al., 2020). The benefit of using YouTube in social research is that information is easily accessible (Saffi et al., 2020). The ease as to which information is accessible is witnessed by the way in which YouTube is consulted for health information (Okagbue et al., 2020). Recent research has investigated the reliability of health information uploaded to YouTube (Denham et al., 2020; Okagbue et al., 2020). Content produced and uploaded on YouTube by care-givers of stroke survivors and was used to identify care-givers' needs and recognised as a good source of knowledge (Denham et al., 2020). Reliability of information can be trusted when people's opinions and personal experience is sought, as people are sharing their own opinions. Content available on YouTube is useful to provide insights into issues pertaining to them. Content shared was believed to be social support and an information resource (Denham et al., 2020). YouTube has been used as an open source in the medical field to patient education

(Okagbue et al., 2020). As such, YouTube was generally found to be useful in recruiting patients for medical research, peer support, advancing patient loyalty, patient health education, and patient support and empowerment (Okagbue et al., 2020). Findings from Okagbue et al. (2020) highlighted that the source of information impacts the validity of the information. In this research, the source is men and women with disabilities, their families and carers, themselves.

The evocative information from disintermediated videos including number of times viewed, the number of likes and the number of dislikes were not recorded for this research. A recent study using YouTube by Saffi et al. (2020) analyzed the number of times videos were viewed, specifically health information about migraines. By using this information, the impact of that information shared on YouTube about migraines could be analyzed. The idea was that people searching online about migraines would discover a tremendous amount of information that may be misleading and false. A valid point that Saffi et al. (2020) presented was that the developer of the channel should be regarded to ascertain the validity of the content. This research assessed validity of information by investigating and analyzing the YouTube channel's developer. This research was not seeking to identify the impact of information shared on YouTube about disability group housing had. Rather, the content of the disintermediated videos was sought. The researcher sought the content of the videos to answer the research questions, as opposed to the potential impact that the videos may have had. This unobtrusive research was a qualitative research approach concerned with collecting information rich data via the transcription of narrative on videos. A quantitative approach or mixed method approach could have been utilised by recognizing the number of likes and views, however has not been included for this research.

Novel social research has creatively included information summoned from YouTube in the research process. Transgender advocacy using YouTube has been used to explore the construction of critical transgender narratives of some Spanish trans YouTubers (Tortajada, Willem, Platero Méndez, & Araüna, 2020). This research contributes to the research exploring how the freedom of expression available on YouTube is harnessed by communities that may be discriminated against and oppressed. A different mode of information is revealed by using YouTube to seek

information. The space can be used for political leverage where human rights are challenged. YouTube appears to be a space where minority groups that experience disadvantage can freely advocate for their interests. People with disability want to share their thoughts and feelings on YouTube. Sometimes engaging people with disability in research can be challenging because individuals are not able to talk about their thoughts and feelings. These factors highlighted YouTube as a valuable data collection method in the exploration of disability group home violence, abuse and neglect.

In this chapter, I have presented a forensic step-by-step exploration of the six YouTube searches that were summoned during the data collection to demonstrate clearly how unobtrusive research methods were deployed in this research. A thorough understanding of how personal judgement was exercised by the researcher during the data collection process was provided to ensure that the research could be replicated. The way meaning was made during the thematic analysis was provided to ensure that the reader trusts the validity and reliability of the research findings. This chapter supported the original contribution of knowledge by demonstrating that the unobtrusive research methods deployed in this research provided trustworthy and reliable information to explore what people with disabilities, their families and carers, disclosed on YouTube about their group home living experiences. Further, this chapter supported the original contribution of knowledge by demonstrating the convenience that unobtrusive research methods offer research into people with disabilities. Unobtrusive research methods using information collected from the internet is quick and cost effective, enabling research into social issues unaffected by world pandemics, as face-to-face interaction with participants was not required. Lastly, this chapter supported the original contribution of knowledge by explaining how the thematic analysis made sense of the information that was revealed on YouTube to affirm and extend the existing theorization of disability group home violence, abuse and neglect. The thesis now moves to present the findings that emerged from the research.

## **CHAPTER 5**

### **THE NEOLIBERAL GROUP HOME: NEOLIBERALISM DISADVANTAGES PEOPLE WITH DISABILITIES**

For decades, the care of people with disabilities belonged to the state. Along with the marked shift to neoliberal principles guiding the market economy, the provision of services in the disability sector has moved to the quasi-free market. This shift has implicated the provision of goods and services to people with disabilities. These implications affect the lives of men and women with disabilities living in group homes. People with disability are displaced in a neoliberal world. Disability group homes reinforce ableism and exist within neoliberal structures to further disadvantage the disability community.

In this chapter, I conceptualize neoliberalism and the impact that the shift to a neoliberal economy has had on people living with disabilities in group homes. A major theme that emerged from the thematic analysis of the data set was neoliberalism, and how supplying disability services in the market impacts the quality of care provided to people with disabilities living in group homes. Men and women with disabilities were unified in their experiences that group homes were neglectful, capturing evidence which was then uploaded publicly to YouTube of substandard living conditions. I use an integrated literature review to locate information within the existing theorization of disability studies. To understand how neoliberalism oppresses people living with disabilities, I discuss how the neoliberal ideology supports ableism. To understand the here and now, the history of disability politics is considered. This chapter contributes to the original contribution of knowledge by using the narrative of men and women with disabilities, their families and carers, to affirm and extend the existing knowledge about disability group home violence, abuse and neglect. I discuss what people with disabilities, their families and carers, have disclosed on YouTube about their group home living experience, specifically in relation to poverty, unmet needs, impoverished and neglected facilities, and poor health and the overcrowding of group home facilities. Men and women living within disability group homes experience individualized poverty and describe barriers to accessing their basic daily needs.

Further, I contribute to the original contribution of knowledge by discussing the benefits that YouTube offers people with disabilities by analysing why individuals, their families and carers, choose YouTube to expose these experiences. I use the data set to demonstrate that residents leverage multimodal devices to capture evidence of the poor substandard living conditions that they are subjected to. I contribute to the original contribution of knowledge by considering the strengths that unobtrusive research methods offer research into people with disabilities. I consider the disintermediated videos uploaded to YouTube by individuals and their contribution to the evidence base of disability group home violence, abuse and neglect. Finally, I contribute to the original contribution of knowledge by discussing how the information that is revealed on YouTube affirms and extends the existing theorization of disability group home violence, abuse and neglect. I use the content sourced from YouTube to argue that service providers are driven by profitability within the market, rather than the moral social conscience underlying the welfare system.

### The injustice of individualized poverty

Classic liberalism is an ideology and policy model that emphasises personal and economic freedom, while the state has a small role either through regulation or taxation (A. Ryan, 1993). It is a model that expresses scepticism about government's ability to be able to benefit the people (Ellerman, 2020). In classic liberalism, individuals are free to pursue their own interests (A. Ryan, 1993). The concept at its loosest terms has been linked with the rolling back of programs associated with welfare and the emergence of a set of political-economic policies. The concept of liberalism has developed notably since originating from the eighteenth-century philosophers and nineteenth century laissez-faire economic policies. In the mid-twentieth century, the liberal model fell into disfavour during the Great Depression, where it became apparent that there was a greater need for the role of government in managing economies (Barnett & Bagshaw, 2020). Western governments drew upon economic theories of JM Keynes and economic intervention through welfare states in the exercise of promoting prosperity (Palley, 2005). Welfare states became increasingly popular in the 1940s and 1950s, while at the same time a counter argument circulated that state intervention would lead to totalitarianism (Barnett & Bagshaw, 2020). In the 1960s, Friedman argued for the efficiency of economic

performance through the primacy of markets and competition, and a lesser role of the state (Palley, 2005). Neoliberalism emerged in the 1970s and has since evolved.

Since rising in the 1970s, the concept of neoliberalism has had three defining key elements: privatization of markets, limiting of public expenditure, and government deregulation (Barnett & Bagshaw, 2020). Neoliberalism is a concept that is ill-defined and has a taxonomy of uses (Flew, 2014). Neoliberalism places competition at the centre of social life (Barnett & Bagshaw, 2020; Hartwich & Becker, 2019; Wilson, 2017). Neoliberal ideologies permeate social, cultural and political-economic forces, while the promotion of market competition by government is favoured rather than the care and security of citizens (Wilson, 2017). Welfare is believed to create dependency and bureaucracy. Social infrastructures such as social security, public education and unemployment benefits are subject to the welfare imagination rather than said to encourage entrepreneurship. The aim of neoliberalism is to create a competitive market environment that is efficiently run by private enterprises. The philosophical grounds of neoliberalism are believed to extend competitive market forces, consolidate a friendly-market constitution and promote individual freedom (Jessop, 2019). This personal freedom also has the downside and associated consequences associated with individualism. Living in a competitive state breeds individualism, where concepts like agency, autonomy and self-determination are important (Wilson, 2017). Individualism creates a hierarchy and places the individual and society at opposite ends, where each occupy mutually exclusive poles (Keating, 2012). Individualism places people against their peers.

Neoliberalism has influenced our worldviews, beliefs, values and traditions that have held us together and bind the public. It has influenced popular culture that people engage with within the context of their daily lives.

If neoliberalism provides the economic conditions for the makings of the contemporary citizen, then ableism provides the psychology (Goodley & Lawthom, 2019, p. 237)

Neoliberalism is not just a description of a situation, but also a prescription for action (Dougherty & Natow, 2019). Jessop (2019) has argued for four forms of neoliberalism; neoliberal system transformation, neoliberal regime shifts, economic restructuring processes and potentially reversible neoliberal policy adjustments.

Each four differing in radicalisation. Dougherty and Natow (2019) argued for its use to describe the public administration varying in specifics. Zhou, Lin, and Zhang (2019) applied a neoliberal critical discourse to interpret urban inequality, spatial manifestation and the emergence of urban governmentality, arguing that this is an area where neoliberalism has been most often invoked. Issar (2020) argued for a neo-Marxist, neo-Foucauldian approach to neoliberalism to partition race from the contemporary workings of capitalism. These differing ways of understanding neoliberalism has provided a lens for which the mechanisms of capital accumulation have been analyzed.

Many different understandings of neoliberalism have emerged from dominant ideologies of global capitalism to forms of governmentality and hegemony, theory and policy discourse. Neoliberalism has been associated with an institutional framework characterising particular forms of national capitalism (Flew, 2014). Flew (2014) argues that the different understandings of neoliberalism are not mutually compatible and the term needs to be narrowed. The strongest definition of neoliberalism comes from Marxist political economy that heralds its dominant ideology of global capitalism (Flew, 2014). Here the term is associated most strongly as a political ideology associated with globalization and financial capitalism. While the basis of the term neoliberalism has been in economics, a taxonomy of uses for the term neoliberalism has been evidenced across the humanities and social sciences (Boas & Gans-Morse, 2009; Callison, 2020; Lee Mudge, 2008). These terms have supported ideologies that oppress the disability community.

People living with disabilities are economically challenged by neoliberal structures and psychologically challenged by ableist ideologies. The neoliberal-ableist life is a lonely life in a deeply individualistic and individualising world (Goodley & Lawthom, 2019). These dominant structures and ideologies further oppress an already vulnerable community. A contemporary attack on society and social justice in the name of market freedom has been argued to be a direct result of neoliberal rationality (W. Brown, 2019). Men and women with disabilities are at the centre of this neoliberal rationality. People living with disabilities are disadvantaged in a neoliberal market (J. Gibson & O'Connor, 2010; Goodley & Lawthom, 2019; Sakellariou & Rotarou, 2017b; Stillman, Bertocci, Smalley, Williams, & Frost, 2017).



Neoliberalism favours ableism and is an unattainable ideal for people living with disabilities (Goodley & Lawthom, 2019). Neoliberal policies that adopt ideals of self-reliance and responsibility impact heavily upon people with disabilities that experience structural disadvantage within the economic and health care system (Sakellariou & Rotarou, 2017a). Under neoliberalism, the extent of one's ability determines their success (Tabatabai, 2020). Individuals that rely on state support are considered "defective by reason of their financial dependence" (Bielefeld, 2016). Relying on government support to provide financial support and facing high unemployment, the effects of living below the poverty line is often felt daily within a market economy governed by neoliberal principles. The data set captured the financial challenges experienced by residents within group homes.

To live on such a small income is unrealistic for me (Rebel Fighter, 2018d).

I'm also pretty much broke (Rebel Fighter, 2018f).

Historically, the moralising discourse surrounding people living with disability classified them as the deserving poor, dependant on charity and pity (Soldatic & Morgan, 2017). Such discourse reinforced the segregation of people living with disability within the four walls of the institution and removed from civility (Soldatic & Morgan, 2017). Emergence of neoliberalism redefined the citizenship of the person with disability. Citizens have been directly impacted by neoliberal structures. Neoliberalism as a political and economic world view has dominated since the 1970s, with its only threat to power being the global financial crisis in 2008 (Mackenzie & Louth, 2020). In a neoliberal welfare market, deserving citizens are expected to navigate their way through a capital market towards self-reliance (Harvey, 2007; Mladenov, 2015). Ableism has supported and empowered neoliberal ideologies that favour the autonomous, capable and healthy citizen (Goodley, 2014; Soldatic & Morgan, 2017). Neoliberal governance has re-classified people with disabilities as marketized citizens. As market citizens, individuals with disabilities that experience financial difficulties may feel pressure to secure employment as a means of overcoming poverty. A conversation between two group home residents recorded and uploaded onto YouTube captured this pressure to secure employment as an

option to free themselves from the effects of poverty. The data set revealed that credit cards and debt were used to cover daily living expenses.

P – See I suck at math that’s why I’m no good with money.

L – My friend I’m telling you, you sold yourself short.

P – But I’ll have no money next time. Unless I pay the minimum. You know how you can pay the minimum.

L – Yes but then you’ll have to pay the interest and that’s going to be

P – A bitch

L – A pain in the arse too. So what I suggest you do is to find a fucking job and make money (Rebel Fighter, 2018f).

The basic disability income was insufficient to cover daily living expenses, and individuals struggled to manage their finances. Debt was relied upon to meet daily living expenses, and securing employment seemed to be the only way out of the poverty experienced within the group home. How realistic this was for the resident was unknown, but factors taken into consideration was the resident’s incapacitated state, being a wheelchair user. This demonstrated that the resident carried the burden of responsibility of managing his own finances, as opposed to the welfare system where the responsibility for caring for the disability community is collective. “Marketizing social care is a contentious and complex topic” (Joseph, 2020, p. 17). People living with disabilities do not have the same capacity for work and yet may be forced into the labour force. This abuse is part of the disability group home living experience for some.

Neoliberal discourse has mobilised impaired bodies as members of the labour market for precarious low wages, few labour regulations offering protection, and few positions (Soldatic & Morgan, 2017). People with impairments do not have the same opportunities at securing employment when competing with able-bodied individuals. Such discourse encourages individuals with disabilities to secure employment, while the standard of work and low remuneration devalues and dehumanises. Some of the

first policies concerning people with disabilities associated with neoliberalism were deinstitutionalization and direct payments, which gave individuals power to manage their own care (Mladenov, 2015). If unable to secure employment, welfare payments ensured the most vulnerable people remained entrenched in poverty.

While having access to limited funds, it has been argued that choice and agency are afforded to citizens in a neoliberal market, while resilience has been championed as one of the most important resources for surviving poverty in a capital market (Mackenzie & Louth, 2020). Bigby, Bould, and Beadle-Brown (2017) found that people with disabilities living in group homes experienced restricted lifestyles associated with low income. People with disabilities that are not able to effectively participate in a consumption-based economy are at risk of being forced into further hardship and poverty (Mackenzie & Louth, 2020). The data set revealed that men and women with disabilities living in group homes struggled to meet their daily living expenses. They looked for other ways to meet their financial obligations, including credit card debt and entering the labour force. The disability community are at high risk of experiencing a perpetual cycle of poverty.

Just try your hardest to upgrade your credit and use prepaid cards. It's not worth trying to get a credit card right now or whatever. If you're all in the same boat as me and I'm trying to say just keep your credit cards and work with your case workers and stuff and see if they can help you up your housing credit. So now my housing credit is low (Latrice Allen latriceallen@live.com, 2017c).

People with lower cognition can experience difficulty managing their money (Wahed et al., 2020). The data set captured men and women experiencing financial hardship and unable to break out of their cycle of poverty. The data set revealed that men and women with disabilities have been disadvantaged and often lack the capacity to manage their low income. Unable to break out of the cycle of poverty, individuals remained in need of group homes.

The good side of living in a place like this. You have a roof over your head so it's a place to be if you're houseless or homeless. Number two, the rent is

cheap. So, you know, the rent is cheap, you've got cheap rent (Latrice Allen latriceallen@live.com, 2017k).

Living independently may not be an option for people with disabilities. The group home may be the only course of action for people living in individualized poverty. Residents chose to discuss these challenges when speaking about their group home living experiences, which were recorded and uploaded onto YouTube. The data set affirmed that people with disabilities experienced individualized poverty within a neoliberal market. The daily financial struggle experienced by residents, combined with the shared expenses within group homes, made group home living attractive. Financial difficulties kept people trapped in poverty and dependent upon the system. Individualized poverty meant people with disabilities were forced to work for low incomes. This potential abuse of people with disabilities was revealed as being part of the group home living experience.

The benefits that YouTube offered to the disability community in this example was the ability to capture the narrative of poverty that residents experienced within the group home. An authentic and unscripted conversation between two group home residents documented content that was raw and vulnerable. The strength that an unobtrusive research method offered in this example was the ability to capture a naturally occurring conversation that two men chose to record and upload in their own time. They were completely in control of the content and the topic discussed. By observing the disintermediated video, the information revealed existing disability literature that argues that individuals with disabilities experience individualized poverty within a neoliberal market.

### Inadequate provision of services

Neoliberalism has meant growing and unmet need consequences for health provision (Barnett & Bagshaw, 2020). The promotion of individual responsibility in a neoliberal market may place collective health at risk. Individual 'choice' takes preference over the collective ideologies of 'public good' and 'community' (Barnett & Bagshaw, 2020). The correlation between ill-health and inequality is well established. Health outcomes ranging from the more serious life expectancy and mortality rates to the less severe, such as mental health and chronic health problems, are impacted by

inequality across countries of all types (Pickett & Wilkinson, 2010). Poor health outcomes are reflected in the social determinants of health, including income, housing, food security, employment and educational opportunities (World Health Organization, 2008). These poor health outcomes have been attributed to the 'great reversal', the global shift to neoliberal ideologies that occurred in the 1980's (Palley, 2005). Poor social conditions are not accidental but rather they are a consequence of neoliberal policies (Barnett & Bagshaw, 2020). Group homes have been subjected to neoliberal policies. The disability sector itself was believed to be under achieving in totality. The data set revealed the shortage of group home accommodation in the market, demonstrating that the neoliberal market was not sufficient at adequately providing housing for people living with disabilities.

I'm on every waiting list so that doesn't mean I'm going to get housing anytime soon (Latrice Allen latriceallen@live.com, 2017g).

You have to wait two decades to get into a group home and there's a waiting list to get into a group home (Jake Thorn, 2018).

They say there's too many people on the waiting list, and they're trying to clear up the waiting list again. So hopefully I get in this time. I've been on the waiting list for pretty much five to ten years or longer. So, that's that on housing (Latrice Allen latriceallen@live.com, 2017f).

Men and women with disabilities that wanted to transfer to other disability accommodation found themselves on a waiting list. The data set revealed a shortage of disability housing on the market. Not-for-profit organisations throughout the world have traditionally been entrusted with the role of addressing social issues and social services for disadvantaged communities (Muir & Salignac, 2017). Not-for-profits can operate outside of a profit-maximisation constraint, being able to continue to provide welfare services despite the bottom line (Muir & Salignac, 2017). The fact that these not-for-profit organisations have typically been mission driven rather than profit driven has enabled them to work towards a common social goal (Brezis & Wiist, 2011). Such organisations were traditionally entrusted with providing for the welfare of the vulnerable communities in their care. The global capitalist

trend towards disability services being provided by the market has meant a shift in service delivery focus. The ability of the free market to adequately provide disability services has been questioned (Hall & Brabazon, 2020; Muir & Salignac, 2017). The question is whether men and women with disabilities are truly better off in a market environment. In a neoliberal market, service providers were driven by profitability. Individuals believed service providers were more concerned about finances than providing a quality service.

All they're concerned about is the money man. That's all they're concerned about. That's all they care about at the end of the day (Raphael Hardwick, 2015).

These companies, from my perspective, got my money to provide a service. They look at how much money they can make from each individual person so their idea is to get a hundred people in here so they can make more money, and not look at each individual need. Whether they can meet the need or not. That's the problem with when you got no money (Joshua Weidemann, 2018).

They do only care about money. That's about it because they care about their money and their appointment only. I mean, more bad news. They care about their employees and the money so you got to think each resident is cost \$10K for each person. For everyone that is in a program, each mentally ill person, doesn't matter how great or how small, is cost \$10K. So, they care about only the money and placing them in whatever house (Latrice Allen latriceallen@live.com, 2015b).

I think they're supporting them and some other ones, from the top of my head, just to get funding to keep them going (Latrice Allen latriceallen@live.com, 2015a).

The data set revealed that men and women were unified in their belief that people with disabilities were being exploited by service providers. Residents believed service providers were profit driven and, in the market to make money, rather than consumer focused. Services provided by the group home were impersonal.

Residents were well aware that service providers profited from their disability and perhaps a lack of compassion was felt by residents. Choice and control can only be achieved when individuals are given an opportunity to exercise that choice (Muir & Salignac, 2017). The rights of people with disabilities to exercise choice is compromised when service providers make decisions about who they will house based on profitability. The elements of a free market economy including competition, individualism and self-interests overrides elements of trust, cooperation, altruism and compassion of a socially orientated approach (Brezis & Wiist, 2011).

Group homes are places where service providers help people with disabilities to meet their fundamental needs. Annison (2000) compared the understanding of what constitutes a home in disability literature using the contribution of three scholars, O'Brien, Sixsmith and Despres. With the findings, Annison (2000) presented a multi-faceted approach to group homes which compared the relationship of attributes of a home to Maslow's need hierarchy. This consisted of fundamental needs, intermediate needs and meta-needs or growth needs. Fundamental needs were related to psychological needs for food, water warmth and shelter, including a safe environment and adequate spatial room (Annison, 2000). Intermediate needs included the need for safety, security, belonging and social acceptance (Annison, 2000). Intermediate needs included building friendships and having a sense of privacy and control. Meta-needs or growth needs included the ability for self-expression and self-actualization within the home (Annison, 2000). Meta-needs were largely activity based. The data set revealed that men and women with disabilities living in group homes did not believe their fundamental needs were adequately being met within the home itself.

Why do the people in the group homes always get punished? Always get the short end of the stick? Can the state or the government or the people that support the government tell me that because if we're paying for transportation, then shouldn't we get transportation? If we're paying for the food, shouldn't we get the food? If we're paying for the room and board, shouldn't we get the room and board? If we're paying for the rent, shouldn't we get to live there as long as we want? If we're paying for the staffing, if

we're paying for the staffing to do what we want, shouldn't we be asking what we want them to do? They shouldn't get the say of saying, "nope we're not going to do that, nope we're not going to work with you on that, nope we're not going to do this for you." They don't have that say since we're paying them so because we're giving them their cheques because we're giving the staff their cheques, we're giving the staff their money for working for us, because we're giving a portion of their money to them for working for us. Nobody ever knows that but it's true so I guess my question is why, why so many people object to this and make statements over this and make regrets about this and have regrets about this and make a fuss about it? Why not make it right? Why not make it to the point where we can actually handle the business. Why not make it to the point where it's promised what you do for us. Why not make it to the point where it's promised that the people in the group homes are promised for what has been promised to them, give them what they're promised? Don't take from them. Don't do things that are wrong. Don't do things that are not meant to be. I mean, why make a fuss about it? Why do things wrong? Why not do things right through the state? Why not do things right through the government? Why not do things right if it's a government group home? I mean, it's licensed through the government. Group homes are always licensed through the government so otherwise they won't be a licensed group home. So, I guess that's my point of view. Make it right with all the people in the group home or have assistance with staffing so thanks for watching (Nada Saue, 2018).

The removal of the state from commercial activities is a product of neoliberalism (Barnett & Bagshaw, 2020). In a deregulated market, service providers have control of the delivery of service provision with minimal intervention from government. This deregulation and removal of government from the provision of disability services was shown to impact the lives of men and women with disabilities living in group homes. Residents felt their basic needs were unmet within group homes. Group homes were places where basic human rights were violated and people with disabilities felt like victims of the system. Being trapped within the group home and feeling as though they were helpless, there was the sense of a lack of power. Residents spoke about



the struggles and challenges they experienced to have their basic daily living needs met.

I have had nothing but problems with management and trying to get the hours and the care that I want (Rebel Fighter, 2018d).

I had to fight to get three showers a week (Rebel Fighter, 2018d).

I don't understand why they can't shower me every day (Rebel Fighter, 2018d).

I'm just exhausted from trying to fight and fight to get my need. I'm just exhausted (Voices4 allneeds!, 2018c).

The data set revealed the challenges experienced by residents to have their basic daily living activities supported. Basic essential support such as showering was challenging for residents to achieve. Dependent on the system yet ideally responsible for their own citizenship in a neoliberal society, people with disabilities found themselves in a powerless position within the group home environment.

If staff can't help me achieve what I need them to help me to achieve, then how can I achieve great things? (Joshua Weidemann, 2018).

If meeting basic daily needs were unattainable for men and women with disabilities living in group homes, achieving life goals were unrealistic and impossible. The data set revealed that residents lacked vision and hope for the future as a result of not having their basic daily living activities adequately supported.

According to the World Health Organizations' Constitution, access to health care is a basic human right. Research shows that people with disabilities continue to face several barriers when accessing health care, while reporting higher unmet needs compared to the non-disabled population (J. Gibson & O'Connor, 2010; Sakellariou & Rotarou, 2017a; Stillman et al., 2017). Group housing is a provision of healthcare for people living with disabilities. Without these basic daily living activities being supported, the impact on those with disability could be detrimental on wellbeing. Group homes failed to meet intermediate needs of residents.

My mental fortitude constantly is challenged. These staff don't even want to cut up vegetables. They don't even want to make home-made food. They don't want to do anything. They sit in front of a TV all day and that's what they do and it's incredibly depressing. I can't get them to even want. They give me disgusting looks, they give me attitudes all day. It's like they don't want to work with me. I understand that the reasons why they don't is because I've had to report them for neglect. When you leave me in faeces and you refuse a basic human right of a shower and you just refuse to take care of me as an individual, I have a problem with that. And I have a problem with, you know, people just not giving a shit. They're more than capable of doing things with me. They just don't want to (Joshua Weidemann, 2018).

Staff leave me in faeces and refuse, and basically say we're not wiping you or we can't wipe you (Joshua Weidemann, 2018).

I have got high blood pressure which they all know, which now I'm on high blood pressure medicine and I've got staff that are refusing to shower me. They're saying it's too hard to do. We got staff that are refusing, or having a real hard time, whipping a butt, and they're saying that's really hard to do. Personally, if I could do it if I would do it. It's not as hard as people are making it out to be (Joshua Weidemann, 2018).

The data set revealed that staff were often blamed for basic needs being unmet. Care that was compromised posed a risk to individuals living in the group home environment and reliant on support to function. For people who "have (or are believed to have) an attribute that marks them as different and leads them to be devalued in the eyes of others" (Major & O'Brien, 2005, p. 395), maintaining a sense of self may be important (Nario-Redmond, Noel, & Fern, 2013). It is vitally important that compassionate support be given to people with disabilities living in group homes. The impact of poor care on self-esteem and wellbeing was documented on YouTube by individuals with disabilities as having a detrimental effect on the lives and wellbeing of residents.

I've lost all respect for myself. I've lost all of my own pride and dignity and respect for myself because it's hard to have respect for yourself. It's hard to care for yourself when people don't care for you. My life personally has been affected by this because this is all I do. All I do, eat, shit, sleep, piss, eat, shit, sleep, piss, like all I want in life isn't what I want. They're suppressing me from what the quality of my life is because they don't support what I want in my life to be. I'm not a caged animal. I mean, you wouldn't even do this to a dog. You would let a dog out to poop (Joshua Weidemann, 2018).

I don't have a good quality of life so it doesn't make me motivated to do anything (Joshua Weidemann, 2018).

It's cold in this group home. The food is unbearable. I eat just, you wouldn't want to feed your dog this shit. It's unbearable (Rapheal Hardwick, 2015).

The data set captured information rich narrative about the feelings and experiences of the group home environment, and how this impacted self-esteem. Such narrative is rich and robust. This depth of information may not be obtained through obtrusive research methods when an interviewer is present. Observing information and self-disclosure of this quality is a strength of using unobtrusive research methods in the field of disability studies. People with disabilities are not afforded the ability to live in their own home because they need support fulfilling daily living activities. For men and women living in a disability group homes, their living environment failed to meet the needs of a home environment. A home environment is one that meets fundamental, intermediate and meta-needs, which the group home failed to do. Residents relied upon support from staff but described instances of neglect where staff failed to provide sufficient care. The data set revealed that staff were often neglectful, unhelpful, unsupportive, lazy and inefficient. This had a detrimental effect on the wellbeing of residents.

YouTube was shown to empower the voices of people that were marginalized and oppressed by their environment on a daily basis. People with disabilities that found themselves in neglectful situations were able to speak out to the public by recording their experiences on disintermediated videos uploaded onto their YouTube channels.

The quality of the information was rich and robust as feelings were freely conveyed. This quality of information would be unlikely to be sourced from obtrusive research methods such as interviews or surveys. This is a strength of unobtrusive research methods in the field of disability research. Further, the video format enabled data to be captured that flowed freely and was not restricted by a keyboard or literacy. People with disabilities spoke at their own pace. This encouraged deep and insightful narrative to emerge from the data set. This rich information was used to extend disability theory about neglectful group home experiences.

### Impoverished and neglected facilities

The social determinants of health are impacted by residential environments and therefore residential environments play a major role in determining the quality of life for individuals (Kavanagh et al., 2016; Kyle & Dunn, 2008; Veitch, 2008). Despite the impact that residential environments have on health, people with significant disabilities including intellectual disability, brain injury, spinal injury, multiple sclerosis and cerebral palsy, have limited housing options (Australian Institute of Health and Welfare, 2007; Bridge, Flatau, Whelan, Wood, & Yates, 2003; Connellan, 2015; Wiesel, 2015). Group housing remains the dominant accommodation option for people with disabilities where resources are limited (Beadle-Brown et al., 2007; Bigby & Beadle-Brown, 2018). Many governments have introduced individualized funding in the disability sector (Lord & Hutchison, 2003). While people with disabilities struggle to meet their daily living expenses from welfare payments, service providers in a neoliberal market profit from marketable services. This does not seem ethically fair and equitable. When market forces determine market supplies, profitability becomes the driving factor for service providers. Marketization causes the need for calculability, efficiency and profit to undermine humanistic principles that were traditionally strong in the welfare market (Mladenov, 2015). The radical marketization of the welfare state in westernized nations throughout the world has transferred the care of people with disability from government owned institutions to privately owned and managed group homes (Mladenov, 2015). Daily routines can become mechanical and target driven as the focus shifts from individuality to efficiency. Such principles work against autonomy and self-determination.

Through its promotion of competition and self-interest, marketization displaces solidarity. Yet solidarity provides the social, structural (economic) and moral (value) basis of public provision, even in its most individualized and consumer-orientated forms (Mladenov, 2015, p. 23).

Within the disability sector, solidarity and collaboration between service providers for the best interests of individuals with disabilities has been something that has typically strengthened the system. The shift to neoliberal principles and the care of the vulnerable to profit-seeking organisations has placed disability care at risk of compromised quality.

The community location of group homes originally intended to socially include people with disabilities in the community that had previously been isolated and excluded from those without disabilities. Men and women with disabilities deserve to be afforded the experience of living within a home rather than simply an existence within an institutional house. The term “home” has been misapplied to many residential facilities that have housed men and women with disabilities over the years (Annison, 2000). Group homes have provided a substandard living experience to the disability community.

The creation and experience of home is an important contributor to a person’s humanity and their positive social perception by others (Annison, 2000, p. 251).

The home experience is more than simply having fundamental needs of shelter and safety met by the provision of suitable housing. Homes are places that foster wellbeing. The concept of what makes a place a home rather than a mere house was explored by service providers during the early phases of deinstitutionalization, when relocating individuals to smaller group home settings within the community (Annison, 2000). Part of the notion of “home” incorporated the physical structure and architectural style of the building (Annison, 2000). This is where fundamental needs of shelter and housing were met. The physical structure of residential disability group homes contains meaning for people living with disabilities.

In the process of depopulating total institutions ‘the community’ became an epithet for places that looked least like the segregated spaces that were the historical experience of people with disabilities (Milner & Kelly, 2009, p. 48)

Transferring individuals from institutions into the community setting had the appearance of creating community inclusion for people with disabilities during

deinstitutionalization. The home-like structure itself represented and symbolized community inclusion. Importance was given to the presentation of the group home facility (Milner & Kelly, 2009). The condition and presentation of group homes contributed to feelings of resident wellbeing. The data set revealed that the group home residents lived in substandard and impoverished group homes. The living conditions were unsatisfactory and fundamental needs were not being met. Residents used the video mode of YouTube to capture visual evidence of the substandard living conditions, which could not be disputed.

Hi this is me, Latrice Allen. Part 3. I just made a part 1 that showed like the whole kitchen, the topic I wanted to talk about. That I showed evidence of Steadfast not really doing so much (Latrice Allen latriceallen@live.com, 2014d).

The data set highlighted that people with disabilities could speak on their own terms about topics that they deemed to be important. People with disabilities often have their legal capacity brought into question or experience difficulties making others believe or understand the level of threat they are facing (Geary & Brodie, 2020). These barriers and challenges stop people with disabilities from accessing the justice system (Geary & Brodie, 2020). Self-determination, agency and empowerment was captured on film when residents took initiative to capture evidence on video of their poor living conditions. While service providers failed to act and provide a better service, individuals used YouTube to advocate for better living conditions. By capturing the poor living conditions on video, the experience of people subjected to these conditions was indisputable.

Mondays is my wash day so technically I'm supposed to stay at home but apparently Oi Oi House has a broken water pipe, the one that runs the whole house (Latrice Allen latriceallen@live.com, 2017h).

I have dust and mould in the window seal. The whole window itself is just, see that green stuff? That's mould and that's how it's been. See the other window. It's worse. This is when I moved in because when I moved in, I did a check as well. Took pictures that I needed. Look at that. There's even mould

to the point where that is growing right there. See that? Make sure you get that clear view right there. Yep. That's mould. It's been like that since I moved in (Voices4 allneeds!, 2018b).

Hey everybody. We got nice stuff, somewhat, and a hole down there (Latrice Allen latriceallen@live.com, 2017b).

Like seriously eww. Who does this shit in a group home? Like right there, the mould. See right here in the corner and there's mould over here. No one's cleaned this bathroom for days. That's the garbage right there. Missing a towel rack. The sinks disgusting, look you can see grime all the way under there. Under the faucet and the sink hasn't been cleaned. You can see there's a dead bug there. Here stains. Not cleaned there either. I never really have these either. Or these much. You always have to do it. This is where they supposedly have to keep the cleaning supplies for the bathroom. As you can see all that's under there is toilet bowl cleaner. So that's probably why they haven't been able to clean the bathroom. We do have supplies. Oh look there's Mr clean on the counter. Isn't that a safety hazard for people? It says Mr Clean there. Right there, and a weird bottle so it could be whatever. The counter has all this fire hazard stuff so who in the world even licenses a place like this. Like the toilet's not even cleaned. Look at that. There's poop and look at the corners. And on the toilet seat, there's like crap there. Ok people don't clean, they say they clean but staff don't do anything. Look (Voices4 allneeds!, 2018a).

Men and women with disabilities were united in their experience of living in substandard group homes. Many videos captured group home environments that were neglected. Disintermediated videos were used to capture evidence that group home facilities which residents were subjected to were unsafe. Mould, insects and broken washing facilities would impact the hygiene and health of residents living within the home. YouTube was used to reveal to the public the true state of living conditions for the disability community that were reliant on the group home. The title of a particular disintermediated video demonstrated in the data set was, "Abused and neglect (Part 1)" (Voices4 allneeds!, 2018a). The video captured

evidence of the substandard and impoverished group home facility that housed the resident.

I have looked up the difference between black mould and toxic black mould. That is why I've been so sick in here. Nasally stuffed up, swollen throat, nausea, severe headache. That's all signs of toxic mould infestation and it's not just from how my room was (Voices4 allneeds!, 2018c).

Residents disclosed unsatisfactory living conditions that were of a serious health and safety concern. Such conditions were harmful to resident health. Men and women with disabilities experienced facilities and environmental surroundings that were toxic to their health and wellbeing. Memory and perception of events may be distorted for people that experience cognitive impairments due to intellectual disability, brain injury or mental health conditions, and their recollection of events may be affected (Dowse, Dean, Trofimovs, & Tzoumakis, 2015). The evidence captured on film could not be disputed. With little housing options and being powerless within their own home, YouTube enabled individuals to speak out about the injustice they were experiencing. Facilities were reported to be a danger to people's health. Infestations of insects and bugs within the group home facility was a common occurrence reported by residents living in the group home environment. Residents spoke about infestations of insects within their living environment.

I was cooking and the thing just fell down due to termites (Latrice Allen latriceallen@live.com, 2014c).

Something happened to their kitchen. Oh my God, it was like corroded with bugs and stuff (Latrice Allen latriceallen@live.com, 2015c).

Here's some more bugs. They like to hide under the windows and come out at night. See those little things there? They're inside (Voices4 allneeds!, 2018b).

I'm so disgusted with what's going on here. It's just not a healthy environment for anyone. We've had bedbugs. We've had cockroaches. I've



had problems for eight months with getting a door locked, still not working. Refrigerator still not working. No hot water (Joshua Weidemann, 2018).

With infestations of bugs and insects, group homes were not a pleasant or comfortable environment for residents. These conditions posed a risk to resident health. Residents reported that group homes did not spend money on updating furniture, and instead provided second hand or less than average furniture. Residents were unified in their belief that service providers did not want to spend funds on improving the living conditions for residents. Service providers were believed to be negligent in their provision of facilities.

They just bought shitty as outdoor pillows from hotel furniture that were already ripped. They just cheap skates (Latrice Allen latriceallen@live.com, 2014e).

They do only care about money... they don't care about fixing up the place (Latrice Allen latriceallen@live.com, 2015b).

YouTube was used to prove the poor and substandard facilities were disclosed on YouTube by men and women with disabilities who were subjected to live in. The condition of housing affects health through a range of interrelated mechanisms including people's emotional link to their dwelling, affordability of housing, physical condition of dwellings, and physical and social conditions of the neighbourhood where housing is located (Novoa et al., 2014; World Health Organization, 2012). When housing fails in any of these areas, people's health can be negatively affected (Novoa et al., 2015). Research has shown that people facing housing problems experience worse health than the general population (Novoa et al., 2015). The video format of YouTube enabled residents to capture evidence of the living conditions on video to support claim that group homes were a hazard to people's health. YouTube is a public platform and became an entry point into the substandard group home experience. Residents were captured evidence of facilities that were unsafe, unsatisfactory and unhygienic. Residents believed that service providers thought they were undeserving of better facilities and treatment.

The company doesn't want to upgrade windows, upgrade doors, screen doors as much, due to residents' illness and they do break things like furniture and what not. They do take forever to give us brand new furniture which we really don't have any brand new furniture as much (Latrice Allen latriceallen@live.com, 2014e).

They don't want to buy us brand new furniture because people pissing on it (Latrice Allen latriceallen@live.com, 2014e).

Residents themselves expressed that they were blamed and held responsible by service providers for the poor condition of furniture. Men and women with disabilities felt that they were considered undeserving. Residents reported that explanations provided by service providers of a lack of funding to leave facilities broken and without repair.

Lately they've been saying that they don't have enough money to fix up everything. We've been waiting for things to be fixed up for at least 3, 4 years now. Some things they do fix but it takes at least six months to a year to get it done (Latrice Allen latriceallen@live.com, 2014e).

Things are not getting done over there. Let's see. Stuff like things that need to be fixed and stuff like that (Latrice Allen latriceallen@live.com, 2017k).

A delay in property maintenance was reported. People with disabilities within the neoliberal market may disproportionately affected (Sakellariou & Rotarou, 2017a). It was suggested that finances were being wasted and misspent.

They still are picking on areas and wasting money on everything. But then you got to think, where did the money go? (Latrice Allen latriceallen@live.com, 2015c).

Say you get a grant. Say you get a grant for the coffee shop and a grant is like \$25K. And all of a sudden in that year you don't know what happened to it. What happened to that \$25K? (Latrice Allen latriceallen@live.com, 2015c).

Residents living in poor group home conditions used multimodal devices to capture disintermediated videos that questioned the spending of finances by service providers and management. Family members of people with disabilities living in group homes used YouTube to advocate for better living conditions for their disabled family member.

Why are we giving billions of dollars to these agencies that aren't doing what they're supposed to be doing with their money that they're getting? Why are they just like telling people, "there's no place for your son", like they told our son that a million times, that there's no group home? Well ok, we'll get our own house for him, bye (Autismwarriormama, 2017).

Despite rules and regulations that facilities needed to be upgraded to abide by health and safety regulations, it was believed by residents that it was not a priority for the group home to meet their health and safety obligations. YouTube enabled the disability community to go to the public with their concerns without being censored. A study by Petri, Beadle-Brown, and Bradshaw (2020) revealed five common themes for self-advocacy; "speaking up", "informing and being informed", "using the media", "supporting others or being in the community", and "organisational duties". People advocate for a variety of reasons. The parent advocate of an autistic man interviewed her son's carer and captured his responses on disintermediated video. The video was then uploaded onto YouTube comprising disability self-advocacy. The mother leveraged YouTube as evidence that group home facilities were unsuitable and spatially inappropriate to adequately care for her son's disability, to speak out and inform others.

We need an open space. All the corners, the tables, the walls, if we're screaming for help, if he's having a seizure and the care giver is busy doing the dishes, we can't scream through the wall. You can't hear us so much (Autismwarriormama, 2017).

Because his other room was so small, and having three people in there, he does feel claustrophobic like there's no space (Autismwarriormama, 2017).

It's very overwhelming for him (Autismwarriormama, 2017).

And now here's this cramped room. Now this is it. This is his whole living space right here with all these people in here. The two carers. Which is necessary. He absolutely needs two people at all times minimum. Sometimes he needs three people. Three to one. And four to one. So, you know it's very reasonable staffing support. So, this is the whole room. Compare that to what you just saw. When he would have a melt-down or something. Say he had a seizure here. Then here's the wall. Then say the caregiver was over here making the juice or something or filling up the stuff and then there's all these walls and you're bumping into things. If he has a melt-down, banging into this and then trying to get through here in this one little space. Or you went over here and now you're trying to get through this door. You've knocked into the coffee pot. I can't tell you how many went on the floor. Hundreds of dollars for us. You can't believe the money that parents and families with autistic people spend on things that get broken, smashed (Autismwarriormama, 2017).

The visual images captured on film and uploaded onto YouTube provided compelling material for disability advocacy. Images moved beyond words to provide indisputable evidence that people were not having their fundamental needs met. Media is considered a tool to transmit or receive information as part of advocacy, and media is often seen by advocates as integral to achieving targets (Petri et al., 2020). Disability advocacy, including intellectual disability and autism self-advocacy, has largely been under-researched (Campbell & Oliver, 2013; Petri, Beadle-Brown, & Bradshaw, 2017). In this case, the advocate described the facility being dangerously too small for her son's behaviour and the footage captured evidence of the facilities themselves. The facility was unsafe for vulnerable residents, falling short of health and safety requirements. YouTube enabled the mother to participate in the disability advocacy narrative. She did not believe the group home should still be operating. The disintermediated video format captured evidence of substandard facilities provided a sense of power for the disability community.

Now they're trying to fix up stuff because they know that they will get busted if I squeal (Latrice Allen latriceallen@live.com, 2017j).

Residents expressed some sense of power by voicing their dissatisfaction with the condition of facilities. By using YouTube to disclose service provider neglect, the disability community may have felt they could make a difference.

Ok well obviously the home needs to be shut down (Voices4 allneeds!, 2018c)

The data set revealed that some providers should be out of operation and not be providing group home services to the community. Impoverished facilities were common amongst group homes, with residents disclosing multiple experiences.

So now we're going to talk about my experiences at these group homes, and yes that's plural because I stayed at one for three days and then moved to another one because it was so horrible (Vicious x Cycles, 2015b).

Residents used YouTube to disclose their dissatisfaction with the disability group home service that they were provided. YouTube was used as a tool for self-advocacy. Family members of residents used YouTube to advocate for their family member. Images of poor facilities were collected by people with disabilities, their families and carers, as evidence of the disadvantage that residents were subjected to. Shocking images supported the narrative of those producing the disintermediated content.

The benefit that YouTube provided people with disabilities, their families and carers, was a public platform where information could be freely shared. The information was used to reveal service providers neglecting their responsibility to provide an adequate standard of care for residents, and advocate for better living conditions. YouTube provided people with disabilities, their families and carers, an outlet for challenging disadvantage and injustice, and for exposing human rights violations. The authenticity and reliability of substandard facilities captured on video provided compelling evidence to support the claims of abuse and neglect of people with disabilities living in group homes. This information is valuable when extending the theorization of disability group home violence, abuse and neglect.

### Poor health and overcrowding of the group home environment

Health and health care suffers at many levels when corporations control the market (Brezis & Wiist, 2011). Extensive evidence shows that people with disabilities

experience significantly poorer health outcomes than able-bodied individuals (Emerson et al., 2009). These poorer health outcomes are not related to the impairment itself but to other social conditions that impact upon lifestyle (Emerson et al., 2011). Poorer health outcomes of people with disability and mental health conditions include higher rates of ischemic heart disease, stroke, high blood pressure and diabetes (Emerson et al., 2011). Research shows that people with disabilities living in the community experience poor nutrition, inadequate diets and nutritional deficits (Bertoli et al., 2006; Bryan, Allan, & Russell, 2000; Humphries, Traci, & Seekins, 2004; Robertson et al., 2000; Springer, 1987). Material and psychosocial hazards in the environment of those living with disabilities include poorer housing conditions and inadequate diets, impacting the poorer health conditions associated with disability (Sen, 2001). Disability group housing provided a substandard quality of service which impacted the health and nutrition of group home residents.

All I'm eating for the last two weeks is frozen food and it really affects me. Because I was eating frozen food as a child and I'm very much used to it. However, my house manager got me off of that and I was very grateful for that, for the opportunity to eat stuff like stuffed shells, home-made baked mac and cheese. Tuff like steaks, hamburgers, home-made food, and now I'm eating frozen food which is affecting my blood pressure. I have got high blood pressure which they all know, which now I'm on high blood pressure medicine (Joshua Weidemann, 2018).

The food is so nasty, it's unbearable for you to eat and swallow. Sometimes I have went to bed without eating anything because I don't want to eat the nasty food or something (Rapheal Hardwick, 2015).

It's cold in this group home. The food is unbearable. I eat just. You wouldn't want to feed your dog this shit. It's unbearable (Rapheal Hardwick, 2015).

Solutions to inadequate diets in community setting depend upon who is responsible for providing an adequate diet (Humphries et al., 2009). In a neoliberal economy, service providers are responsible for providing adequate diets and staff and

employed to either prepare food or support food preparation. This failure falls upon service providers and is a failure of the system itself.

These staff don't even want to cut up vegetables. They don't even want to make home-made food. They don't want to do anything (Joshua Weidemann, 2018).

One thing I don't get is why people in group homes have to pay their funding to live there and then they get shut down most of the times with their funding because A they don't get their transportation that they paid for or B they don't get their food that they paid for with their funding or C they don't get the room with their funding. If they have to share the room of the housing when they're told that they have one space to them but they have to share it with the people when they're promised that they get space to themselves. Why, I guess my question is, why do the people in the group homes always get punished? Always get the short end of the stick? Can the state or the government or the people that support the government tell me that because if we're paying for transportation, then shouldn't we get transportation? If we're paying for the food, shouldn't we get the food? If we're paying for the room and board, shouldn't we get the room and board? If we're paying for the rent, shouldn't we get to live there as long as we want? If we're paying for the staffing, if we're paying for the staffing to do what we want, shouldn't we be asking what we want them to do? They shouldn't get the say of saying nope we're not going to do that, nope we're not going to work with you on that, nope we're not going to do this for you. They don't have that say since we're paying them so because we're giving them their cheques because we're giving the staff their cheques, we're giving the staff their money for working for us, because we're giving a portion of their money to them for working for us (Nada Saue, 2018).

The inadequate food was blamed upon the staff. Under neoliberalism, where staff are paid to do a role, there is the expectation that they would fulfil their duties and cook a meal. The data set revealed that residents believed this not to be the case. Disability group home overcrowding has been recognized as social determinant of

health and impacted the increased spread of covid-19 amongst group home residents (Soltan et al., 2020). Overcrowding of group home accommodation and the lack of choice regarding who residents reside with has been recognized as concerning (Jim Mansell, Beadle-Brown, & Bigby, 2013; Wiesel, 2011). Men and women with disabilities do not have the same opportunities for accommodation that able-bodied people have, and the data set demonstrated that they most often share accommodation for economic reasons.

You're really not supposed to have consumers that are 24-hour material living in here, but they do place them here. I guess because there's no room and the 24 hours or the sixteenth, so they place them in the semi-independent and cause the rest of us hell. Believe me, a lot of hell (Latrice Allen latriceallen@live.com, 2014f).

So anyway, we have a new resident that's from Samo. He needs to be in a care home type. Steadfast does not have any money to fund. They're broke as hell in Hawaii. I'm not talking about mainlands Steadfast. Why Steadfast broke is as hell, they have five companies that supporting their arse. Shookford Plus is one of them. I think they're supporting them and some other ones, from the top of my head, just to get funding to keep them going (Latrice Allen latriceallen@live.com, 2015a).

The data set showed that men and women living with disabilities were often believed to be placed in supported accommodation based on service provider needs rather than resident needs. The data set revealed that residents were sometimes housed by service providers to fill a gap and for the income the person with the disability would generate. When people with different care needs were housed together, it could be problematic for other residents living in the group home.

So I felt like the people in my building who were more severe and I guess more handicapped were getting more attention and care than me and that they were trying to rush through my bookings to get to those clients instead and yeah (Rebel Fighter, 2018e).



People that have more severe disabilities will get priority over you. I also feel that my care was being overlooked here and, in some cases, it was being rushed to accommodate the other clients (Rebel Fighter, 2018d).

The demands of the other people living within the group home was reported as impacting upon the level of support that others with needs received. People with greater needs were seen as taking more time and attention away from others with perhaps not as demanding needs. A cause of unsatisfactory care or even a cause of neglect was attributed to the demands of the others living within the home that needed to be cared for.

The aspiration to provide housing for those in greatest need does not always lie comfortably with the aspiration to achieve social mix (Wiesel, 2011, p. 281).

Men and women with disabilities did not have the power to choose housemates. Rather, service providers were in control of who they provided housing for. Some residents reported feeling as though the people with greater support needs were given priority and more attention than those that were able to live more independently. They felt that the other residents in the house was a reason why their care and support was overlooked and neglected. Decisions about how individuals were housed were made by the service provider, and often based on funding rather than suitability. The impact that this profit-driven decision had on residents was adverse. This data demonstrated that the market driven by profitability has adverse effects on the wellbeing of men and women with disabilities. It demonstrated that individuals with disabilities were compromised in a free market and did not have the choice and control that otherwise would be thought.

Hey guys it's me Zack back on my Zack shitter account. Basically, you know, fuck Bill, fuck Tay, fuck Johnny, fuck all of them because they think they can run the group home and take my money. Well you know what? Fuck them! Because honestly, they ain't shit. They're a bunch of pussies that use people all the group home members, like you know, the clients. They're basically being used and being treated like shit and I've taken advantage yes. And I've had it. So fuck those mother fucking pieces of shit pussy bastards assholes fuck faces fuck cunts and fucking fucks because these mother fuckers can't do

anything so fuck those bastards fuck those shits fuck those assholes and fuck their bits. Now I'm going to tell you one more time, I'm going to start a brand new rhyme. Fuck them. Am I right? Damn right yeah. Oh man they get me so worked up sometimes. They try and get up my ass for stupid ass shit. Well I'm through with this shit. Fuck them. Fucking chew bags. Fucking douche shits. Fucking pieces of crack shit mother fucking pieces of crack head, slobber knocker pieces of cock sucking, ass hole raping pieces of dark poop and fucking ass crack monger pieces of shit pony dick ass crack eating all this shit, making their breath smell like fucking ass crack shit and eating shit while they shit out of the toilet and throwing it up and pushing it back up their ass and fucking fuck them. Because they're fucking ignorant and they're all about the money. Well you know what? Fuck them bitches, I'm out. Fucking assholes (Ace 187 on your ass, 2017).

As the market adjusts to the demands of the consumer, individualized housing has emerged as an alternative housing and support model for people with disabilities (Carnemolla, 2020). Critics of the market argue that markets typically fail as they provide poorer quality services in the drive to generate profit (Muir & Salignac, 2017). It is an assumption that consumers will choose the highest quality care to meet their needs in a supply and demand market (Muir & Salignac, 2017). Residents believed disability service providers in the group home market were driven by profitability rather than charity. Group homes were not the ideal selection that men and women with disabilities always chose to live in. YouTube as a public platform provided a space where men and women could contribute to the narrative influenced by neoliberal policies. People with a disability have a right to autonomy and self-determination. This right can be lost in a paternalistic system that supplies needs and regulates the conduct of those under its control in matters affecting them as individuals.

In this chapter, I presented one of the main themes to emerge from the findings: the impact that neoliberalism has on disability services. Disability services being provided within a neoliberal market was shown to impact the disability community. I used an integrated literature review to contextualize and make sense of the findings. The analysis revealed that people with disabilities living in group homes experience

individualized poverty and struggled to meet their financial obligations. Men and women with disabilities, their families and carers, used disintermediated videos to show their discontent to their impoverished and substandard living conditions that they were subjected to. Men and women with disabilities were unified in their belief that service providers struggled to provide a satisfactory service for them with the financial pressures of the market. Finally, overcrowded group home environments were demonstrated to contribute to the poor health and wellbeing of group home residents. In the next chapter, I present another main theme to emerge from the research; the re-institutionalization of the disability sector.

## **CHAPTER 6**

### **RE-INSTITUTIONALIZATION OF THE DISABILITY SECTOR: THE OTHERING OF THE DISABILITY SECTOR**

The inclusion of people with disabilities into a world dominated by ableist ideologies and structures has challenged targets of community inclusion for the disability community. Deinstitutionalization of the disability sector was the grand idea aimed towards better social outcomes for people with disabilities. The appearance of group home structures to house and care for people with disabilities has replaced institutional settings. Many of the same barriers to community inclusion have been replicated by the emergence of group homes. This has been coined re-institutionalization of the disability sector. Opportunities and quality of life continue to be thwarted for people living with a disability by the re-institutionalization of the disability sector.

In this chapter, I reveal the consequences that re-institutionalization has had on people with disabilities living in group homes. A major theme to emerge from the data set was the consequences that deinstitutionalization has had on people with disabilities living within group homes. I present the discussion of group home violence through the lens of ableism to understand how the group home structure oppresses residents. Men and women with disabilities shared common experiences. These common experiences were contextualized and interpreted within existing disability theory. While disconnected from the community, I argue that YouTube is used to create online communities that create connection for men and women with disabilities using YouTube to discuss their group home experiences. An integrated literature review constitutes the findings and verifies what is already known about disability group home violence, abuse and neglect. Further, disability theory is extended by interpreting the findings with reference to the research questions, specifically by analysing the benefits that YouTube offers people with disabilities. It is expected that any discussion about group home violence would include a deliberation of the impact that deinstitutionalization had on the system.

## Disempowered by re-institutionalization

I have decided to move out of the group home because it's too institutionalized and it is run like a nursing home and I want to be more independent and make my own choices (Rebel Fighter, 2019a).

Prior to the 1970s in industrialised countries including Australia, care of people living with disabilities was largely by institutions, predominately state funded public hospitals (Chenoweth 1990). Deinstitutionalization in the 1980s was intended to place people with disabilities into the community, to solve the segregation issues and to move towards community inclusion. Many countries responded to the United Nations (2006) Convention on the Rights of Persons with a Disability by moving from institutional services to community services (Beadle-Brown, Beecham, Leigh, Whelton, & Richardson, 2020). People living with disabilities wanted to be included in the community rather than segregated within institutions. Group homes have replaced institutions in principle but not theory. Group homes have continued to foster an environment of exclusion that perpetuates violence, abuse and neglect. This process has been termed 'trans-institutionalization' and 're-institutionalization'.

They're just throwing these people in these cramped institutional settings, even though they're calling them group homes. That's not really an alternative. They're still being placed together and overwhelmed (Autismwarriormama, 2017).

Institutions were high care facilities that were rigid and strict, where people were segregated and separated from society. Deinstitutionalisation intended to integrate men and women with disabilities into the community by relocating them from facilities into group home accommodation (Bigby & Fyffe, 2006). While the intention was to integrate people living with disabilities into the community, many of the same structures continued to operate but at an atomized level and within a community setting. The transition to group home accommodation may have been better understood as another phase of de-institutionalisation (Wiesel & Bigby 2015). The move from institutional to community-based living for people with disabilities is considered, without a doubt, the most significant change of human services policy in the 20<sup>th</sup> century (Chenoweth 2000). While group homes intended to resemble

suburban homes, individuals with disabilities living in this care arrangement continue to be treated like service users and have staff routines, rosters and priorities imposed on them (Keogh, 2009). Similar to institutions, large power imbalances exist between residents and staff (Keogh, 2009). Group homes continue to strip people of their freedom, privacy and choices as they are forced to fit into rigid routines that maintain structure.

When you move into a group home, you're giving up your privacy and you're giving away your freedom and you're giving away your choices (Rebel Fighter, 2018e).

I would say a lack of privacy, a lack of freedom and a lack of choices because for example, I wanted to eat my breakfast in my room today because my leg was sore and my back was sore so I didn't want to transfer in and out of my chair just to go to breakfast. But then I was told that I had to. Frankly they never gave me good reason as to why I have to. When I moved in here, I was under the impression it was going to be independent living, I could make my own choices. But clearly that's not the case (Rebel Fighter, 2018e).

Individuals spoke about the lack of privacy and freedom that they experienced living within the group home environment. It has been argued that efforts to deinstitutionalize disability services has resulted in the same structures, routines and cultures of institutionalization being transposed into community settings, starkly contradicting the goals of community living (Chenoweth 2000). Group home environments continued to be ruled by rules and schedules.

You have to follow certain rules and you have to follow a certain schedule (Rebel Fighter, 2018e).

Individuals living in group homes used YouTube to express their dissatisfaction with the institutionalized lifestyle that they were subjected to. Residents felt they were discriminated against within the group home and spoke about having their freedoms restricted. Religious freedoms were specifically reported as being stifled in the group home environment.

Just wanted to talk about religion and group homes. Some group homes don't allow your religious belief because they go against it (Latrice Allen latriceallen@live.com, 2017a).

Everyone here has multiple religions and so they're not supposed to discriminate. But then again, they are discriminating (Latrice Allen latriceallen@live.com, 2017a).

According to the International Covenant on Civil and Political Rights, individuals have the right to practice their faith. Residents should be free to their religious beliefs, but felt restricted within their own home. Human rights established by United Nations were established after the horrors of World War 2, when it became apparent that protective safeguards at a domestic level were not sufficient to protect people (Tomuschat, 2008). The findings from YouTube revealed that group homes were a place where people were restricted of their human rights, specifically their right of religious or spiritual expression. The data set also revealed that individuals felt that they were not included in their own care.

Prior to be given service termination notice, the program has at minimum, and I was unaware that they talked to my support team, I haven't heard from anyone else, and they made a request to my case manager for intervention services or other professional consultations or intervention service to support you in this program. I was never even verified that even happened (Voices4 allneeds!, 2018c).

Residents were excluded from conversations about them. Their human rights were taken away and they were disempowered in the system, by the system. To live peacefully within the group home, residents needed to submit to the routine imposed on them by management and staff. By giving up autonomy and control, residents became manageable by staff and powerless in the system. Once independence was broken by institutionalization, the restrictions, routine and schedules that restricted freedom became a place of safety. Individuals found a sense of safety in knowing what to expect next. This occurred by giving up autonomy and submitting to the rigid rules and routines within the group home.

I kind of feel like everyone is treating me like a helpless baby now (Rebel Fighter, 2018c).

I was set to move out. I had a day and time and everything. I'm scared. Well I'll make it look like I'm scared then, I don't want to move. I started crying and arguing and saying no I'm not ready, I don't want to (Voices4 allneeds!, 2018c).

As people became institutionalised, they lost their independence and became fearful of rehabilitation and transitioning to a life outside the confines of the group home environment. Research has shown that enabling and empowering support that helps people to do as much as they can and then comes alongside and completes what they cannot do themselves, as opposed to support that simply does it for, is a key determinant of quality of life for people with disabilities in group homes (Jim Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008). This model of care is known as "active support" (Beadle-Brown, Hutchinson, & Whelton, 2012; Beadle-Brown et al., 2016; Bigby & Beadle-Brown, 2018; Stancliffe, Jones, Mansell, & Lowe, 2008). While different models of active support exist, the core principle common to all is that workers empower and enable the individuals they support to live an active and fulfilling life (Beadle-Brown et al., 2020). The data set showed that once institutionalised, residents became so protected within the home and segregated from the public that they feared being on their own and resisted independence. Overwhelmed by a sense of powerlessness, residents resisted an opportunity to regain independence. Individuals overwhelmed by fear of being alone outside the group home used challenging behaviour to resist independence. Self-sabotaging any opportunities to regain freedom meant that they did not have to move out into the community.

Back in 2013 or 2014 I was meant to move out on my own and then I personally, it was my fault, I dug my heels in and I rebelled against it because I was scared. I didn't want to move out on my own. I didn't know what to do or anything and they said service will be there. And I said no I don't want to. I purposely had behaviours so I could stay there (Voices4 allneeds!, 2018c).



Even when outreach services were offered outside the group home, individuals had become so institutionalised that they resisted change. Resistance was fuelled by fear of change and being alone. Although support was offered outside the group home, attempts to transition individuals to a life of more independence was hindered by the rigid rules and restrictions that had been fostered by the group home environment. Re-institutionalization disempowered individuals and kept them in a state of dependence on the system.

L – No I want you to stay for your own social and then because I think you can do it. Mind you, I think it's for me too but I think you can actually do it.

P – No I can't, I can't.

L – But you're too fucking lazy to do it and you don't want the responsibility. You're scared of responsibility because you're scared, you're going to fail but you're not going to fail.

P – I think Luigi's right. I think he's right about both (Rebel Fighter, 2018f).

The data set revealed that men and women with disabilities lost motivation and drive when housed by group homes. By giving up responsibility of their own lives and allowing the staff to control their daily living activities, motivation to make their own goals was foregone. While the group home had good intentions, it had unintended outcomes for people with disabilities. The group home did not encourage independence and freedom, but rather people became institutionalized by the group home routine and structure. Residents expressed dissatisfaction with the living conditions within the group home and the quality of care they received from support staff. Residents found that the group home environment did not support their desire for autonomy and independence. They were restricted in the lives they were living. The disability group home became a place that further disabled rather than supported. Meta-needs were not met within the group home, and this impacted on the wellbeing of residents.

I would recommend the group home if you're a person with high special needs, so basically if you need help with everything then I still think this is a

good place to be. I just don't think it is a good place for me anymore. I'm actually looking to move somewhere. I'm not sure yet because I can't take these rules and like I said, I have no freedom and my privacy is really really non-existent here and I don't feel like it's for me (Rebel Fighter, 2018e).

While rules, routine and schedules were used by group home staff to maintain order, it also resulted in the loss of independence and institutionalization of group home residents. Men and women with disabilities preferred more flexibility and did not appreciate the lack of autonomy within the group home. Residents were willing to change accommodation to a location that provided more help and attention.

I am moving far away and I am moving to a smaller community which is good. The group home will have more help and assistance for me so that's good (Rebel Fighter, 2018g).

They're also going to help me find new activities and they will help me out in the community, which this group home, which this supported housing will not do at this home (Rebel Fighter, 2018g).

The data set showed that residents wanted to be supported to access activities and the community, however were unable to do so. The desire for community inclusion was expressed and documented on disintermediated videos uploaded to YouTube. While residents were disempowered, disadvantaged and oppressed by the inability to fulfil their basic daily activities, YouTube empowered their narrative. Residents used YouTube to speak out about the oppressive system they were subjected to. YouTube was used by people with disabilities to describe experiences of boredom, control, a lack of privacy and a lack of independence. The benefit that YouTube provided the disability community was the space to speak publicly about the consequences of re-institutionalization without being prompted. This demonstrates that the structure of the group home environment is of concern for people with disabilities living in group homes. The benefit that YouTube offered the disability community was an unmediated platform to voice their opinions freely and at their own discretion. By using unobtrusive research methods to analyze the content that the disability community has posted, it can be seen that group homes are a form of

re-institutionalization. Men and women with disabilities, their families and carers, created information that observed the chaos of grouping people together for convenience. The information revealed on YouTube affirms that deinstitutionalization of the disability sector was more suitably re-institutionalization of people with disabilities.

### Restricted by the principle of normalization

A criticism of institutionalization was the ideology of normalization (Wiesel & Bigby, 2015). 'Normalization' as defined by Nirje (1969, p. 181) was "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the normal and patterns of the mainstream of society". The normalization principle was based on the approach that cognitive challenged people were generally deviant and needed to be managed (Nirje, 1969). The concept of normalization assumes that people with intellectual disability should live as normal a life as possible (Björne, 2020). Normalization occurs when people with disabilities are forced to comply with a routine of what is expected and what is considered normal. Largely unskilled disability staff holding positions of power decide what is considered normal, while those who abide within the home fit into the routine or schedule (Björne, 2020). It was believed that by making people fit into a schedule that mimics the general population or broader society, people with intellectual disability are given a life that is as close to normal as possible (Wiesel & Bigby, 2015).

The principle of normalization was formulated over the years to develop the understanding of how it oppresses people living with intellectual disability. Wolfensberger (1980, p. 80) further developed the formulation of normalization in the 1980s by stating,

Utilisation of culturally normative means (familiar, valued techniques, tools, methods), in order to enable person's life conditions (income, housing, health services etc.) which are at least as good as that of average citizens, and to as much as possible enhance or support their behaviour (skills, competencies, etc.), appearances (clothes, grooming etc.), experiences (adjustment, feelings etc.) and status and reputation (labels, attitudes of others etc.).

The formulation of the term understood that people with disabilities were being shaped and changed through the process of normalisation to become more

acceptable to society (Chenoweth, 2000). An individual's group home living experience can be understood through the lens of normalisation. Normalisation refers to the context that a person lives within, not the individual themselves (Björne, 2020). This ideology disempowered people living with a disability and served to reinforce otherness. By complying with what staff enforced as normal by the general population, residents could live peaceably within their home.

A central theme to the formulations of the principle of normalization was that people should live in their own homes rather than institutions (Chenoweth, 2000). While a move towards independence and community living enabled through group homes in the community was desired, group homes functioned through routine. Routines and structures enforced in a group home setting continued to be based upon institutional ideals that fostered 'good residents' around ideas about what was beneficial for the individual (Svanelöv, 2019). Participation from residents was required for residents to be accepted by staff as 'good'. Any behaviour that deviated from what was expected within the group home living environment was problematized. Such problematizations disempowered and restricted men and women with disability. The system men and women found themselves in was often intimidating and overpowering. A tension existed between support staff being needed in the lives of men and women with disabilities to empower them through the provision of support, versus staff contributing to the function of normalization.

People lived in group home accommodation because they needed support to perform activities which able-bodied people take for granted. Staff were required in group homes to provide support throughout the day and night. A delicate balance between fostering, helping and supporting individuals achieve their daily living activities in their everyday lives existed (Svanelöv, 2019). Group home accommodation continued to share this principle of normalization as residents expressed that they were not empowered to control the structure of their own daily living activities, but rather forced to fit into a schedule by staff.

You're just sitting down after you've made yourself a nice big ass breakfast and then staff on the other hand have the mother fucking nerve to tell you, "you need to take a shower" (Mark Cinque, 2019d).

The reason the schedule bugs me is because I am very independent. I am proud of the independence that I have and due to me being extremely independent, it bugs me that they tell me when I can shower and when I can't. It literally bugs me. It irritates the shit out of me (Rebel Fighter, 2017).

Ok look bitch, first of all I just got done cooking my breakfast here and I woke up not too long ago taking my fucking meds and I just had a hard ass week at work. You can't just let me chill for the day? Damn (Mark Cinque, 2019d).

The transcript from these videos revealed that men and women with disabilities living in group homes were forced to carry out basic living activities, not on their own terms, but as directed by group home staff. Residents living in a group home needed to conform to specific times for daily living activities. Group home staff reminded, directed and instructed residents respecting which activity was needed to be performed next in their day. This structure and scheduling of activities removed freedom, flexibility and choice from people with disability. Svanelöv (2019) connected such behaviour from staff to normative views of doing things and claimed that scheduling daily living activities embedded an authoritarian power structure. Staff used their power to enforce and control the activities of residents. Often, scheduling of daily activities was not welcomed or appreciated by residents, but rather annoyed individuals.

I fucking hate being woken up in the morning, especially in the week. I have to take my meds then. I also have to make sure everything is all nice and neatly put away and aside in my room and I'm dressed and I'm showered and my meds are taken and I've had my breakfast. I hate all that shit. Damn! (Mark Cinque, 2019b).

I fucking hate being woken up in the damn mornings. Shit. Why can't it be the fuck quiet? Especially when it comes to me taking my meds. I hate that loud ass shit when I'm trying to take my meds in the fucking damn morning (Mark Cinque, 2019b).

Residents in a community setting desired freedom and autonomy to control the flow of their daily living activities. The group home mimicked institutional structures on a

smaller scale. The strict routines and schedules reinforced by staff on a daily basis implicitly acted to undermine resident independence and autonomy. Privacy within a group home was not possible with staff that worked to schedules and reinforced routine. Principles of normalisation were evidenced through staff maintaining structure and repetition by exerting authoritarian power. Able-bodied staff were in a position to exert authority over the impaired resident. Structure, routine and repetition were enabled through authoritarian power demonstrated by staff. Any independence that residents felt they possessed would need to be intentionally foregone to live peacefully within staff authoritarian power structures imposed by the group home environment. A study by Murphy and Bantry-White (2020) found residents living in group homes had little or no control over their own lives. The data set summoned from YouTube affirmed Murphy and Bantry-White's (2020) findings.

I feel like living here honestly, I cannot live my life successfully and to the fullness that I'm meant to be (Voices4 allneeds!, 2018c).

I just don't think it's fair that just because you're handicapped you have to put up with a lot more crap like when it comes to housing or personal care or other things. I just don't think it's fair. If you're unhappy somewhere, you should be able to move. At this point I don't even care if my new place is wheelchair accessible. I just need a roof over my head and a toilet, that's all I need. I just can't believe this is happening and I'm so pissed off with it. By the way, management said that I'm allowed to stay in this group home if I want to but I don't want to so there's been a lot of stuff that happened to me while I've been living here. That I can't go into details with, but there's just a lot of crap and honestly, I kept putting up with it but I'm sick of paying for it and yeah, I just don't want to live here. I want to live in my own apartment again and cook my own food and do my own grocery shopping and do my own laundry even. I never thought I would say that. I just want freedom again and I don't know if my parents really understand how sad and almost, I would say, depressed, I've been lately. To be perfectly honest with you guys, because on my YouTube channel I try to be honest. I've had some thoughts about doing the unthinkable thing. An act. An act that I wouldn't suggest anybody go

through with, but I've just been feeling so, so sad and angry all the time and just, living here hasn't helped the situation (Rebel Fighter, 2019b).

The data set affirmed the findings from Murphy and Bantry-White (2020) that people with disabilities experienced daily restrictions in their life and were not regarded as citizens capable of full inclusion in society. Residents wanted to be in control of their day and when they were not afforded this opportunity because of strict rules, frustration surfaced, even to the point of contemplating self-harm. Tension within the group home environment existed between residents and staff. While the group home was a place of residence to the men and women that lived there, it was also a workplace for the staff. Men and women with disabilities felt that being in control of their daily living activities, such as showering and taking their medication, was of high importance to them. They ascribed the meaning of independence to being in control of the timing of these daily living activities. Able-bodied people living independently within the community may take this freedom and autonomy for granted. YouTube was used by families of people with disabilities to capture what they expected a group home to provide their children that were living with impairments.

Now if your disabled little one can benefit from being in a group home, they can gain independence, they can enhance their self-help skills, and they can get individualized attention from trained staff. As my children get older, I want that for them. My ultimate goal for them is to live life to the fullest and to give them a chance to blossom. Thank you (Vanessa Thomas, 2013b).

I want my children to live the best life ever and living in a group home can enhance the residence independence. They can acquire daily living skills, self-help skills that can make them more independent. And I know if mine or many skills that they can acquire that I may not be capable of teaching them and it may definitely take some trained individual to get that job done. Let's consider why a person would want to consider to live in a group home instead of with family. If a family member is incapable of caring for the person with the disability, because of health problems or even physical problems, then a group home would be a good placement. Now if a family member was a care giver, they may have passed away and there is no one there to take on that

role or being the care giver. You know it takes a person with a lot of patience and love and a person who is not afraid of hard work or responsibility. You know a care giver can be a difficult one at most. But as I said before, you want your disabled loving one to be as independent as they can. If the family desire for the loved one to learn some daily living skills and to be able to function more independently, a group home is a good placement. When I was trying to train mine to acquire those daily living skills, there were many times of trial and error (Vanessa Thomas, 2013a).

The data set revealed that family members had the expectation that group homes would support independence. They expected their disabled family member with disability to be taught daily living skills and be given an opportunity at a more fulfilling life supported by trained staff. For vulnerable men and women living with a disability, the ability to fulfil daily living activities can give them a sense of independence and autonomy. The data set revealed that men and women with disabilities living in group homes were not able to fulfil their daily living activities in their own time. They were often prompted and forced into a routine and structure by staff that were in charge of the group home. The principles of normalization served to disempower people with disabilities, rather than empower them. The need for routine may assist staff run the home, especially in a group setting where the competing interests of many residents may be present.

YouTube captured residents' dissatisfaction with the principles of normalization and did not appreciate having to fit in to the group home schedule. Residents did not want to be prompted and told when to complete daily living activities by staff members within the group home. Men and women with disabilities wanted autonomy and to be in control of their own lives. The data set revealed that this was often not possible within the group home. Family members expected the group home to facilitate independence for their family member living with impairment. This was in contrast with what actually was happening due to principles of normalization. The benefit of YouTube is that individuals with disability, their families and carers could express their expectations about group home living and disclose their lived experiences. These expectations and experiences could be compared with existing disability theory by using unobtrusive research methods and a thematic



analysis to identify the main themes. The strength of using unobtrusive research methods is that people are speaking on their own terms, in their own time about issues that they have decided is important to them. The experiences are free from the Hawthorne effect and therefore valid and reliable for use in disability research.

## Dehumanized through ableism

People want to leave me alone and try to treat me like a human being. They want to treat me like I'm a number, I'm a client in a group home. What am I, a client? A client yeah (Jose Baez, 2016).

One of the driving forces behind deinstitutionalization was the idea that institutions were places where people were dehumanized through poor living conditions and underlying social values (Wiesel & Bigby, 2015). Deinstitutionalization of the disability sector was advanced through advocacy and knowledge about the disabling practices that were oppressing people with disability. The way societal structures, agents and empowered professionals have viewed social and treatment needs of people with disability, and the role institutions have shamefully played to fulfil those perceived needs, have dehumanized individuals (Keith & Keith, 2013). Yet group homes were meant to be the break or breach in this system. The data set revealed that people with disabilities living in group homes continue to feel dehumanised by their group home experience. The same underlying social values existed when men and women were cared for by institutions. Not much seems to have changed.

Disability discrimination based upon the preference that is given to an able-body can be understood through the theory of ableism. Ableism is the,

Network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as diminished state of being human (Thomas, 2004, p. 19).

Ableism and disablism are conceptually located within the same paradigm. Together they create a meaning system. The socially created aspect of disability which is distinct from impairment places limitations on a person's physical or mental functioning and often creates disabling environments, because of the prevailing ableist social structures (Ellis & Kent, 2011). Ableist thought is constructed when

people themselves think that if they are without impairment, their body is the correct body (Goodley & Runswick-Cole, 2011; Harpur, 2012). Such thought immediately places people living with impairment as the lesser human being. Just as sexism is discrimination based on gender and sexuality, and racism is discrimination based on race, ableism is discrimination based upon the preference that is given to an able-body.

The way people with disability are gathered within the group home is based on stereotypes and therefore dehumanizing in itself. People with disability are categorised according to perceptions of salient attributes (Keith & Keith, 2013). Residents within the group home were categorized according to their deficit and placed within a facility on the grounds for requiring support for their incapacitated state of being. The categorization that placed people together within the group home environment was one of impairment and a state of being as less-than-able.

Hello my name is Kyle Demichael and I live in a group home. I thought group homes were supposed to be, let's say nice or great or something, but it's somewhat nice but not really. See it's about people with disabilities and people that need help. There's all kinds. There's bed resting ones, there's non-talkative ones, violent ones, disability. Some people don't talk. There's good hearted ones, there's misunderstood ones, people without families or with families (Kyle demichael, 2019).

Once categorized according to their impairment and placed together within accommodation where needs could be supported by able-bodied staff, recognition that needs differed surfaced. While the categorization was imminent on impairment and struggle, individuals said they were impacted by these varying levels of support. Residents were misplaced in the group home environment.

The head manager of my group home should have known not to put someone as independent as I am in a group home like this because it's just not the right setting for me (Rebel Fighter, 2018b).

Ableist structures within the group home fortified the authority of able-bodied staff. People living with a disability had a certain expectation about who should be housed

and how they should be housed. Men and women with disabilities that believed they were independent disclosed on YouTube that the group home was not the right place for them to live. This belief appeared to be based on the restricted lifestyle within the group home accommodation setting. Residents were dehumanised within the group home structure. The idea that the able body is superior to the impaired body, and the impaired body needs to be 'fixed', is an idea that has plagued humanity. It is this underlying ideology that underpins the act of dehumanisation that occurs within the group home environment. This thought governs group homes and strips individuals of their human rights. It is true that human rights often become diluted in practice (Power, 2013). As human rights are diluted, people become dehumanized and their self-esteem corroded.

All I do, eat, shit, sleep, piss, eat, shit, sleep, piss, like all I want in life isn't what I want. They're suppressing me from what the quality of my life is because they don't support what I want in my life to be. I'm not a caged animal. I mean, you wouldn't even do this to a dog. You would let a dog out to poop. It is so inhumane (Joshua Weidemann, 2018).

The group home environment was one where residents felt they were mistreated and dehumanized by the governing ableist structures. Group homes perpetuated violations to human rights for men and women with disabilities. Individuals living within the group home expressed having their dignity and worth compromised. This impacted personal self-worth and self-esteem.

I've lost all respect for myself. I've lost all of my own pride and dignity and respect for myself because it's hard to have respect for yourself. It's hard to care for yourself when people don't care for you. My life personally has been affected by this because this is all I do (Joshua Weidemann, 2018).

Individuals that experienced dehumanization have had their self-worth and self-esteem chipped away at constantly, resulting in feelings of being less than human. When an individual is aware on a daily basis that they are not afforded the same rights and privileges as others in society, their self-worth would be gradually eroded.

The group home does not have the right to make decisions for me. The decisions and the choices in my life are mine alone and my life is to do with what I please to do with it and I'm just sick of people trying to control me and tell me what to do because no one knows what I need better than I do and that's pretty much all I have to say on that (Rebel Fighter, 2018a).

Group home living did not fulfil the expectations of freedom and living an independent life that people with disabilities, their families and carers, had hope for. The data set collected revealed that strict group home routines were enforced by staff, often times without explanation. Residents desired freedom and flexibility in their daily living activities, however described staff enforcing rigid daily routines. Residents described having staff interrupt the natural progression of their day with competing agendas. Institutional authority hierarchy has been observed to create dehumanizing environments (Zimbardo, 2006). It is this hierarchy that is reinforced by the group home structure. Group homes were places where able-bodied staff exercised power and imposed rules, routines and regulations on impaired residents. Ableist structures governed group home dynamics and reinforced ableist ideologies. The manner in which staff carried out work activities within the power of their hierarchal position could have been impersonal and have contributed to the dehumanization of individuals.

Some PSWs they scrub you way too hard or they scrub you way too fast. This is just uncomfortable all round and yeah just uncomfortable and painful in some cases so just be gentle. Take your time, don't rush clients (Rebel Fighter, 2018h).

Hey I'm still getting ready, ok? I'll be out in two minutes, ok? Give me two minutes (Mark Cinque, 2019b).

Men and women with disabilities did not want to be rushed by staff. The comfort of their own home was destroyed by the power that hierarchal positions held to ensure schedules, time frames and routines were maintained. Men and women with disabilities living in group homes are afforded dignity when they are treated like human beings and offered full disclosure in their dealings (B. E. Gibson et al., 2012).

In many cases, group homes destroy autonomy and dignity. Individuals were not offered explanations for decision made within the group home environment. Rather, staff exerted power and authority, which proved to be problematic for residents.

I would have eaten in my room today but I was told I couldn't do that and to this moment I still don't understand, especially when they don't have a table that reaches up to my height (Rebel Fighter, 2018e).

Ideals of what was good for individuals were imposed by staff without an explanation. Men and women living in group homes should be afforded dignity by being provided information regarding reasons for decisions, routines and regulations imposed upon their lives. The data set revealed that this was not the case. A lack of meaningful activities, social isolation and communication difficulties are often experienced by residents within the group home (Nankervis, Ashman, Weekes, & Carroll, 2019). While the intention of group homes is to foster activities and support people with disabilities to live a meaningful life, the data set proved otherwise. Group homes were a place where residents felt lonely, trapped, unhappy and bored. Boredom experienced within the group home environment exasperated feelings of hopelessness, negatively impacting quality of life.

I just feel like a dog that deserves to take a shit and you know I just feel like I am a dog or I am caged up because I can't go around and walk a hundred times but that's what my life is right now (Joshua Weidemann, 2018).

Being in group homes on the weekend mother fucking suck especially when you have to deal with staff that treat you like shit and treat you like a damn animal too. I hate that shit. That shit is all fucking waste, it can all go to fucking hell (Mark Cinque, 2019d).

All I see is the four walls in my living room, four walls in my kitchen, four walls in my bathroom and four walls in my bedroom. I don't go out and do anything with my life (Joshua Weidemann, 2018).

Residents disclosed on YouTube being that they were bored within the group home. The boredom was dehumanizing. They compared being trapped in a group home to

being an animal being trapped in a cage. People felt they were treated like a number. Residents said their group home environment was impersonal.

People want to leave me alone and try to treat me like a human being. They want to treat me like I'm a number, I'm a client in a group home. What am I, a client? A client yeah (Jose Baez, 2016) .

The data set revealed that men and women with disabilities were dehumanised by their group home living conditions. While group homes were segregated from the community and people within the group home were isolated, YouTube media provided an important tool that residents used to empower them and fight the abuse experienced. YouTube was used to document the injustices and argue for what individuals with disabilities desired from their group home accommodation.

While the residents in the YouTube videos disclosed accounts of dehumanisation, the videos empowered them. Men and women with disabilities living in group homes and being subjected to the structure forced upon them, displayed principles and choice and control when posting content to YouTube. They used their media platform to speak out about their dehumanizing conditions. This was a form of advocacy. The strength of using material that has been contributed to a public platform in an act of advocacy is it can be assessed to determine what is truly important to the disability community and disabled people themselves. Group home residents were subjected to the system in which they lived in. Posting their own content to YouTube empowered them and gave them something in their lives to exercise control over. Information that is controlled by the disability community and free from the influence of others should be used to affirm existing disability theory.

### Online communities and the struggle for connection

Deinstitutionalization of the disability sector was a bid to include people with disabilities in the community. It failed to do so and resulted in their re-institutionalization. Despite being an aim of disability policy since the 1980s, social inclusion of people with disabilities has been difficult to achieve (Bigby & Wiesel, 2019). Despite group homes being located in the community, people with disabilities continue to be excluded from mainstream economic and political spaces, trapped as

a prisoner in their own home (Milner & Kelly, 2009; Shakespeare, 2014). The internet and social media provide a space that people with disabilities can be present. Individuals with impairment can be both present and participatory in online spaces without leaving their own home. Social media platforms are a place that people can find connection. Men and women with disabilities use social media to build communities (Sweet et al., 2020). The creation of online communities can negate feelings of isolation and loneliness often experienced by the disability community. People with disabilities may find that accessing the community is a barrier to social inclusion, as it may be difficult to leave the confines of the home. Social media however is accessible with internet access. Men and women with disability can use the online spaces to discuss topics of their choice.

Hi this is me, Latrice Allen here. Just wanted to say hi to everybody. Just wanted to talk about the courses of life (Latrice Allen latriceallen@live.com, 2014d).

The research demonstrated that residents within group homes used the internet to build communities of connection. The disability community used YouTube to share their sensitive life experiences with viewers. The study of convivial encounters for people with disabilities has been explored as a means of social inclusion (Bigby & Wiesel, 2019; Bredewold, Haarsma, Tonkens, & Jager, 2020). The discourse of providing a 'safe' space for men and women with disability has been used as a justification at times to keep people segregated (Bigby & Wiesel, 2019). As abuse against people with disabilities has occurred in specialist and mainstream disability services, this is not a reason to segregate those with impairments (Bigby & Wiesel, 2019). People with disability should be able to access the internet at their discretion, to use as they desire. YouTube as an online space provides many advantages to men and women with disability. A convivial atmosphere is not easy to measure or described in words, but rather it makes people feel safer to engage with others (Bigby & Wiesel, 2019). This research shows that men and women with disabilities have been shown to access online spaces at their own discretion, and YouTube as a social space has conviviality. Men and women with disabilities appeared to feel safe to discuss their lived group home experience on YouTube.

Hello this is me, Latrice Allen. Just wanted to show you the group home where I'm at. This is the kitchen. Room. Hallway (Latrice Allen latriceallen@live.com, 2014a).

For men and women in group homes that may be isolated, YouTube provided a method where friendships could be made and people gathered around similar interests. YouTube was interactive as viewers could comment on videos and residents received messages from the online community. YouTube was also a way of keeping friends outside the group home updated and informed. Viewers could comment on videos. A comment is a way that online collective debates can grow around a topic (Bessi et al., 2016). Evidence existed that men and women with disabilities wanted to grow their online community and online presence through the attraction of followers. The online community was one that was expected to attract followers that would continue to watch updated videos and build friendships. People were regularly asked to subscribe to the channel.

Anyway like I said, have a good evening and subscribe (Rebel Fighter, 2017).

Anyway thanks for watching. Subscribe and there will be a Christmas video coming very very shortly. Thank you (Rebel Fighter, 2017).

Share this video. Like this video and subscribe to my channel. There will be more content coming (Rebel Fighter, 2018d).

I would like to get more viewers if it is possible and subscribers (Rebel Fighter, 2018g).

YouTube benefitted the disability community because they could use their topical videos to create communities of similar experiences and similar understandings. Communities of interest formed by users can cause reinforcement of ideas and biased narratives (Del Vicario et al., 2016). "Users mostly tend to select and share content related to a specific narrative and to ignore the rest" (Del Vicario et al., 2016, p. 5). For the disability community, communities of interest formed on YouTube could benefit users by supporting and validating unjust experiences that others outside the group home may not validate or necessarily believe. The mode of



speaking into a camera and uploading videos may benefit people with disabilities, as the format may be more entertaining than reading social media comments and writing responses to engage with others.

Merry me, this is me Latrice Allen and I wanted to talk to you about Steadfast housing part 2 again (Latrice Allen latriceallen@live.com, 2014f).

Just me again, part 4 or 5. As I was saying, the company does have one house that's up to date and it has solar panels, has resident burglar safe windows, upgraded kitchen (latrice Allen latriceallen@live.com, 2014b).

Merry me this is me, Cheyanne. Just wanted to talk about Steadfast housing again (Latrice Allen latriceallen@live.com, 2014c).

Video media enabled viewers a window directly into the group home. Many men and women with disabilities living in group homes used YouTube was to discuss their experiences living within the group home environment itself.

I would also like to discuss my experiences in supported housing very quickly (Rebel Fighter, 2017).

Men and women used YouTube to discuss topics that were important to them. They documented issues that they felt were of significance. YouTube gave residents an outlet and a means to capture important information. Information which they decided was important to them.

Hello. Patrick here. Just wanted to jump on here and talk about something that is very important to me and affects me quite a lot and I'm surprised that I didn't make a video talking about this topic before (Rebel Fighter, 2018h).

The disintermediated videos were used by residents to discuss what they believed to be problems within group homes. The use of video recording was proven to be a place where they voiced their dissatisfaction with group home living. The personal opinions of people with disabilities were captured on video. Different explanations were given for the violence, abuse and neglect that residents living in group homes experienced.

I'm just wanting to do an update on stuff, this housing experience. This is part 2 of what I was talking about earlier this month. This issue is going to be about financial crisis (Latrice Allen latriceallen@live.com, 2015c).

I showed evidence of Steadfast not really doing so much. I will upload that when I get done finishing up what I'm talking about for the topic (Latrice Allen latriceallen@live.com, 2014d).

Residents shared information about their group home experiences to educate others. This was a form of information sharing. Residents offered information so that others in a similar situation could learn from their experiences. YouTube enabled the sharing of experiences so that people could learn from each other.

Please somebody learn from my mistake (Rebel Fighter, 2018b).

The idea of learning from each other and from each other's mistakes and experiences gave a real value to YouTube's sharing services. It was more than just a video sharing platform but one where knowledge, ideas and experiences were shared and gleaned from. YouTube enabled men and women living in group homes to have a sense of purpose, belonging and value. A scenario captured in a video and uploaded to YouTube illustrated that videos were created to keep friends outside the group home informed. This demonstrated that YouTube was a means of communicating with the outside world for those confined to a group home. YouTube viewers became an online community of friends for people that may be isolated.

This video was made basically to reassure my friends here at Mississauga, just because I'm leaving the area that it doesn't mean that I'm leaving their lives forever (Rebel Fighter, 2018g).

This video was made because I wanted to say thank you to my friends for this saga and I've really enjoyed my time here in the city. Although I am looking forward to moving on. Although that seems to be upsetting all my Mississauga friends here, I really am looking forward to starting a new chapter in my life (Rebel Fighter, 2018g).

And just so my friends know, I'm probably going to come back to Mississauga to see you guys at least once a month (Rebel Fighter, 2018g).

Individuals built communities with their YouTube channel and kept friends updated about their lives. YouTube was a place for connection and community. YouTube enabled a voice to the outside world. It facilitated communication and was a place where people felt safe to speak their truth. YouTube empowered the voice of people that found themselves to be disadvantaged by the system they were in, providing a window of truth into a world that was kept hidden from public view.

Residents living within group homes could feel a sense of being socially dislocated beyond service settings, having few friends. A study by Milner and Kelly (2009) found that most participants living in group homes experienced a sense of marginalization because of few friends and lack of interpersonal intimacy, greatly compromising their quality of life. YouTube was used by men and women with disabilities to engage with an online community. They spoke to an online community that became a friend and an outlet for their troubles and concerns. People with disabilities build communities with social media and share content to educate others from their own community (Sweet et al., 2020).

The whole point of this video is to, I mean the whole point of my channel, not just this video but the channel, is to educate people and hopefully it helps with somebody that are going through the same stuff (Rebel Fighter, 2018d).

The online community may have been others living in group home accommodation. Topics may have been expected to attract other like-minded people living in similar situations, encouraging others to go public and share their experiences. Residents spoke to the viewers with the impression that viewers would continue to watch videos that were posted in the future. Men and women with disabilities invited viewers to share the often very personal experiences of their life together. YouTube made sustaining friendship possible.

And a few other ideas I have up the pipeline which I don't want to talk about quite yet. Ok see you guys in the next video, bye (Rebel Fighter, 2018b).

A fondness was expressed towards the viewers. Emotion was expressed and an importance was shown. Residents that engaged with their followers showed the expectation of an ongoing relationship or ongoing engagement.

Thank you again for watching and to my friends, I love you guys and I wish you all the best and I hope this isn't goodbye to my Mississauga friends (Rebel Fighter, 2018d).

Interaction existed between the men and women with disabilities making the video and their online community. One of the findings from this study was that residents within group homes often lacked activities and were bored. Their online community could provide activity for them through interaction and friendship. This could negate feelings of boredom and isolation.

Remember to subscribe. Remember to like and comment. People watching can always suggest topics for me and I will make a video on the topic that you suggest. Suggest for me (Rebel Fighter, 2019a).

For residents that were often isolated, inactive and bored within a group home, YouTube interactions provided an activity for men and women with disabilities that could access the internet. This reinforces the importance of men and women with disabilities having accessible computers and phones. YouTube enabled through internet accessibility provided not only important socialisation and advocacy opportunities, it provided activities for those that were often isolated from community involvement. An online community is a place of inclusion where disability can be removed. YouTube broadens mainstream understanding of disability experience by inviting mainstream culture to see itself through the eyes of others. Mainstream society travel to places authored by people with disability. People with disabilities seeing through each other's eyes allows them to see alternative reflections of their community. YouTube permits people who are 'inside' the community to see what it is like for people who are 'outside' the community. A chance to listen and learn from communities on the 'outside' of mainstream society can create a more inclusive way of being together. This provides the unobtrusive

researcher material to analyze that is reliable and robust that should be included in disability theory about group home violence, abuse and neglect.

In this chapter, I presented a main trope that emerged from the findings; that people with disabilities experienced the consequences from the re-institutionalization of the disability sector. The findings were contextualized within an integrated literature review to make meaning of what people with disabilities, their families and carers, disclosed on YouTube. Re-institutionalization of the disability sector contributed to experiences of violence, abuse and neglect for the vulnerable people living within group homes, destroying human rights. Deinstitutionalization of the disability sector did not achieve what it set out to achieve, with people experiencing human rights violations. YouTube was used by the disability community to negate the impact of community segregation and build a community of support. In the next chapter I present the third main theme to emerge from the research; that group homes foster harmful interpersonal relationships.

## **CHAPTER 7**

### **HARMFUL INTERPERSONAL RELATIONSHIPS: POWER, CONTROL AND RESISTANCE**

Men and women living with disabilities commonly report feeling lonely and isolated. Experiencing access barriers and stigma, people with disabilities spend much time alone, compared with able-bodied individuals (Trevisan, 2020). This prevents them from engaging with others outside their home environment (Trevisan, 2020). Daily interactions with staff and other housemates often provide the only social outlet for individuals with disabilities living in group homes. These relationships and interactions are complex in nature. These relationships are affected by power imbalances and the complexities of other people's lives. The outcome of interpersonal group home relationships is often destructive and harmful in nature.

In this chapter, I discuss how the group home environment fosters the optimal conditions for harmful interpersonal relationships to develop. The relationships within the group home may be the only opportunity for individuals to have meaningful relationships. A major theme to emerge from the data were that harmful interpersonal relationships within the group home environment contribute to experiences of violence, abuse and neglect. This chapter shows that YouTube is used to expose the damaging relationships that occur within the group home environment, and how YouTube was used to reach out of the group home and build new relationships online. Through organizing these often-disparate videos, differing by length, form, intensity, intent and topic, it is clear that individuals living in group homes are unified in their view that dynamics within the home itself are disrupted and often detrimental to their health and wellbeing. Staff power is often used to control the group home, impacting resident autonomy and control, impeaching human rights. Conflict and violence are usual occurrences. The findings are contextualized within existing disability literature by using an integrated literature review to support interpretation. A discussion about challenging behaviour is included in this chapter, because challenging behaviour disrupts the group home environment and affects all whom share that space. This chapter contributes to my original contribution to knowledge by using the experiences about group homes

disclosed on YouTube by people with disabilities, their families and carers, and contextualizing them within existing disability literature. By comparing the findings to existing disability literature through an integrated literature review, different modes of information are revealed on YouTube that is currently absent from the theorization of group home violence, abuse and neglect. The interpretation of the data set is extended by considering the benefits that YouTube offer people with disabilities, and the strengths that unobtrusive research methods offer research into people with disabilities.

### Dignity destroyed through relationships

Homes are more than a physical space in which every day life is situated. Therefore a multi-faceted approach is needed to understand them (Annison, 2000; Sixsmith, 1986). The experience of a home setting can foster feelings of autonomy (Welch & Cleak, 2018). Aspects of a home environment are essential to a person's sense of wellbeing. This includes the presence of people and the ability to have relationships with them (Sixsmith, 1986). Engaging in meaningful relationships and activities is considered important, as it is the vehicle in which many quality-of-life outcomes is achieved (Jim Mansell & Beadle-Brown, 2012; Jim Mansell et al., 2008; Jim Mansell, Felce, Jenkins, De Kock, & Toogood, 1987; Risley, 1996). Interactions with peers is essential for wellbeing and contributes to quality of life experiences for people with disabilities just the same as the wider population (Van Asselt-Goverts, Embregts, & Hendriks, 2015; Van Asselt, Buchanan, & Peterson, 2015). Social relationships within the group home can contribute to a sense of belonging and happiness. The grouping of residents together provided an opportunity for residents to meet others and develop friendships.

I met some really good friends here. I have a good social life here. It's pretty awesome actually (Rebel Fighter, 2017).

Me and the room-mate stayed up talking until four in the morning and she's awesome (Vicious x Cycles, 2015b).

Group homes are a place where people with disabilities have the opportunity to interact with others that share a similar life experience. This becomes a commonality

between them. Little research exists that has studied peer-to-peer interactions between people that are cognitively impaired in supported accommodation settings (Nankervis et al., 2019). People with disabilities are likely to be more lonely and experience greater isolation than other vulnerable population groups (Shakespeare, 2014). Because of high support needs to accomplish daily living activities, quality of life goals are compromised for men and women with disabilities living in group homes (Jim Mansell, Ashman, Macdonald, & Beadle-Brown, 2002; O'Brien, Thesing, Tuck, & Capie, 2001). Bigby et al. (2017) found that despite people with disability sharing spaces in group homes, individuals still felt lonely. Regardless of the socialization opportunities and residents' ability or willingness to take advantage of them, people with disabilities have the right to experience dignity within the safety of their home environment. That was not the experience reported, however.

So that was my first day at the new group home. Fist fights, getting lost, getting harassed by my old manager and almost assaulted, and all this within the space of a couple of hours. But today, today is my second day at the new group home. I wake up, everybody's calm, everybody's chill. I wake up, we do chores and clean up the house. I finish unpacking and now I went to my counsellor's appointment, my ENDR therapist. And now I'm here talking to you. So I guess in the end everything turned out ok and thank God for that, because I am not used to things turning out ok (Vicious x Cycles, 2015d).

From the moment an individual entered the group home environment, they would experience tumultuous relationships. The emotional roller coaster of the group home environment was one that residents needed to navigate. Interpersonal relationships are the primary indicator for quality of life for people that are cognitively impaired (Hostyn & Maes, 2009). A large portion of people that experience cognitive impairment display challenging behaviour (Murphy & Bantry-White, 2020). These challenging behaviours can impact upon others sharing the same space and living in the group home. While being grouped together with other people with disabilities could be an opportunity for friendship and commonality, often being grouped with others meant that residents experienced discomfort and unsafety from the behaviour of others.



Violence and impairment are knotted together as a pathological whole (Goodley & Runswick-Cole, 2011, p. 603).

Where people experience disability, they quite often experience the negative effect of violence also. Violence occurs at the intersection of disability and group home accommodation. Disability and violence are intrinsically woven together. Disability and violence co-existing together intensify the injustices and consequences of both. Abuse is not limited to acts of physical force but can include psychological harm involving emotional or verbal aggression (Krug, Mercy, Dahlberg, & Zwi, 2002). Humiliating, belittling, name-calling and threatening are some of the actions that constitute emotional and verbal abuse. These actions, while perhaps not physically causing harm, can have long lasting and negative consequences for victims. Both the World Health Organization and the public health approach classify physical, sexual, emotional, and financial abuse and neglect as acts of violence (Shakespeare, 2014).

Regardless of the type of abuse, it will certainly result in unnecessary suffering, injury or pain, the loss or violation of human rights, and a decreased quality of life (Krug et al., 2002, p. 126).

Violence causes suffering within the disability community and impacts an individual's quality of life. People with disabilities are both victims and perpetrators of violence (Mueller, Forber-Pratt, & Sriken, 2019). Challenging behaviour can add another layer of complexity to social interactions between people with disabilities (Nankervis et al., 2019). Challenging behaviour is often violent in nature. There is a range of factors that lead to challenging behaviours unique to each individual with disability (Emerson, 2001). Communication difficulties are often associated with the presentation of challenging behaviours (Kevan, 2003; Smidt, Balandin, Reed, & Sigafos, 2007) and also inactivity and a lack of occupation (J. Mansell, 1993). The data set investigated through this doctoral research revealed that housemate's challenging behaviours impacted the group home environment, adversely affecting the lives of others living within the group home.

From the moment residents entered the group home, they could experience violence and abuse. Having access to an adequate home environment is necessary for people living with disabilities to live a happy and meaningful life. Assessing the adequacy of home environments can be conducted through the concept of social dignity (B. E.

Gibson et al., 2012). Social-dignity was proposed by B. E. Gibson et al. (2012) as a normative ethical grounding measure that accesses dignity-enabling conditions within different contexts. Social dignity understands the home environment as being more than a physical environment but also as a relational space (B. E. Gibson et al., 2012). B. E. Gibson et al. (2012) found seven conditions that were necessary for an adequate home, being:

Self-expression, safety and security; meaningful relationships; community and civic life; participation in school, work and leisure; respectful care relationships; and control, flexibility and spontaneity (p. 12).

Social dignity is experienced by the individual when they are afforded respectful relationships and social interactions.

The house mates. Because sometimes you want to enter a home with certain housemates, you know. You just can't click with or you can click with. There's going to be problems that will flick you over. When that happens, take care of the dramas that's going on (Latrice Allen latriceallen@live.com, 2017k).

Housemates could disrupt the group home dynamics. Housemates were a significant factor of the group home living experience. The YouTube videos provided a very distinctive view and set of source materials.

I've had my room mates call me an asshole. But you know, my roommate doesn't take any responsibility. It all falls on me. Then I get really stressed out because I'm the only one doing anything (Joshua Weidemann, 2018).

The residents are driving me up the wall right now and then lately I've been smoking again. You don't smoke! But you ought to know when I do smoke, something's wrong (Latrice Allen latriceallen@live.com, 2017e).

My guardian knew that I had to go to the urgent care to go get my wrists looked at because of a certain issue with someone and I went in (Voices4 allneeds!, 2018c).

Five fucking things I hate about my house mates here at the group home and also about my co-workers at work. This is the shit I have to go through. That

shit be going on every night every day after work and all that. Then I be saying something like that they be going rude and stuff. Like really? And then I make up and apologize for it and then they be like, “no it’s no excuse”. Like what the fuck? Who really gives a rat’s ass? Like really bitch? I fucking hate group homes. They fucking suck. And then they also want to find ways to go higher up and rat my ass out and shit. Hey look. They want to find ways to go and rat my ass out and shit. They can go rat it out in my ass. What the fuck. Like really? Like they can go rat out my ass. Doesn’t ass need ass? Like they can go rat out my ass. Bitch. Like what the fuck? God dammit. Fuck that bullshit (Mark Cinque, 2019a).

The data set revealed that group homes did not provide adequate conditions for people to feel safe and develop respectful care relationships in their home environment. The environment was one where conflict between residents was widespread. Housemates were a source of discomfort and distress for men and women with disabilities living in group homes. The data set revealed that the group home environment was emotionally charged and conflict between residents was frequent. High conflict meant that the opportunity to develop safe and respectful friendships with others was often missing. A sense of belonging which could be established through healthy interpersonal relationships was damaged by the disruptions caused by housemates’ behaviour.

I see two girls get into a fist fight and I was told by the manager, fist fights are not tolerated (Vicious x Cycles, 2015d).

The conflict in the environment between residents was described as being tumultuous and violent. The impact of living in a shared space meant often there was conflict between housemates. Residents used YouTube to disclose feeling unsafe rather than a sense of belonging. The impact of relationships turned sour can be devastating for individuals within the home (Sixsmith, 1986). Group homes were described by men and women with disabilities to be environments where conflict and drama was frequent. The challenging and sometimes criminal behavior of other residents living within the house can mean that that the home is not a safe place to

live. Violence within the group home environment showed that people could not rest peaceably in their own home.

I feel unsafe. I feel my rights are completely violated (Voices4 allneeds!, 2018a)

I'm so stressed right now. Caused by the situations going on right now (Voices4 allneeds!, 2018c).

We've been having so much drama lately (Latrice Allen latriceallen@live.com, 2017g).

The data showed that men and women with disabilities often felt unsafe in their home environment due to unstable relationships with others with whom shared their space. Other housemates were often intimidating and unpredictable. Living with other people with disabilities could be an encroachment of an individual's human rights. Group homes were described as being an environment where drama was common place and expected. Residents exhibited challenging behavior which impacted upon others living in that space. Challenging behaviour can be triggered for reasons such as "lack of engagement in meaningful activity, social isolation, communication difficulties and boredom" (Nankervis et al., 2019, p. 58). The impact of challenging behaviour adversely affected other residents with whom the space was shared.

Social dignity was destroyed through interpersonal conflict and violence between residents living within the group home. Physical violence between housemates was witnessed and observed by other housemates sharing that same environment. Opportunities for socialization were negated by interpersonal conflict and violence.

The best I can do to protect myself by isolating away with my room locked. Clients can't come in my room without a key (Voices4 allneeds!, 2018c).

To avoid conflict, residents could avoid shared living areas and isolate themselves in their room. By isolating oneself within the safety of the bedroom, opportunities for safe and intimate friendships could be foregone. Instead, residents would seek safety to survive the group home environment. Being alone and isolated within their

bedroom, the resident's private bedroom could be the only safe space within the group home. The bedroom may be one of the only areas where individuals with disabilities had a sense of privacy and safety.

I probably won't be here long so I already know I'm going to get kicked out (Latrice Allen latriceallen@live.com, 2014f) .

This house where I'm at, it's been stressful. So now I probably have to do another move out to, I guess, their Copolay house (p.25).

I have some big news that I am officially moving out of my group home in a year, and a half and I am so excited about that. And so yeah, you will be seeing a lot more vlogs about to come maybe, as soon as I move in and I might give a tour of my apartment. I think it's going to be in Pittsburgh but they haven't really decided where to build it, so I'm on the waiting list for it. So, I hope I get picked and get to move in out of my group home finally, away from the chaos and crap over there (p.122).

The group home was often perceived by people with disabilities as a temporary residence rather than a secure home environment because of the nature of the conflict within. Desperate, helpless and lonely, sometimes their only option was to move away from the conflict. Moving between group homes was common amongst this cohort of people. It meant that residents would be unsettled and unable to feel at home in their living arrangements. This instability would disrupt feelings of a secure home. The group home being one that was expected to be temporary. Residents expected bad outcomes.

Within the first couple of hours of being there, my cigarettes get stolen, which is kind of my fault because I shouldn't have left them out (Vicious x Cycles, 2015d).

We've been having issues of people stealing stuff in the group home property for years and nothing really gets done, so who is to blame? (Latrice Allen latriceallen@live.com, 2014d).

Residents described living in an environment where their belongings were stolen by other residents from the moment they entered the house. Housemate's criminal and offending behaviour disrupted the group home environment and violated the individual's home living space. Conflict caused by other residents was a source of distress for men and women with disabilities, and something that was part of the group home experience.

Being in a group homes sucks, especially when you have to deal with a house mate that acts like a total retard. Oh my fucking god (Mark Cinque, 2018).

Group homes suck. Like really? Oh my fucking god. I have to put up with this shit? Well like in a group home you have to put up with this shit (Mark Cinque, 2018).

We're living in a very crazy hell (Jose Baez, 2016).

Men and women with disability reported that they were impacted by the behaviours of their housemates with whom they shared accommodation with. The challenging behaviours of others impacted those sharing the house. Peer behaviour disrupted the home environment, destroying social dignity within the group home. YouTube captured personal lived experiences of the group home environment from men and women with disabilities that described the disabling and challenging circumstances that they were subjected to on a daily basis.

Housemates needing support often had their own problems, which manifested in the group home and affected other residents sharing the same space.

So they place them in the semi-independent and cause the rest of us hell. Believe me, a lot of hell. Suicide attempts, everything, you name it. Or drug overdose, or drugs on property, you bring it on. It's everything (Latrice Allen latriceallen@live.com, 2014f).

Lots of drama meaning that sometimes you might hear something, stealing, threat, lying, cheating, you know, or as the Christians say, John 10:10. John 10:10. Satan kills and steals and destroys. That kind of dramas. But you know,

everybody has different beliefs and different religions and those categories. So, just bash anything (Latrice Allen latriceallen@live.com, 2017k).

The data set revealed that people placed in group homes often experienced many challenging social issues. These social issues included self-harming, drug abuse and theft. These challenging behaviours were classified as drama by group home residents using YouTube disclose their group home living experience. Challenging behaviour can be triggered by different factors at play within the environment people with disabilities find themselves living in.

There's going to be problems that will flick you over. When that happens, take care of the dramas that's going on. Your doctor, lawyer, case worker or whatever that is working in your corner for you (Latrice Allen latriceallen@live.com, 2017k).

The reason why I left Steadfast is because there is a guy name Johnny Brooks who... who is called a Christian, womanizer, rapist. Which means he would lure, he will sweet talk women to be a Christian, go to church, be friends with you then after you agree to go to church with him, on the day of going to church he will have sex with you before church. So, he's sick in the head, yes, illness or into his case worker, but anyway. So, he's been chasing me down. So that's why I left Steadfast. I'm happy at Alleapano now. So I'm just saying that's why I left. That's why I left Steadfast, if you want to know (Latrice Allen latriceallen@live.com, 2017l).

A critical realist perspective of challenging behaviours recognises that behaviour is more than a result of impairment, unmet needs and difficulty communicating. It recognises that challenging behaviour occurs at the intersection of personal, social, cultural, environmental and regulatory practices (Dowse 2017). The group home is an environment where disability, criminality, challenging behaviour, mental health and violence interplay. Experiences of hostility, disruptions and violence destroy social dignity within the group home.

I just wanted to talk about medications and group homes. I'm hearing a lot of people in group homes here overdosing or can't handle their medications.

They either have to change doses, up doses, change medication, and they still have side effects (Latrice Allen latriceallen@live.com, 2017d).

They act like crazy cos they're already crazy. And then they have pills and act even more crazy (Latrice Allen latriceallen@live.com, 2017d).

Residents appeared frustrated about other resident behaviour and group home living conditions. There seemed to be little to no choice in the way individuals were grouped together. Rather they had to accept the hand they were dealt and navigate the group home environment, which was often a place of conflict and competing interests between housemates. The conflict within group homes destroyed social dignity and forced housemates to isolate themselves for their own safety.

Underlying violence is the experience of overwhelming shame and humiliation (Gilligan, 2000). Vulnerability to violence is influenced by psychological defense mechanisms, including feelings of guilt and remorse (Gilligan, 2000). People with an intellectual disability may lack the capacity for deeper reasoning and understanding, therefore being more vulnerable to feelings of shame and humiliation. Shame can result from,

feeling slighted, insulted, ridiculed, rejected, disrespected, dishonored, disgraced or demeaned; feeling inferior, inadequate, incompetent, weak, ugly, unintelligent, or worthless; suffering "loss of face", "narcissistic wounds", or an "inferiority complex" (Gilligan, 2000, p. 1802).

Existing feelings of lower self-worth resulting from a lack of education, unemployment and occupying a lower social class make one more vulnerable to feelings of shame and humiliation also (Gilligan, 2000). People with a disability experience more life challenges and disadvantage, commonly experiencing low levels of income, educational attainment, employment, superannuation, health and wellbeing (National People with Disabilities and Carer Council, 2009). People with a disability experience shame and humiliation that is further compounded by their life challenges. While group homes were places where violence was frequent and privacy was lacking, men and women with disabilities expressed a desire for a safe place to live that was free from violence. Residents expressed a desire for what they wanted in a violence-free group home environment.



I deserve to live in a healthy, safe, by the way which means no violent people, no yelling, no assaults, no nothing, but I do not here (Voices4 allneeds!, 2018b).

Individuals with disability expressed what they needed on YouTube. They expressed a desire to live in an environment that was safe. They desired to live in an environment that was free from violence and where they could flourish. What was evidenced however in the disintermediated videos was often environments which were dehumanizing, unsafe and where human rights were grossly violated. Peer interaction was often volatile and dangerous. Challenging behaviours and the use of medications to manage the health of residents impacted the welfare of others sharing that environment. YouTube captured evidence that conflict between housemates was problematic and frequent, with residents seeking safety either by isolating themselves in their own bedrooms or by leaving the group home altogether.

### Broken relationships between staff and residents

I don't trust staff. They have made me sit in the far back and in the middle seat because they don't trust me. Well, that's mutual because I don't trust them (Voices4 allneeds!, 2018c).

Relationships between staff and residents were often described as being broken. The data set revealed that a lack of trust often existed between staff and residents. This lack of trust would impact the group home living experience. Relationships within the home environment contribute to the experience of home. Having the ability to sustain meaningful relationships includes the ability to give and receive love, care and support (B. E. Gibson et al., 2012). Sustaining these relationships through close proximity is enabled through the shared home environment. Often staff are the people closest to the residents, and bonds are formed with paid carers.

A study by Pockney (2006) found that people with intellectual and learning disabilities considered paid carers to be central figures in their lives and often times closest in terms of intimacy. Intimacy with paid staff meant that individuals could, "talk to them easily, they would listen to their problems, helped them with their college work, spoke clearly, gave them individual attention, made them laugh, took them out, and

were enjoyable company” (Pockney, 2006, p. 4). This study showed that clients appreciated staff who accepted them for being who they were, would provide sufficient practical support and also emotional guidance. All participants in the study chose to select the term ‘friend’ to describe their paid carer rather than a more formal title, such as carer or staff. This was a stark contrast to the paid carers, who rarely considered those they cared for to be closest in terms of intimacy or friendship. It was evident that there was a stark contrast in the way staff and service users perceived their relationship. Because of limited social experiences and friendships outside the group home environment, people with intellectual and learning disabilities had few life experiences and reasoned that their relationships with staff looked and felt like friendships (Pockney, 2006). Such an inference was not confirmed by the data set. However, the labelling differentiation between ‘friend’ and ‘carer’ was significant.

Concurring with the previous research findings from Pockney (2006), the data set found that individuals with disabilities within group homes could form meaningful bonds with staff most intimate to them. An individual documented on YouTube the importance of a friendship with a staff member that he had made within his home and the dissatisfaction when feeling the friendship was not being supported by management.

Anyway, so I had this staff. I always want her to be my staff. I really like her and we close bonded. We had a bond. We still do and two months ago they said to the staff and I, they said this is going to be your personal staff and we were both happy. We were both happy and then about a week ago or so, well those two months were perfect, no behaviours, nothing. Everything smoothly. Then two months ago the office wanted, I mean they took her off the schedule and everything and like I got upset yes. I got upset yes and I’m still cussing at them. It’s like you’re dealing with people’s lives and feelings and all that, mostly in one and it feels like, yes, some people treat us disability people like shit, like we’re trash and some be like, oh no, I’m not messing with him (Kyle demichael, 2019).

Management changed the shift times of the deeply valued staff member and the resident interpreted this change as management not supporting his care needs. Management did not place the same value on his friendship with the carer as the individual did. The paid staff member had developed a friendship with the person living with disability that impacted him intimately. While the individual could not exercise control over whom cared for him because of the power of management over staff rosters, he could voice his dissatisfaction through YouTube. YouTube became a tool to empower his voice and provide feedback about the service he was receiving within the group home.

What sets a house apart from a home is the social aspect of transactional relationships which occur within its special structures. People with disabilities living in group homes require assistance performing daily living skills, home related skills and social roles (Annison, 2000). Support may be required bathing, dressing, budgeting, cooking, neighbouring and hosting (Annison, 2000). Residents benefitted by having meaningful relationships with staff. YouTube frequently disclosed conflict within the home environment.

I know there's a lot of group homes that staff make up stuff or they make up rules later or they don't tell you all the rules when they get you in, but they make up all the rules later on kind of deal (Latrice Allen latriceallen@live.com, 2017a).

Group home management and leadership has a direct impact on the experiences of residents living within the group home itself (Bigby & Beadle-Brown, 2018; Rice, Rosen, & Macmann, 1991). Improved outcomes occur when staff are responsive to the specific needs of individuals (Bigby & Beadle-Brown, 2018). Competent leadership within the house is essential for effective group home environments that enable and empower individuals. The data set revealed that residents believed group homes were not managed properly.

The discharge papers says the reason for the evaluation is anxiety by the doctor and the psychological evaluation accessed by the behavioural nurse said it's due to situational stress, and that would be right now. My situational

stress is this whole entire home and the company, the way it's run (Voices4 allneeds!, 2018c).

Due to situational stuff I'm slow in speech and stuff but like how is it ok to get treated this way and I get blamed for it (Voices4 allneeds!, 2018c).

The resident herself used YouTube to disclose her reason for her situational stress. She believed her admission into the emergency department was a result of the way the group home was managed. Bigby and Beadle-Brown (2018) reported that front-line management practice through the use of practice leadership improved quality of life outcomes for people with intellectual disability living in supported accommodation. Efficient practice leadership within the house meant better outcomes for residents, as staff had a model to follow. The data set illustrated where residents felt staff were impersonal and lacked expertise or commitment. Staff did not make an effort to engage with residents, and residents believed that this negligence impacted their group home living experience.

As far as I'm concerned, I have done every step possible to protect myself from maltreatment and I am not having difficulty actually taking care. Yeah I have mental disorders. It should be disabilities, but I've dealt with them just fine. In fact, I've removed myself from further potential situations of verbal aggression from staff and two clients. The step I've had to take, granted it's not healthy but there's no other way that anyone has been willing or attended or tried to fix the problem, and they turn around and try to blame that I'm the problem. I don't get informed of anything regarding my care. I mean this, today is the first-time staff ever have ever attempted to talk to me. They've never even come in my room while I'm awake. They don't knock and say, "hey can I come in?" I've got to say yes and then you can leave. Ok it's time to go. They don't associate with me (Voices4 allneeds!, 2018c).

The data set revealed that residents believed that staff did not want to engage with them. Staff were described as being neglectful towards residents living within the group home. Men and women with disabilities expressed a desire to have staff pay attention to them and demonstrate an interest in them. This was often not the case.

Personalised, compassionate care was something that was described as often missing from the group home environment.

These group homes, they hire illegal workers. So you don't even know who these people are. You know, they could be child molesters, murderers, who knows. They're illegal so no one knows who they are or where they come from. Probably using a fake name and stolen social security number. And of course that doesn't help the clients and a lot of the workers don't communicate in English (Autismwarriormama, 2010).

People with disabilities used YouTube to disclose that they were sensitive to their relationships with carers whom were providing the closest care. Attention by staff to the personal details, including using a client's name, could strengthen the relationship and the personal care experience. The relationship between staff and residents had a deep impact on residents living in their home. YouTube was used to provide feedback about services received. If an individual felt disempowered and dehumanized by the service they received, YouTube provided an outlet to empower their voices, enabling control of their feedback at their discretion.

Power (2013) illustrated an example of a service provider that adopted independent living models of support that viewed clients individually, one person at a time. This method saw individuals as possessing strengths, preferences and aspirations. By adopting this client-centred practice, men and women with disabilities were placed and the centre of processes and had their needs identified, with choices around staff that would best meet their individual needs. Staff were recruited based on whom would work best with the individual client, establishing shared interests and ways of working closely together. Conflict between residents and staff emerged as a prominent theme in the research suggesting that a lack of coherency between staff and residents existed. This disagreement manifested also around staff roles.

You're supposed to know how to monitor meds and shop and do whatever. You're supposed to know how to do everything (Latrice Allen latriceallen@live.com, 2017g).

Staff are being more like complaining that they don't want to do it. They're actually just having me do their job (Latrice Allen latriceallen@live.com, 2015b).

Nothing gets done around here (Latrice Allen latriceallen@live.com, 2015b).

I had to play the role as the staff. Why does consumers have to play the role as staff? You call them, they don't respond. They're either off property doing whatever (Latrice Allen latriceallen@live.com, 2014a).

Staff sometimes just leave the property, don't make sure that the residents that are suicidal are taking their meds or what not properly (Latrice Allen latriceallen@live.com, 2014a).

Staff were employed to work within the group home and held positions of power. Expectations about what staff were employed to do differed between residents and staff. A tension was observed between resident chores and staff roles. Men and women with disabilities believed staff used their position and power to enforce routine while not fulfilling their job role. Residents expressed in the YouTube data set that staff were negligent rather than fulfilling what was expected of them, and placed an expectation on residents to be independent. Rice et al. (1991, p. 59) state that, "the delivery of residential services to persons with developmental disabilities relies heavily upon the competence and motivation of direct-care staff". If staff lack insight into disability and motivation to fulfil their job, this would impact the amount of support offered to residents. Disability support work is more than simply manning a house or prompting residents to do their chores. A certain level of skill is required from workers to teach life skills and understand how disability is impacting them. Rice et al. (1991) suggested that workers perceived their roles as being one of maintenance and supervision rather than training and developing resident living skills. Where residents felt that staff were not fulfilling their work duty, YouTube was used to express this dissatisfaction with staff and the service provided. YouTube also captured the residents' solution to this problem, to do the work themselves. Residents complained about staff performance.

I give this group home eight ninety every single month but they don't get anything separate. But anyway, I give this group home eight ninety and that's point number one. Number one, she's supposed to do whatever I ask her to do. Do whatever I ask no matter what (Rapheal Hardwick, 2015).

Residents held the belief that they paid for a service and staff were expected to deliver that service. YouTube information revealed negligent and unresponsive staff. Staff were described by residents as being unresponsiveness towards client needs, and placing people with disabilities in a vulnerable positions. Residents used YouTube to disclose accounts of group home staff members fulfilling their work obligations.

Staff are being more like complaining that they don't want to do it. They're actually just having me do their job (Latrice Allen latriceallen@live.com, 2015b).

Consumers should not be doing staff's job. Staff should do their job (Latrice Allen latriceallen@live.com, 2014a).

YouTube was commonly used by individuals as a tool for providing feedback about poor service and treatment. An example was evidenced when an incapacitated client was left stranded without explanation from his carer in a broken-down car. The resident was abandoned in the vehicle for hours while his carer went to seek help, without keeping his client informed of his actions.

He went to the bank with his mechanic. He took off with his mechanic to get parts for the car. I didn't know that the car was going to a garage. I didn't know where this guy was for four or five hours (Joshua Weidemann, 2018).

Abandoning an individual with disability in a broken-down car illustrated a breach of duty of care, as well as the dehumanisation of people with disabilities by service providers. Once more, this data set revealed these hidden stories of marginalization that would not be available without domestic video equipment, intuitive software and YouTube.

## Resisting staff authority

Group home staff exercise authority over residents with disabilities (Antaki & Crompton, 2015; Antaki & Kent, 2012). Staff are positioned to support residents to fulfil their daily living activities and help residents meet their intermediate needs, as residents are unable to do so independently. Intermediate needs include the need for safety, security, belonging and social acceptance (Annison, 2000). This includes building friendships and having a sense of privacy and control (Annison, 2000). The authority that staff exerted over residents was not always welcomed by men and women with disabilities.

They feel the need to parent you. They're not your father. And tell you what to do and I absolutely hate being told what to do. You can ask any of my friends, anybody who knows me. I absolutely hate being told what to do. If you're going to do that, I'm going to yell at you and I'm going to be a complete son of a bitch because I hate it. I hate it. I would rather they just come in, be polite, do their job and get out. That's what I would like (Rebel Fighter, 2017).

However due to my disability, and it will definitely, I can definitely show you the reports where I need kind gentle reminders. Not firm mean ones and they never do. They just ask and asking is not a reminder in my mind for my disability, because I forget short and long term. I will not remember unless they say, "hey can you do this?" And they have to be persistent and then after a while once I have it memorised ok, I have to do this on this day around this time then I can do it. But they have not reached out to do it nor attempted to. If any hardly (Voices4 allneeds!, 2018c).

Residents experienced the interactional dilemma of staff instructing them, despite a need and desire for independence. A clear tension existed between the need for support and the desire for independence. When staff used their authority to claim high entitlement to be obeyed, a sharp profile of the institutional world in which men and women with disabilities lived was evidenced. These experiences were spoken about and captured by group home residents on YouTube. Staff members in group homes commonly used directives without offering explanation (Antaki & Kent, 2012). A study by Antaki and Kent (2012) into group home contingency, entitlement and



explanation in staff requests to adults with intellectual disability, found that explanations made by staff revealed something the staff member knew and the resident seemed not to know. Antaki and Kent (2012) found that by asserting a deontic authority, staff members would draw on an epistemic authority to coerce an individual into doing something. When presence of an explanation was missing, an invasive and forceful nature was imposed upon men and women with disabilities.

Why group homes suck on the weekends. Here's an explanation for you. Ok first of all you're just sitting down after you've made yourself a nice big ass breakfast and then staff on the other hand have the mother fucking nerve to tell you, "you need to take a shower" (Mark Cinque, 2019d).

Ok look bitch, first of all I just got done cooking my breakfast here and I woke up not too long ago taking my fucking meds and I just had a hard ass week at work. You can't just let me chill for the day? Damn. Damn. I'll tell you what you're going to do. You're going to get the fuck off my back. You're going to stop telling me what the fuck I need to do and you're going to let me do what I want. Ok? That's how it's going to work. You're here to get paid ok? I'm here on the weekend to do what I want to do. Ok? You got that bitch? So, get the fuck away from me. Let me eat my damn breakfast and let me do whatever it is the fuck it is that I want to do (Mark Cinque, 2019d).

You're a vulnerable adult, can't make decisions, can't do this, can't do that (Voices4 allneeds!, 2018c).

They don't always listen to that. They've always wanted to find the nerve to give you things to do that suck. Like take a damn fucking ass shower. They always want to find ways to question your hygiene. How does your room? Like really? Like how is your laundry? Like oh my fucking god. Like who really gives a fuck really (Mark Cinque, 2019d).

When choices were taken away by support staff in the simplest interactions, residents lost agency and a sense of control over their environment. When staff questioned resident hygiene, the power and expertise lay with the staff, while residents were in a position of observation within their own home. The living

environment was described as rigid and inflexible, with a clear routine. This mirrored institutional living rather than independent community living. The experiences disclosed on YouTube suggested that there appeared to be a lack of freedom and autonomy.

I got harassed by a staff here, morning staff. And she said that I dress provocative (sic) because the director is actually worried. Shouldn't be dressing like that kind of attitude, talking shit and then the next day the morning staff goes, "oh make sure you put a jacket on yah" (Latrice Allen latriceallen@live.com, 2017j).

The simplest decisions about daily living activities such as showering and which clothes to wear, were often taken away by staff in a position of authority within the group home. YouTube was used by men and women with disabilities to challenge the line between staff duty of care and resident personal freedom, a problematic area which was volatile and contested by residents. Residents used YouTube to voice impeachment on rights.

I was being assaulted you know, harassed like that, by how I dress. It's actually against the law, against disability rights to do that (Latrice Allen latriceallen@live.com, 2017j).

Resident behaviour escalated when their sense of power and autonomy was lost. It is in the daily interactions between support staff and residents that the visible manifestation of agency and personal self-determination will be evidenced (Antaki & Crompton, 2015). A loss of power in interactions with staff was reclaimed through the use of YouTube, which individuals exercised power and control over, especially the content contained. Unlike sexual abuse and violence, emotional and psychological abuse from staff may be unintentional (S. Robinson & Chenoweth, 2012). These unintentional behaviours could have devastating consequences in the lives of people with disabilities. Staff are less friendly and more assertive and when communicating with people that exhibit challenging behaviour (Willems, Embregts, Bosman, & Hendriks, 2014). The data set showed that aggression was used to resist staff directive and control.

She proceeded to say this is my workspace and I demand that you do it and I basically told her that if she doesn't like it, then she can leave, there's the door, and she refused so I think I told her, I think I just said I want you to leave or something like that, and then she said no and then I raised my voice a little bit more and said I really want you to leave. And then she finally did after five minutes of me yelling at the top of my lungs and then as she was leaving, I referred to her as an animal. Now that was not appropriate of me, that was not right of me but that was how I was feeling in the moment so yeah. I don't pretend to be a perfect human being but if you treat me with respect and dignity, I will try and do the same. I just felt like I wasn't being treated with respect (Rebel Fighter, 2018e).

Residents demonstrated insight into why they used challenging behaviour. They resisted directives and control. Challenging behaviour had a function. Interactions between staff and clients often contribute to challenging behaviour (Hastings, 2005; Hastings & Remington, 1994). Interactions between staff and clients have been shown to exasperate challenging behaviour (Bailey, McComas, Benavides, & Lovasz, 2002; Lambrechts, Van Den Noortgate, Eeman, & Maes, 2010). Residents were aware that their challenging behaviour was difficult for staff and perhaps could not be managed. Staff were documented raising their voice in reaction to challenging behaviour from residents.

David - I'm being forced to go on a trip with a crazy bitch.

Driver – Watch your mouth Carl, calling me a bitch. Watch your mouth.

David – For what?

Driver – Watch your mouth. That's not necessary calling me a bitch. That's not necessary. A crazy bitch. You're recording this too. Two can play this game. Call me a bitch. Say it again. Say it so Manny can hear it. Say it so Manny can hear it.

David – No he won't. Give me Manny's number so I can tell him that you're pretty much senile!

Driver – Crazy bitch too.

David – Senile. Senile. I've had enough of you. I've had enough of your crap. You deserve to be fired! You are the most worst staff here!

Driver – Hey hey hey. Calm down! All this is not necessary! (David Graycat, 2017).

During conversational interaction between staff and residents, staff can either promote or discourage a discourse of agency when participating in daily living activities (Antaki & Crompton, 2015). Interaction between staff and residents impacts powerfully on the group home experience for men and women with disabilities living in group homes. By giving individuals choice, individuals can foster a sense of control over their environment, supporting personal agency (Antaki & Crompton, 2015). The promotion of agency underpins ideologies of self-determination and person-centred models of support, which are favoured in the world of disability. Individuals used YouTube to voice their disapproval of staff directing them and taking away their personal choice and control of daily living activities through the use of directives enforced by their position of authority. While the distribution of authority within the group home removed individuals' autonomy, agency and independence, the use of YouTube to voice concerns reinstated a sense of autonomy, agency and independence for men and women living with disabilities.

### Inappropriate use of staff power and control

The topic of today is basically about people who take advantage of others. My brother is schizophrenic. He's twenty-five years old and he was in the hospital for about three months, or close to three months. So two and a half months to be exact, and the group home man, parenthesis, had his card, his food card, his money card and money he got out and discharged out of the hospital. I come to find out there was nothing on the card. No money. I know he had to pay his rent while he was gone. Yeah, I get that you have to pay for your spot, I get that. But when you get back and the spot is your couch and it's not an actual room, that's what peeved me off because you're taking advantage of those who can't do for themselves (It's So Cassey TV, 2017a).

Staff hold positions of power in the group home because of their paid position of employment and duty of care to residents. This power can be used inappropriately, in a way that abuses residents. The way abuse and neglect are operationalized is key to the way it is responded to and people with intellectual disabilities are protected (S. Robinson, 2013; S. Robinson & Chenoweth, 2011). A thorough understanding of the types and severity of behavior that harms people with disabilities is needed to respond appropriately to abuse and neglect. The data set provided an understanding of the types of violence, abuse and neglect experienced by men and women with disabilities in group homes. Any behavior that causes harm can be abusive, neglectful or exploitative.

They kick me out of this room that I'm in right now. They kick me out of my own room (Rapheal Hardwick, 2015).

Staff could use their positions of authority to reduce the power and encroach on the personal space of residents living within the group home. This misuse of staff power was harmful for people with disabilities. In the disability field, and particularly in S. Robinson (2013) framework for understanding emotional and psychological abuse and neglect of people with intellectual disability, harm is understood as being the result of the misuse of power and control (S. Robinson, 2013). S. Robinson (2013) approaches violence as something that is not always obvious but as something that causes psychological harm. At the center of her approach is power.

She tried to crack a whip on all the clients. Is that her job? Does she get paid to do that? Probably under the table maybe (Jose Baez, 2016).

The inappropriate use of staff power was questioned by residents. Able-bodied staff forced and coerced group home residents. The data set confirmed that within group home accommodation, staff held power over residents, and this power was wielded to control, restrict and direct the less able. The history of accommodation services was one where choice and control has been in the power of staff and management running the service itself (S. Robinson & Chenoweth, 2011). This idea of power was central to Robinson's (2013) conceptualization of group home violence. Scott Yates (2015) confirmed that not all institutions are the same but that the role of power

needed to be recognized, because power functioned in the same way in such situations. Staff power was used to control individuals and restrict their freedom. Conceptual approaches to understanding abuse and neglect share several features to do with oppression, isolation and dehumanizing of people with intellectual disability, increasing the conditions under which abuse was likely to occur (S. Robinson & Chenoweth, 2011). The misuse of staff power created circumstances where abuse prevailed.

They treat the consumers like crap. Now there was a previous staff before that almost killed us and stole from us, and did all weird shit to the consumers (Latrice Allen latriceallen@live.com, 2014a).

Staff that misused their power and authority could take advantage of people with disabilities living in group homes. People with disabilities were vulnerable. They were disadvantaged and trapped within a system that was designed to support them. Often times, the staff that were meant to be empowering people with disabilities used their position to steal from and take advantage of this vulnerable community.

The people are treated unfairly. They are treated without respect. They are abused in group homes and I can say that from a personal viewpoint. I have been hit in group homes. I have been abused. I have been sexually harassed (Mark Cinque, 2019d).

Individuals disclosed on YouTube that they were harmed within the group home. This harm included physical violence towards men and women with disabilities. Residents were subjected to the treatment from staff. This was often detrimental to resident wellbeing.

We just had an incident with one of the staff, claimed that she was joking about, to a resident about hitting or threatening to hit her cos she claimed that it says in the doctor book of backward psychology that you can threaten and cause violence to a resident or patient that is hurting themselves. So basically, she was saying to this patient or consumer, because this consumer was having a nervous breakdown and was hitting herself. And she told the consumer, "I can hit you for you, I can calm you for you, I can do this for you".

That there's no such thing stating that in the medical field. It is against the law to threat or joke about any violence with a patient (Latrice Allen latriceallen@live.com, 2018a).

She thinks that she can belittle me (Jose Baez, 2016).

The data set revealed experiences where men and women with disabilities were abused by staff. Staff power was wielded to threaten, intimidate and harass group home residents. This kind of treatment could have long term effects on the wellbeing of men and women with disabilities. The group home environment reinforced the power imbalances between staff and residents, cultivating an environment where abuse could flourish. The power held by staff within the group home enabled the blaming of residents for difficulties and complications that arose.

They blamed me. Said I was being rough on it etc. I wasn't (Voices4 allneeds!, 2018b).

I stood up to a roommate and told her what she is doing wasn't right and she told me well they're doing their jobs wrong. Which is true. And everything here is wrong. I'm going to get blamed for it (Voices4 allneeds!, 2018c).

The only thing they fixed in my room would be the light and the things here and my bed because it did break once because I was moving around a lot. And they blamed me. Said I was being rough on it etc. I wasn't (Voices4 allneeds!, 2018b).

They call me manipulative and a liar. I think they should look into themselves because that's quite the opposite. I'm fighting for what I know is right (Voices4 allneeds!, 2018b).

Janet Tailor is a resident staff that they hired here and was causing me a lot of head issues, calling me a liar about chores, due to my injury, and I'm saying that I don't do chores at all and if I didn't do chores and I was a liar (Latrice Allen latriceallen@live.com, 2014g).

The placing of blame upon the victim was enabled through an imbalance of power and the discourse that people with disabilities are lesser than other citizens in society. Without a voice within the group home, social media became an important median to voice concerns and get the word out about the inhumane treatment experienced. Understanding violence, abuse and neglect is key to responding to it. Where blame lay would impact upon how problems were solved. Rather than the staff or organisation take the responsibility for providing a safe environment, blame was often put on the men and women with disabilities living within the group home. Staff theft of resident belongings was a form of abuse that was enabled through staff power. Family members of men and women with disabilities living in group homes witnessed instances of abuse through theft and used YouTube to disclose such experiences. Family members were often powerless to staff management and staff, using YouTube to empower their voices and advocate for family members. Family members used YouTube to disclose incidents where family members had been stolen from and taken advantage of by staff.

So, he (staff member) went and got him a new phone and said oh that's his way of paying him back all the money he took for the two and a half months and I'm like, are you kidding me? Are you kidding me? So now we're left trying to figure out how we're going to fight this because I don't feel like you have compensated my brother enough (It's So Cassey TV, 2017b).

Theft by staff was overt and in a way that took advantage of someone that was powerless and with less capacity to understand or negotiate relationships. Abuse of men and women with disabilities occurred when staff stole from the vulnerable adults under their care. YouTube enabled family members to disclose in a public space what was occurring in the privacy and secrecy of the group home. The environment was highly volatile with conflict amongst residents and between staff and residents. Residents used resistance in an attempt to reinstate autonomy. Staff resisted autonomy with violence to maintain power. The result was conflict between staff and residents within the group home.

They do hate when residents try to stick up for themselves (Latrice Allen latriceallen@live.com, 2015b).



Abuse of power enabled and reinforced through the group home design chipped away at people's lives and dignity. Staff were also described as being perpetrators of violence. Residents observed group home managers that used violence towards their housemates within the group home.

They had been threatening my room-mate, they had been screaming, one of the house managers almost hit her and it was just a big mess (Vicious x Cycles, 2015c).

Even when residents found a group home that they were happy with, the violence in the environment soon meant they needed to leave.

I get there and, you know, it's actually like a home. There's curtains, there's couches, there's pillows. The place looks nice. It's really well kept and it feels like home to me and so I walk in and I'm pretty much like, I can just feel the energy in the house. It's good energy. There's a good spirit there and you know, once I meet the people, take the tour, and I see they've got good activities. They've got a rigid schedule and they've got times for everything and places for everything, and I see my room and turns out that a girl lives there that I've known since I was four years old. So I'm pretty much sold at that point. I'm like, I know they're pretty much crazy. I need to get out of there. So, I make a move and the whole time I'm trying to pack up my shit and get out. The house manager is staring at me, glaring at me, and following me around and all this stuff and it's just ridiculous (Vicious x Cycles, 2015c).

Even when the facilities were sufficient, the hostility and violence experienced in the environment meant that the group home was uninhabitable. Group homes were places where human rights were being violated. YouTube was used by individuals to express what they desired from their group home experience. People wanted to live in a safe place, free from violence and harassment. Residents felt that was their right. YouTube benefited men and women living with disabilities in group homes as it provided a means to express themselves and document the violence they were subjected to within their own home. Individuals were described as having troublesome behaviours and social issues that adversely impacted upon others

sharing the same environment. While physical abuse is obvious, emotional and psychological abuse and neglect may be harder to detect and report. The misuse of power and control within these homes harm those that are meant to be cared for (S. Robinson & Chenoweth, 2012). Policy development, research and practice aimed at making these places safer for people to live in are absent of the voices of people with disability (S. Robinson & Chenoweth, 2011). The untold, undervalued story of thousands of individuals living with disabilities and posted on YouTube demonstrated that violence, abuse and neglect was problematic in group home accommodation.

The content created by men and women with disabilities documenting their group home living experience captured raw and unfiltered firsthand accounts of interactions with other housemates whose behaviours they described as being violent and problematic. This content summoned from YouTube and used as information for unobtrusive research methods was free from bias, as it was created on the terms of the individuals themselves. While the perspective of the individual disclosing the information, the data were reliable and robust. The information provided a deep and insightful understanding of group home violence exasperated by the residents within the group home itself. Housemates discussed housemates. Using an unobtrusive research method to access this material provided an analysis which was from the perspective of men and women with disabilities. The narrative of the disability community could be gleaned from and included in the conceptualization of disability group home violence. Data already existed. Men and women with disabilities that have revealed that these experiences were traumatic in nature did not have to discuss these events again to be included in research. They disclosed the events on their own terms, using YouTube as a mode that they had control over what they posted, and their own content.

In this chapter, I presented one of the main themes to emerge from the findings; that group homes provided the opportune environment for harmful interpersonal relationships to develop. While group homes were often the only opportunity for people with disabilities socializing, the challenging behaviour of residents impacted and affected others that shared that same environment. These harmful interpersonal relations contributed to experiences of violence, abuse and neglect experienced by people with disabilities living in group homes. Conflict between

housemates was often disruptive and violent. Staff often maintained their positions of power through behaviour which was threatening to residents. These interpersonal relationships were harmful and damaging, the group home environment providing the opportune set up for violence, abuse and neglect to flourish. The integrated literature review enabled the findings to be contextualized. The next chapter presents the fourth and final main theme that emerged from the data set.

## **CHAPTER 8**

### **BREAKING THE SILENCE OF DISABILITY: DOMINANT NARRATIVES THAT SILENCE THE DISABILITY COMMUNITY**

The voices of people with disabilities, their families and carers, are silenced by dominant ableist narratives. These dominant narratives are reinforced by cultural representations of the impaired body presented by dominant media structures. Social media platforms provide the disability community with an unfiltered opportunity to challenge dominant representations of disability. The disability community can use social media platforms to contribute to configurations of disability. Social media platforms are advantageous in that they can be controlled by the individual, their family or carer themselves. This means that people with disabilities, their families and carers, can be empowered by the mode of communication and flexibility that social media provides.

In this chapter, I argue that YouTube is used by people with disabilities to break their silence about group home violence, abuse and neglect, and regain a sense of power in their lives. A main theme to emerge from the analysis of YouTube videos analyzed through unobtrusive research methods was that YouTube is used by the disability community to break silence and challenge dominant ableist ideologies. Silence is reinforced through ableism. Challenging behaviour and restrictive practices are incorporated into this chapter because they have arisen through ableist agendas, policies and assumptions about housing and the patterns of daily life that have been imposed upon people with disabilities. Ableism is the lens through which the reasons for silence is understood. When individuals with disabilities do not have a voice, they will find other methods to resist ableism. An integrated literature review is used to contextualize the findings within existing disability literature. My original contribution to knowledge is using the voices of men and women with disabilities to affirm existing disability theory and then to extend theory by considering the benefits that YouTube offers people with disabilities. Further, I support the original contribution to knowledge by considering the strengths that unobtrusive research methods offer research into people with disabilities. I then extend theory by

exploring the different modes of information that is revealed on YouTube that is currently absent from the theorization of group home violence, abuse and neglect.

### **Ableism configured and perpetuated through dominant media structures**

For much of human history, knowledge and knowledge generation about disability has been in the hands of able-bodied people. Those recognized, legitimized, or certified as knowledgeable or expert in disability have predominantly been fully functioning. Historically, the voices and experiences of people living with disabilities have been missing from knowledge, debates and issues regarding them. Expert opinion has been valued over lived experience of the people living with a disability themselves. The deaf community and the hearing world, or dominant culture, have opposing beliefs when it comes to cochlear implants that can enable the deaf to hear, being seen as either access to opportunity or as an oppression (Goggin & Newell, 2003). Whether seen as opportunity or as an oppression depends upon the underlying worldview (Goggin & Newell, 2003). The deaf community challenge ableist worldviews of disability.

The majority of members of the deaf community are typically born deaf and define their community in terms of specific sociolinguistic practices, languages and spaces. Protective of their language and opposing cochlear implants, they view the implant as invasive and unethical (Goggin & Newell, 2003). Deafness involves community, and sign language as a unique and natural way of communicating. The hearing world, or dominant culture, has opposing views. The hearing world defines deafness as an impairment and the cochlear implant as ethical (Goggin & Newell, 2003). This is an example of conflicting cultural perceptions. These two contrasting knowledge systems are founded on what is considered nice, normal and natural. The cochlear implant is one example where varying levels of conflicting cultural perceptions exist, depending upon underlying values. Dominant media structures have had an important role in influencing cultural perceptions.

Dominant media structures have configured people living with disabilities using negative stereotypes of either, sick and needy individuals, or like inspirational superheros, also known as supercrips (Haller, 1997). The supercrip is presented by

dominant media as an inspirational person with impairment that becomes glorified for their efforts to overcome their own disability (Schalk, 2016). Dominant media configurations of the supercrip have been challenged because of its potential to damage and further oppress the disability community (Schalk, 2016).

Several scholars assert that supercrip narratives not only set unreal expectations for people with disabilities to “overcome” the effects of their disabilities through sheer force of will, but also, simultaneously, these representations depend upon our ableist culture’s low standards for the lives of disabled people (Schalk, 2016, p. 74).

The supercrip image is an unfair expectation and narrative for people with disabilities to live up to. It is ironic that Christopher Reeves, famous for his role as Superman, became constructed in the media as a heroic celebrity with quadriplegia, gaining supercrip status. Reeves became quadriplegic in a horning accident and carried his disablist views into his activism by searching for a cure in stem cell research. His story of becoming disabled and searching for a cure reinforced the dominant social discourse that disability needs fixing. Reeves was considered by the disability community as not representing the views of people living with disabilities, and was disliked by many disability activists (Shakespeare, 2014). His views were not supported by or reflective of the disability community. Not only did the media turn Reeves into a hero, the media muted the voices of people with disabilities and preferred the narratives of people that amplified the argument in favour of stem cell research (Gerard Goggin & Christopher Newell, 2005). Dominant media structures were dominated by the voices of able-bodied, pro-research voices (Shakespeare, 2014). Expert opinions were valued over the voices of people with lived experience of disability and others who were not in favour of stem cell research. The deeply held view underlying the stem cell debate was that an able-body was of higher value than one with impairment. The quest in stem cell research is to discover and eradicate genes with any defective qualities. This supports the ableist worldview. Ableist ideology continues to underlie the configurations of disability on television and through the media. People with disabilities are configured in stereotypical and disabling ways in Australian media and social media. The critical realist approach to disability recognizes that people are not only disabled by their impairment, but also

by their interactions with society. Being disabled by configurations of disability in the media is acknowledged using a critical realist approach to disability.

Media plays a central role in culturally embedding the profound sense of otherness that many people with disabilities experience (Gerard Goggin & Christopher Newell, 2005, p. 35).

Media coverage of the Paralympics is an example where a profound sense of otherness was reinforced by the media. Ellis (2008) studied how current affairs programming leading up to the 2008 Paralympic Games reinforced social disablement. The Paralympics was configured as an inferior mode of competitive sport. While Paralympians gained air time and media coverage, the sport remained inferior to that of the Olympics (Goggin & Newell, 2003). Paralympians also reinforced the supercrip representation of disability in the media (Ellis, 2008). The configuration of Paralympians in the media further disabled people with disabilities.

The iconography of a person with disability represented in the media is a white male in a wheelchair (G Goggin & CJ Newell, 2005) and this does not represent the diverse experience of impairment. Other disadvantaged groups are often expected to have more diverse representations in the media compared to people living with disabilities. Rodan and Ellis (2016) extended the work of configurations of identity in the media by studying disability, obesity and ageing. Rodan and Ellis (2016) found that prejudicial attitudes regarding what was considered acceptable constructs of the body regarding disability, obesity and ageing, were represented on television. Just as media has been used by disability activists to contribute to the narrative and representation of disability in the media, the representations of disability on YouTube contribute to the narrative on group home experiences. YouTube became an important avenue for sharing explicit ideas and experiences.

Whereas limited repertoires are presented on television, new media forums offer new models for constructing and circulating identities (Rodan & Ellis, 2016, p. 5).

This research demonstrates that the disability community has used online media to challenge dominant ideologies of disability as a method of activism. Social media platforms provided opportunities for many voices to contribute to discussions on key social issues where television and news media does not. Unlike television and news

media, social media are disintermediated platforms and people with disabilities have the power over the content they upload and post. Their voices are not muted by an intermediary as is the case with television and news media.

People with disabilities are empowered by their use of disintermediated social media to influence the way disability is constructed and represented in society. The online space can be leveraged by the disability community to share their varying experiences of cultural oppression. Disability communities often form online around discussions of disablism.

The online community of disability becomes a key site for the discursive shaping of shared values (Goggin & Newell, 2003, p. 133).

The potential for social media to be used for disability activism has already been seen in cases such as rejecting Christopher Reeves and the stem cell debate. The voices of people living with disabilities may have been muted by the media, but their voices could not be muted online. People with disabilities are often not given a voice in news media (Haller, 1997). Online spaces are a place where people with disabilities can use their voice without it being muted. Individuals have used the online space to challenge ableism. There is no doubt that the media is powerful in influencing cultural attitudes. The internet and social media platforms have created opportunities for people living with disabilities to contribute their own material and views to the public media space. Configurations through social media and other media platforms can be used to influence and challenge dominant disability discourse.

There are great advantages in media platforms being leveraged by people with disabilities in a way that presents the complexities of disability and diversities of narratives, rather than just stereotypical narratives. The internet is a space that is widely and readily available for citizens to access and experiment with identity, culture and social practices. It has also revolutionized society and culture in the sense that more information is available now than has ever been before in history. This information can be accessed and can influence culture. Media is a powerful tool in shaping and governing the social world. Goggin (2015) claims that there is potentially room for explicit discussion regarding people with disabilities as citizens that make



media which influences society, and the way media governs and influences the lives of people with disability. Social media can be used strategically by people with disabilities and their organisations to advocate for issues pertaining to them and also to challenge the representation of disability in the media that further acts to disable them.

Social media have provided many opportunities for people living with disabilities. Research investigating the way people with disabilities are using social media to have a voice into issues pertaining to them and paves the way for disability activism into the future. Men and women with disabilities can use online social media to contribute to discussion based on their human rights. Models of independent living adopted by some service providers researched by Power (2013) in disability accommodation emphasized discussion such as 'having a life', 'doing ordinary things' and 'being a citizen'. It encapsulated an increasing move towards recognizing and talking about people's rights and rights-based training for staff. Recognizing human rights was acknowledged by these service providers as central to offering service that empowers rather than dehumanizes the individuals it supports. Men and women with disabilities can use YouTube and media to contribute to discussion and discourse that shapes this field of thought.

Research has been growing at the intersection of disability, media and activism (Ellis & Goggin, 2015). This research was valuable in its insight into media use and disability. It also provided important insights into general understandings of media forms and other practices associated with audiences, labour and consumption (Ellis & Goggin, 2015). Participation of people with disabilities in the media industry is grossly underrepresented in the media industry. Ableist ideologies and stereotypical configurations of people with disability continue to dominate the media space. People living with disabilities have limited participation in the media industry itself, and the voices of people with lived experience of disability are often muted in public debates that attract media coverage. Media is an influential tool that can be used as leverage in society for disability activism and to influence dominant discourse favourably. People living with disabilities can contribute to the configuration of disability and other issues pertaining to them in the media through their participation in social media platforms and products. As citizens, they have power to participate

in these spaces with the potential of impacting configurations of disability in the media. This research provided an important investigation into how people with disabilities used social media to participate in the disability narrative, providing insight into the opportunities and potential impact that social media platforms provides.

Configurations of disability broadcasted by television and news media, including the stories surrounding Christopher Reeves and the airing of the Paralympics, have oppressed the disability community. These configurations of disability have served to prefer the able body and understand disability as a sickness needing to be cured. This is offensive for people with disabilities. Media has been fundamental at reinforcing such offensive discourses that have permeated civility. The power of media to support and create discourses that oppress and disadvantage minority groups has been acknowledged. Next, I will use the data set to demonstrate how men and women with disabilities used YouTube as a form of media to challenge dominant configurations of disability.

### Challenging ableism with social media

I have used existing disability literature to argue that people with disabilities are configured in stereotypical and disabling ways by dominant media structures. Television and news media have influential power to dominate the masses. The critical realist approach to disability recognizes that people are not only disabled by their impairment, but also by their interactions with society and the world in which they live. YouTube is a social media platform where, unlike dominant media structures, the person with disability can have complete control over what is posted. Summoning information from YouTube as a research method in disability studies is robust because the opinion of the disability community can be obtained, free from bias. This is a form of media that people with disabilities have been shown to harness to challenge dominant discourses and speak out publicly about issues pertaining to them. The data set revealed that YouTube enabled people to challenge the dominant discourses of disability, while speaking of their group home experiences. YouTube was leveraged to challenge dominant disability discourses while speaking about their group home experiences.

Prenatal screening to scan for genetics, justifying the aborting of a foetus based on genetic implications, is common practice in the technologically advanced western world. Abortion of the disabled foetus constructs the lives of people with disabilities as unliveable and undesirable (McKinney, 2019). Prenatal screening is considered discriminatory against the person living with impairment and targets the disability community (Shakespeare, 2014). In disability activist literature, the debate about aborting the disabled foetus based on genetics is interpreted as a vicious plot to eliminate people with disabilities (Shakespeare, 2014). The aborting of a foetus based on genetics is a dominant ableist ideology. It reinforces other dominant ableist narratives that people with impairments are incapable of living a life, and that people with disabilities are unworthy and undeserving. YouTube was leveraged by a group home resident while discussing his group home experience to also challenge this grand idea that the disabled life is not worth living.

My name is Joshua Weidemman and I have CP and I'm doing this video audio recording for a grievance for my agency. I'm doing it to stand up to say that people with disabilities matter. We are capable and we deserve life (Joshua Weidemann, 2018).

The freedom to advocate for the disability community and challenge dominant ideologies is one of the benefits YouTube offers people with disabilities. Being a disintermediated social media platform, YouTube freely captured narrative from the individual with the disability himself expressing his belief that he felt that he was capable and his life worthy. This type of narrative coming directly from the disability community is unfiltered and challenges dominant ideologies about disability. Further, YouTube as an unobtrusive research method offers research into people with disabilities a genuine and authentic voice that is free from bias. Social media platforms must continue to be accessible for people with impairments (Sweet et al., 2020). The opinions of the disability community are available on the internet and can be studied. The data set revealed that it was important for men and women with disabilities to advocate for themselves.

In the field of disability studies, silence exists around issues pertaining to sexuality and reproductive concerns, with the views of the disability community being absent

from the dominant discussions (Addlakha, Price & Heidari 2017). This silence occurs because people with disabilities are not given a voice concerning issues that involve them. People with disabilities have not been represented as sexual beings, and this has impacted their inclusion in discussions of these topics. Instances have occurred where people with disabilities have voiced their hopes and desires to have relationships, but have not been listened to because of long standing silences around sexuality and disability.

I'm much more comfortable with my sexuality that I am being in a wheel chair (Rebel Fighter, 2018d).

It's my life, it's my choices and I really wish my parents would stay out of it and I know this is making me sound like a jack ass, however my parents have never supported me in a lot of things. I mean they did support me going back to college, that they did. But they've never supported my sexuality. They've never understood the reasons as to why I can't always go out in public and do things, because I have social anxiety and some days are just so bad that all I want to do is curl up in a ball and lay in bed (Rebel Fighter, 2018a).

Residents contributed to the disability and sexuality debate by expressing their opinions about their sexuality on their YouTube channels. They used YouTube as a form of social justice education. Social justice education is about learning and embracing difference (Danielle M Eadens & Eadens, 2016). Social media platforms have been used by individuals with disabilities to create social change around disability (Cocq & Ljuslinder, 2020; Haslett, Choi, & Smith, 2020). Social media platforms have been used to challenge identity politics and ableism (Cocq & Ljuslinder, 2020; Haslett et al., 2020). Freely and openly expressing opinions about disability on YouTube is a form of activism. For an oppressed people group whose narrative is underrepresented and silenced by dominant media structures, YouTube provided a platform where men and women could speak freely and publicly on their own terms. The mode of YouTube is empowering for men and women, their families and carers. This research demonstrated that the disability community used YouTube to advocate publicly for themselves. YouTube and the use of disintermediated videos enabled the disability community to challenge dominant disability ideologies.

Disintermediated videos uploaded onto YouTube were free from the control of the dominant media. People with disabilities chose what they posted and what they discussed. They chose to challenge issues pertaining to disability and their group home environment.

Just because you have a physical disability doesn't give your parents the right to make decisions for you, unless you've signed away your rights or you have a mental disorder that makes it impossible for you to make good firm decisions. Then the parents still have the legal right to make decisions for you. But in my case, my parents do not have the right to make decisions for me. The group home does not have the right to make decisions for me. The decisions and the choices in my life are mine alone and my life is to do with what I please to do with it, and I'm just sick of people trying to control me and tell me what to do because no one knows what I need better than I do. And that's pretty much all I have to say on that (Rebel Fighter, 2018a).

YouTube was a space where individuals exercised control over what they posted and could express themselves without being silenced or challenged. This enabled a sense of agency and empowerment. The data set revealed that group home residents wanted to be in control of their own lives. While dominant media structures have been dominated by narratives of cure, YouTube enabled people with disability to have power and control over the discourse presented on their own term, on their own channel. Topics that have historically been silenced, including sexuality and reproductive rights, were free from censorship on YouTube. The uploading of videos to YouTube enabled people with disabilities to add to the narrative surrounding issues that were about them and important to them. Because the disintermediated videos uploaded by men and women with disabilities themselves were free from bias, the content was robust and reliable. Such material should be harnessed in social research. YouTube content could shape configurations of disability and also contribute to disability debates to create social change.

## Silence reinforced through ableism

Ableism is a form of discrimination that is based on the able-bodied being superior to those with an impairment. Disability is associated with ill-health, incapacity and dependence (McLean 2011). Ableism is based upon a dominant hierarchy of knowledge which understands the able-body as being superior to the body with impairment. "Knowledge and belief are distinct yet intricately related components of an understanding of the way things are" (McLean 2011, p.14). These dominant ableist ideas and understandings become institutionalized in the ideas, thoughts and beliefs of able-bodied people, creating barriers for people living with disabilities (McLean 2011). People with disabilities are silenced by these dominant ideologies and hierarchies of knowledge that ableist power structures reinforce. These ableist ideologies dominate the group home environment.

Disability-related silences are mostly created through the confluence of inaccessible physical and social environments and the psychological internalisation of these worlds (Lourens 2018, p.156)

Silence has been used to describe the reality of many people living with a disability who are discouraged from speaking about their disability by dominant culture discourses (Yoshida & Shanouda 2015). The psychological nature of oppression causes many people with a disability to remain silent and voiceless in an array of situations and contexts (Lourens 2018; Watermeyer 2012; Yoshida & Shanouda 2015). Individuals living with disabilities find themselves in a world dominated by the able-bodied, forcing them to remain silent for peace and survival, often in a position where they rely on support. Studies have shown that people with disabilities remain silent because of the way they perceive the world in which they find themselves (Chang, Chou & Han 2018; Chenoweth 1996; Lourens 2018; Watermeyer 2012; Yoshida & Shanouda 2015). Different practices throughout history have attempted to silence the experiences of people living with disability (Yoshida & Shanouda 2015). These dominant ideas are written, spoken and occupy space, creating a hierarchy of knowledge, truth and experiences.

Silence has occupied an array of places, functions, roles and frames in theorizations of power, injustice and resistance. The psychological component of disability (Jose Baez, 2016) causes people with disabilities, their families and carers, to remain

voiceless in situations that are oppressive in nature (Watermeyer 2012). The disability community has long been othered.

I would just like to say that people with disabilities really need to speak out for themselves. Sometimes they do and sometimes they don't and they really need to speak out for themselves otherwise these agencies are just going to walk over you and treat you like crap (Rebel Fighter, 2018h).

When people with disabilities are silenced, they remain voiceless about issues that impact them. When the voices of people living with disabilities are absent from issues pertaining to them, they are objectified (Chenoweth, 2000). The posting of videos on YouTube of personal experiences enabled people with disabilities to break their silences within the group homes. YouTube was used to speak out and challenge ableist ideologies that dominated the group home environment. Silences that were broken exposed injustices and called for collective action through advocacy, ultimately empowering an oppressed community.

Hi YouTube. What's up? What's going on? I am coming here to talk to you guys about a certain issue. It's epidemic. This is, this is, I want this to go nation-wide so people can hear this. That's the aim (Raphael Hardwick, 2015).

The data set revealed that a reason men and women posted to YouTube was because of the potential for their video to reach the masses. YouTube can potentially have great influence, with some campaigns going viral (Kwon, 2019; Turnsek & Janecek, 2019). Content created by the disability community going viral on YouTube benefits people with disabilities, influencing social change. For truly lasting change, silence must be broken (Addlakha, Price & Heidari 2017). Lived experiences are key to exposing the truth about situations and challenging societal structures and social norms (Addlakha, Price & Heidari 2017). It is the lived experiences of people with a disability that provide the best and richest information to expose and break silence.

Hi everybody, it's me Latrice Allen here. Just saying hi everyone. I'm kind of not happy being here at the home. Just want to talk about it (Latrice Allen latriceallen@live.com, 2017j).

Hi everyone in group homes and host homes. Group homes are not what they are. I've been in several group homes and host homes and I've been treated like shit (Callie31701, 2018).

So if you like this video, click the like button and comment your experiences in a host home or a group home please. Or go live and tell me how you've been in a host home or a group home (Callie31701, 2018).

YouTube became a space where people with disabilities connected to discuss and share experiences about their group home. There was a sense of freedom and control that YouTube enabled when sharing testimonials that would be lost using obtrusive research methods such as interviews. Men, women and families using YouTube had control over what they were posting. This gave them the ability to speak their truth.

I had it with these mother fuckers. Anyway, I was just venting. You pretty much right now you all know now this is my therapy corner. I tell you the honest truth my friends (Latrice Allen latriceallen@live.com, 2018b).

I'm always honest on my YouTube Channel (Rebel Fighter, 2018b).

YouTube was a place where residents felt that they could be honest without censorship. Social media platforms and interfaces have radically changed the way people communicate about themselves, with people regularly self-disclosing information to their communities (Luo & Hancock, 2020). This increased self-disclosure has had the effect of improving psychological wellbeing (Luo & Hancock, 2020). Men and women with disabilities disclosed experiences on YouTube about group home violence, abuse and neglect that was authentic and valid. Social media provided a platform where people could connect with a social community and self-disclose information of their choosing to their social network and beyond. The design of YouTube provided the added benefit that people could post content that had been spoken in a conversational style. The conversational style of disclosing information benefitted people with disabilities, as the conversational style of recording narrative could encourage open and honest disclosure. The open and honest disclosure of information was free from the Hawthorne effect. This meant that the information



provided may have been more reliable, valid and robust than data sourced through other reactive methods. This made the unobtrusive research method attractive and informative to research into people with disabilities. The quality of the content summoned from YouTube about disability group home violence, abuse and neglect may be have been more reliable that than information sourced elsewhere.

People with disability are expected to accept all forms of 'treatment' that would assimilate their lives with that of the normate, and they are expected to do this regardless of any physical, psychic or ontological harms associated with receiving such putatively beneficial intervention. This is the curative, cultural imaginary of ableist society (Spivakovsky 2018, p.99)

This loss of personhood is surely a predicament of disability and remains a silent suffering which few people talk about (Ikäheimo 2008). YouTube was used in a way that people with disabilities could maintain a sense of personhood as they exercised power and control over their content and when they posted.

In the future, if there's something going on, I'll post it up on YouTube, because if my rights are violated because I want to tell the truth, there is freedom, the door is open (Jose Baez, 2016).

She filmed me and that's illegal. I'm going to put this fucking up on YouTube and I'm going to expose you (David Graycat, 2017).

When experiencing injustice, group home residents could post their disintermediated videos publicly to YouTube to regain a sense of power and control in their lives. Videos captured their perception of events. There was a sense of freedom and a window to the world outside the four walls of the group home. The stories and lived experiences of people with disability were valuable. They provided the most valuable insights into the world of disability and what it is like for people that are affected by the predicament of disability. People with disabilities willingly shared their feelings and thoughts on YouTube on their own terms and in their own time. This is a major benefit that unobtrusive research methods offer research into people with disabilities. Men and women with disabilities can feel isolated and lonely within their own communities (Macdonald et al., 2018). Disability is a significant factor in the experience of feeling lonely and isolated (Macdonald et al., 2018). Accessing the

internet allows individuals to break through any silences that may be experienced, enabling their voice to be heard.

Group homes are environments where violence, abuse and neglect of people with disabilities are perpetuated. Underlying instances of violence is the experience of overwhelming shame and humiliation (Gilligan, 2000). Men and women with disabilities are subjected to shame and humiliation, often daily in the group home living environment. Vulnerability to violence is influenced by psychological defence mechanisms, including feelings of guilt and remorse (Gilligan, 2000). People with disabilities may lack the capacity for deeper reasoning and understanding, therefore being more vulnerable to feelings of shame and humiliation. Shame can result from,

feeling slighted, insulted, ridiculed, rejected, disrespected, dishonoured, disgraced or demeaned; feeling inferior, inadequate, incompetent, weak, ugly, unintelligent, or worthless; suffering "loss of face", "narcissistic wounds", or an "inferiority complex" (Gilligan, 2000, p. 1802).

Existing feelings of lower self-worth resulting from a lack of education, unemployment, and being from a lower social class, make one more vulnerable to feelings of shame and humiliation also (Gilligan, 2000). People with a disability experience more life challenges and disadvantage, commonly experiencing low levels of income, educational attainment, employment, superannuation, health and wellbeing (National People with Disabilities and Carer Council, 2009). The disability community may experience feelings of shame and humiliation that is further compounded by their exceptional life challenges. This is especially true for men and women living in group homes.

Lourens (2018) documents an auto ethnography of her experiences of being silenced as a person living with a disability. She takes a critical realist approach to her experience and acknowledges both the inaccessible physical and social environments in which she finds herself, as well as how she internally processes these experiences.

Writing openly about my disability experience was not easy because it meant breaking deeply entrenched and long-kept silences. It felt more intuitive and 'safe' to keep quiet than to write about real and often painful emotions, thoughts and experiences (Lourens, 2018, p. 569).

Writing about her disability experience in itself was difficult for Lourens (2018) as she had to break deeply held views about not speaking out and voicing experiences that caused her pain. Lourens (2018) described a situation where she wanted to speak her opinion but remained silent because of her dependence upon the person that was providing her support. She was dependent on them to provide her with transport and providing her support silenced her for a fear of disrupting the relationship. This was an example where the individual with the disability was disadvantaged by her physical disability and physical environment, but also demonstrates how the way she processed her situation caused her to remain silent.

Lourens (2018) spoke about the associated feelings of shame that were tied with the process of silencing for her. Silencing is never just about not having a voice. It goes deeper into feelings of shame and how not speaking up is interwoven with the individual and their own agency. Its effects people on a psychological level and has a follow-on effect that impacts all areas of their personhood and life. The effect of living with a disability could create an inner sense of inadequacy, which would result in feelings of shame and cause individuals to remain silent. While Lourens (2018) had to challenge herself to write about her experiences. Individuals using YouTube to disclose group home violence, abuse and neglect may feel more confident with that method. Lourens (2018) specifically wrote an academic journal to address issues of silencing, however the people that post to YouTube exposed their injustices on their own terms. Their audience was different. In both examples however their voice was given an outlet and their experiences were communicated.

I do feel more confident speaking my mind in situations that do not require a 'bargaining silence' (Lourens, 2018, p. 574).

YouTube as an outlet is free from a bargaining silence. This may be a reason why the people with disability posted to YouTube. YouTube provided an unrestricted platform that they could voice their opinion and speak about their experiences without the fear of repercussion. Residents were able to release what was on their heart without the fear of retribution.

I'm fighting for what I know is right and if that's wrong then they need to suck it up and deal with it and change it then because I'm fighting for what's right

and I deserve to live in a healthy, safe, by the way which means no violent people, no yelling, no assaults, no nothing, but I do not here (Voices4allneeds!, 2018b).

Men and women living with disability in group homes expressed their right to live free from violence, abuse and neglect. YouTube enabled residents to enact agency by giving them some control over their lives. When YouTube was used by residents to speak about their concerns, they had complete power over what was spoken about, giving them an outlet to raise concern and a voice. The group home facilitates ableist agendas that silence men and women with disabilities. Silence can occur for fear of retribution (Chang, Chou, & Han, 2018; Lourens, 2018).

I feel like I might lose my housing over a do of this leg injury that the staff here did. Well I feel uncomfortable, I feel unsafe here in all group homes, I don't care if it's a private group home or whatever. They treat the consumers like crap. Now there was a previous staff before that almost killed us and stole from us, and did all weird shit to the consumers. Oh my gosh, I can tell you stories but I don't want to brag. I don't want to mention names because then I might get in trouble for that (Latrice Allen latriceallen@live.com, 2014a).

Hi guys. I wanted to make a video and I look a little bad, but I actually showered today and I wanted to make a quick video there and tell you guys about some things that's going on in my life. Currently I'm making two Legos, a Star Wars, what is it, falcon, a big one. The big one that you get at the Lego store. And I'm making a small medium size one that's a special edition. It's not out anymore. Excuse me. And so here it is. I suggest everyone goes and sees the jungle book. It's a really good movie. All the characters are good. They all talk. The blue talks. Christopher Walkins in it. It's very good. The kid that they got to play emolgi is amazing. He's really good. It's a good movie. Go see it. Here's another tip. (Bends in close to the speaker and whispers). Don't live in a group home, they suck. I'm sorry to say but they suck. And if you live in one already, I'm sorry. I feel bad for you. Here's another tip. Don't let anyone tell you should. Just do your thing and move away from people. Ok thank you that's all I want to say. So that's all I wanted to say about that.

Ok I'm going to go. I just wanted a quick video. Ok seeya (Andrew Passino, 2016).

The data set revealed that individuals felt they could not speak truthfully about their group home experiences within the home itself. The internet opens up opportunities for personal self-expression in instances where this may have been previously inconceivable (Adam & Kreps, 2009). Where previously men and women may have felt fear for speaking out about their experiences, accessibility to YouTube enabled residents to break the silence about their experiences. Fear of retribution and backlash for speaking about their experiences was evident. This fear serves to marginalize residents maintains the oppression that the disability community experienced. When violence was experienced and police were notified, residents experienced once again, backlash from staff.

They're (police) meant to protect and serve not to protect and serve and then get backlashed by staff (Voices4 allneeds!, 2018b).

The marginalized position of residents within an ableist world view was reinforced through fear of speaking out their truth. A study by Danielle Maya Eadens, Cranston-Gingras, Dupoux, and Eadens (2016) investigating police and social justice for people with disabilities found that the majority of police officers surveyed in their study had little to no training with regard to persons with disabilities. This is especially problematic when "persons with disability come into frequent yet underreported contact with the legal system" (Hauser, Olson, & Drogin, 2014, p. 1). YouTube enabled individuals to speak freely about their experiences and capture their lived experience truthfully and from their own perspective, without punishment. Exercising power and control over content, men and women with disabilities had freedom to discuss their lived experience truthfully. This truthful narrative of group home violence, abuse and neglect is information rich and reliable. The truthful component is invaluable to use to access the validity of existing theorizations of disability group home violence, abuse and neglect. Including the unfiltered voices of men and women with disabilities in theorizations of disability is empowering for the disability community.

People with disabilities are regularly denied their basic human rights on a daily basis, in simple daily living (Williams et al., 2018). A study by Williams et al. (2018) highlighted how an individual may be denied the simplest of choices and used an example of supported shopping to illustrate the point. A carer in a position of power overrode consumer choice based on knowledge about what was best for an individual. The client with disability selected a packet of donuts and his choice was overridden by the worker because of the number of donuts in the packet. The worker shut down his client's choice as it did not fit in with common practices and knowledge about health and diet. The power of the staff member was used to silence the resident. While the intention to give men and women with disabilities choice may be apparent, in reality choice may not be present. The denial of basic human rights may be based on knowledge about what is best for someone. Able-bodied individuals that do not require support have the power to eat what they wish. Whereas the individual with disability often experiences the denial of one's rights.

Disabled people are regularly denied their human rights, since policies and laws are hard to translate literally into practice (Williams et al., 2018, p. 157).

While policy makers are aware of the problems that people with disability face and frame policies and laws in ways that best support their interests, there is a disconnect between policies and laws, and practice (Williams et al., 2018). People with disabilities are often thought of as unable to make their own decisions and lose their power to choose what they like. Individual choice is often silenced and human rights are not respected.

The purpose of this video is to show how extreme the regulations are in group homes. The people are treated unfairly. They are treated without respect. They are abused in group homes ok. And I can say that from a personal viewpoint (Max Sparrow, 2017).

YouTube was used as a platform to speak about group home regulations and how human rights were violated. YouTube content disclosed the belief that group homes were abusive in nature and exploited men and women with disabilities. While there were regulations informing group home practice, YouTube revealed that regulations

were often not met. Individuals uploaded content that disclosed human rights abuses.

I had a very bad experience with the meeting today. I was very pissed off; she did ask me about not doing chores. Then she got in my face (Latrice Allen latriceallen@live.com, 2014g).

The data set revealed that individuals within the group home environment were silenced by staff that reinforced their power. Chenoweth (1996) breaks down institutional silence by conceptualizing both structural silence and communicative silence. Structural silence is silence that occurs because of the power imbalances reinforced by the system and the blame lies within the system itself (Chenoweth, 1996). Communicative silence results from the impairment: the predicament is located within the individual themselves (Chenoweth 1996). Institutional violence and silence are longstanding issues and both of these factors come into play.

These institutions are testimony to how places with long histories of violence and abuse can remain quiet on the issue with little public knowledge as to events happening within them (Chenoweth, 1996, p. 401).

There are multiple factors and considerations that come into play when there is silence around institutional violence. YouTube was used to break silence and speak out.

I wanted to talk about group homes. Why I want to talk about group homes is because bad things happen in group homes. Sure do. Bad things happen at group homes (Latrice Allen latriceallen@live.com, 2014a).

This place sucks. Yeah it really does. This place is so fucking bad (Mark Cinque, 2019c).

Some groups of people are more vulnerable to violence. Women with disabilities are more vulnerable to intimate partner violence (Sasseville, Maurice, Montminy, Hassan, & St-Pierre, 2020). YouTube captured stories about management using violence to scare, intimidate and control residents of group homes. A video titled, "Chased and run off the road by group manager" described being intimidated, physically assaulted and chased by her previous group home manager the first day of

entering a new group home. The resident described being traumatized and violated when trying to escape from her previous group home manager.

So she is like aggressively pushing me. She runs me off the road and into the parking lot and I stopped in the parking lot trying to figure out where I am because I'm disorientated at that point (Vicious x Cycles, 2015a).

I'm like having a mini panic attack while I'm driving (Vicious x Cycles, 2015a).

Being utterly terrified, police were called. The woman continued to describe how she called police but when police attended, there were no consequences or charges. Reaching out to authorities for help proved useless.

So when the cops finally get there, they pull us into a parking lot and try to explain what happened and they end up just cutting everybody loose because they can't get angry at her or she didn't actually do anything wrong I guess, by chasing us down and beating on my car (Vicious x Cycles, 2015a).

The individual with disability explained that police failed to assist her when she called for their help. Law enforcement's role reinforced the powerless position the resident experienced.

If I had of accidently hit her, I would have gone to jail (Vicious x Cycles, 2015a).

The resident believed that had she reacted to the violent behaviour from the manager, she herself would have been punished by authorities. The group home resident was silenced when not believed. She processed this reality on YouTube. The disability community experience violence almost twice that of the general population and represent a third of people killed by law enforcement officers (Perry & Carter-Long, 2016). People with disabilities are also arrested and incarcerated at a higher rate than the general population, with the incarcerated and arrested nearly three times as likely to have experience disability compared to the non-incarcerated population (Vallas, 2016). "Ignoring the systemic and intertwined roles of ableism and intersectionality further perpetuates the status quo of oppression" (Mueller et al., 2019, p. 709). It was understood that violence from staff was accepted, but any



retaliation from residents was reprimanded. When police were called, backlash was experienced towards men and women with disability by staff.

One of the residents is being kicked out. She has to be in a high level care facility due to her outbursts (Latrice Allen latriceallen@live.com, 2017d).

Experiencing violence and faced with the hopelessness of being silenced, moving out of the group home was often the only option for residents living within the group home, seeking safety.

This house where I'm at, it's been stressful. So now I probably have to do another move out to, I guess, their Copolay house (Latrice Allen latriceallen@live.com, 2018c).

I know of a recent one who ran away due to the same shit going on right now. They still haven't found her and they're not going to. Because I'm about tempted to do that too. In fact she's the one who taught me how to do it and I'll gladly do it because it got her safe, it can get me safe too (Voices4 allneeds!, 2018b).

I am choosing to leave the group home. I'm not sure when because I have to find another place to live. Maybe with my boyfriend, we'll see what happens but I'm choosing to leave the group home, and move back into my own place because I want more freedom and I want more privacy and I just want to be left to do my own thing and I just want to be left alone. My parents disagreed with my decision to leave the group home so they went over my head, went into my bank account and paid for the rent and stuff like that. Now this makes me really angry because my parents know how I feel about the group home. They know how I'm struggling to adjust to it (Rebel Fighter, 2018a).

I have some big news that I am officially moving out of my group home in a year and a half and I am so excited about that and so yeah you will be seeing a lot more vlogs about to come maybe as soon as I move in and I might give a tour of my apartment. I think it's going to be in Pittsburgh but they haven't really decided where to build it so I'm on the waiting list for it so I hope I get

picked and get to move in out of my group home finally, away from the chaos and crap over there (Official DeerFire, 2016).

The data set revealed that men and women with disabilities living in group homes used YouTube to reveal to the public the violence and abuse they experienced from staff. Disintermediated videos were chosen because people could talk freely and truthfully about their experiences. The mode of speaking into a camera has advantages to people who may be challenged with technology, spelling and literacy. There was an ease in speaking into the camera. This was uploaded onto YouTube and made public. Individuals revealed that their group home experience was unpleasant and they would not recommend to others to live in a group home. Providing feedback about the group home on one's own terms is a benefit for the unobtrusive researcher inquiring about the group home experiences for people with disabilities, their families and carers. Information made public was free from influence and directly from the individual themselves. Despite the group home living arrangement, this material demonstrates that people with disabilities continue to feel isolated and lonely within their own homes.

Silence is considered a predicament of disability and an essential component to be considered when understanding why people with disabilities use YouTube to disclose experiences of violence, abuse and neglect. YouTube enabled dominant disability ideologies to be challenged and silences broken. I have discussed how people with disability challenge ableist ideologies with YouTube. YouTube empowered people living with a disability in a group home by giving them access to a space where they had power, control and freedom to speak their truth without silencing. I will now discuss how what may be deemed challenging behaviour is actually an effect of the silences produced by ableism.

### Ableism challenged through resident behaviour

Group homes are workplaces for able-bodied staff and are spaces dominated by ableist ideologies. The professionals maintaining the group home and the professionals that are engaged in the care of people with disability are engaged for their expertise. This reinforces their ability and the dominant ideology of ableism. The dominance of superiority is reinforced through this expert knowledge power

hierarchy. Several professions are connected with the group home including “physicians, psychologists, nurses, social workers, speech and language therapists and others engaged in regulating the lives of disabled people” (Nunkoosing & Haydon-Laurelut, 2012). Expert-knowledge reinforces positions of power held by staff towards group home residents. “Where there is power, there is always resistance” (Nunkoosing & Haydon-Laurelut, 2012, p. 202). People with disabilities often challenge the beliefs imposed upon them by able-bodied staff.

Through this expert-knowledge, staff are responsible for writing case notes and making referrals to experts for behaviour that is considered challenging (Nunkoosing & Haydon-Laurelut, 2012). A discourse exists within the house that problematizes residents and keeps them in a position of being troublesome (Nunkoosing & Haydon-Laurelut, 2012). In an environment where staff hold power, residents must submit to the will of the staff. If they contest the dominant discourse in the home, this is deemed resistance and troublesome, or ‘challenging behaviour’. ‘Challenging behaviour’ is problematized, and referrals to experts are made to draw upon their expertise to pacify such behaviour. Residents that disagree with authority are silenced to comply with the dominant discourse and with the staff that hold the power. Silence is reinforced by the group home structure and the conceptualization of ‘challenging behaviour’. The law supports the use of violence to manage this power imbalance and submission to authority through the use of restrictive practices (Steele, 2017). It is these professionals that determine the restrictive practices that are enforced upon people living with disability within the group home. Restrictive practices are non-consensual interventions towards people with disabilities. Individual human rights activate choose, self-determination, privacy and freedom, and are potentially limited by restrictive practices (Hext, Clark, & Xyrichis, 2018). A large proportion of people with intellectual disabilities living in supported accommodation display challenging behaviour (Murphy & Bantry-White, 2020). People living within disability group homes are constantly being watched by the workers dominating their space and this constant observation can restrict the freedom of residents living within that space.

The only time I recommend a group home is if you need twenty-four hour care and you need a long term nursing home kind of setting otherwise I would

never suggest anyone come into a group home. Just because the lack of privacy and everything is just ridiculous (Rebel Fighter, 2019b).

The biggest issue in the group home is privacy and freedom, because they want to know where you're going at all times. I understand why. Because a lot of the people in here are mentally challenged. So I understand the rules I just don't feel like I need them (Rebel Fighter, 2018e).

The reason why I'm looking back on my shoulder is because I don't want certain people around me listening. It's kind of like a private matter. I'm trying to make this as quick as possible (Latrice Allen latriceallen@live.com, 2018a).

I have social anxiety so I'm not able to have any privacy. It's killing me. I feel like I'm being smothered and I really don't like to have to follow a certain set of rules. Now I understand the rules are being respectful to others and stuff like that but for example, I can't sleep in in this group home because breakfast is at nine and they want you down there and they bug you and they bug you and they just won't leave you the fuck alone sometimes and it really pisses me off (Rebel Fighter, 2018e).

Men and women living in group homes were constantly being observed by the able-bodied staff and were required to comply with the structure in which they found themselves. What it means to be a person is reinforced through the hierarchy of power within the group home. The staff in the group home reinforced normalcy through knowledge about how people with disabilities should be living their lives. Residents needed to accept their place as inferior to staff. This often meant that people with disabilities needed to give up their own personhood to submit to the will that was imposed upon them.

Group home residents governed by ableist agendas did not always ascribe to this ableist logic. Feelings of a loss of personhood surfaced through behaviours that were considered challenging, as dissent from normalcy could result in disruption. People living with disabilities may challenge the notions of ability, disability, normalcy and abnormality held by the able-bodied people getting to know them (McLean, 2011).

This challenging of normalcy may be interpreted as behaviour which challenges authority. Behaviour that challenges authority can be deemed 'challenging behaviour'.

Challenging behaviour is often too much of something: too much anxiety, too much agitation, too much answering back, too much noise, too much aggression, too much seeking isolation, too much unwanted emotion, too much anger, too much love. Not enough obedience, not enough talk, not enough sociability are also challenging (Nunkoosing & Haydon-Laurelut, 2012, p. 198).

Troubles are a normal part of life but for the person with the intellectual disability, they themselves are seen as trouble (Dowse, 2017; Nunkoosing & Haydon-Laurelut, 2012). The person with the disability was positioned through dominant discourses reinforced by staff holding authority in the house. Residents may have desired a lifestyle that conflicted with the way staff wanted them to live. Residents had to submit to the expert-knowledge imposed upon them or conflict was experienced.

I used to punch metal walls and dent them. That's how bad it was at my old group home, but that was way back in 2011 to 2012 (Voices4 allneeds!, 2018c).

She thinks that she can belittle me. So I crack a whip (Jose Baez, 2016).

Nunkoosing and Haydon-Laurelut (2012) argue that the order reinforced or imposed by group home staff strips residents of their identity, which residents then had the power to resist authority and maintain a sense of personhood. Fighting to maintain a sense of personhood may underlie the resistive behaviour from residents within group homes. In an attempt to reinforce their individual personhood, residents may be labelled as problematic and troublesome. In order to keep control of the environment that is subjected to ableist views, restrictive practices are used. These restrictive practices are supported by the law (Steele, 2018). Challenging behaviour is more common in people with learning disabilities, dementia, mental health problems, those with acquired brain injuries and other intellectual impairments (Hext et al., 2018). The assignment of an impairment with challenging behaviour links biological difference with abnormal behaviours that classifies individuals as disruptive, dangerous and disturbing (Dowse, 2017). Unmet needs and communication difficulties can result in challenging behaviour and is not necessarily

a result of a clinical diagnosis (Hext et al., 2018). Behaviour that attempts to maintain a sense of personhood may be defined as challenging by dominant hierarchies of knowledge.

Hierarchies of knowledge carried by the able-bodied staff dominated the group home environment and people with disabilities found themselves in a position where they were problematized when speaking up for their personhood. The response to challenging behaviour is to direct a person's behaviour away from abnormality towards normalcy (Dowse, 2017). This reinforces dominant ableist ideologies and silences the person living with disability. Restrictive practices are permitted under the guise of keeping vulnerable people safe and service providers having a duty of care to do so (Dowse, 2017). Restrictive practices can exasperate challenging behaviours, and that is why there is the need for good de-escalation techniques adopted by staff (Hext et al., 2018). Challenging behaviour should be approached as an understanding that something in the person's environment is unsettling for them. Access to multimodal devices and uploading content on YouTube was demonstrated as being a tool that residents used to challenge dominant ableist ideologies imposed within the group home, and resist being dominated by group home staff. Having an outlet for resistance and maintaining a sense of personhood without disrupting the equilibrium of the house, could be understood as a benefit of YouTube in the lives of people with disabilities. YouTube may deflect the need for residents to challenge.

Behaviour that is considered challenging by able-bodied staff and experts is often men and women with disabilities communicating that something is upsetting them. People with disabilities have long been othered and their voices silenced in matters pertaining them. YouTube has been used by disability group home residents to challenge dominant ableist ideologies and resist being dominated by staff. Men and women with disabilities disclosed experiences of violence, abuse and neglect from living within the group home environment. The benefit of YouTube accessibility for people with disabilities is that the individuals were in control of the content uploaded onto their personal channel. The strength of using this data set when considering theoretical understandings of challenging behaviour is that the voices of men and women with disabilities are included and considered in the theorization of group home violence, abuse and neglect.

## Silenced through lawful violence

It gets so bad and I don't have rights anywhere (Voices4 allneeds!, 2018c).

Group homes are restrictive in nature and are places that violate human rights for people with disabilities. People with disabilities are subjected to violence that would otherwise result in criminal punishment, had the victim not been disabled (Spivakovsky, 2018; Steele, 2017, 2018). Restrictive practices are non-consensual interventions that Steele (2018) considers violence towards people with disabilities. When restricted practices are regulated, it means that any civilian that experiences harm at the use of them cannot seek criminal or civil recourse for their use (Steele, 2018). Acts which constitute unlawful violence under both criminal and civil law is permitted by disability-specific lawful violence under the restrictive practice framework (Steele, 2018). For example, the absence of consent is found to be a defining element of unlawful violence (Steele, 2017, 2018). Violence against people with disabilities that occurs in institutional settings such as group homes, mental health facilities, aged care facilities, schools, is often considered 'institutional violence' (Steele, 2017). The use of restrictive practices might be understood as 'systemic violence' because it exists at the intersection of the institution and 'challenging behaviour' (Steele, 2018). When restrictive practices are regulated by a legal framework, this positions restrictive practices beyond the legal definition of unlawful violence and beyond legal liability (Steele, 2018). Restrictive practices are not freely supported by international law.

International human rights developments through The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) enacted in 2008 provides a compelling basis for restrictive practices to be categorised as violence against people with disabilities (Steele, 2017). UNCRPD's approach to disability is a shift away from the medical model and recognises the role of stigma and social barriers in the creation of inequality experienced by people with disability (Steele, 2017). Article 5 acknowledges non-discrimination and equality as human rights themselves, while Article 16 recognises the responsibility on states to protect people with disabilities from violence. Article 12 recognises the right of people with disability to have legal capacity and Article 17 provides for the right of personal integrity. Steele (2017, p. 6)

states that “it is arguable that UNCRPD itself signals a shift towards viewing restrictive practices as violence which is contrary to international human rights norms” (p.6). Steele (2017) argues that restrictive practices should never be state sanctioned against anyone, including people with disability.

The lower legal threshold of violence in relation to restrictive practices reflects a devaluing of disabled bodies and lives (Steele, 2017, p. 7).

Disability group homes were places where violence was used by staff and violence was supported by the system. People with disabilities were silenced because their experiences were not validated.

And you know what, the thing is everybody thinks oh we will call in the authorities and they will do everything. But the group homes are majority made up of mentally ill people and substance abusers and convicts out of jail and when the police and the medics arrive they’re going to listen to the fricken staff! (Max Sparrow, 2017).

Residents with disability used YouTube to disclose experiences of group home violence reinforced by the power structures and dismissed by the authorities. In a powerless position, YouTube provided an opportunity for individuals to express how they process their truth.

Now I one time was up a night and an employee came in. He threw a chair at me and then he started hitting me with it and I ran for my phone and I started calling police. And he laughed and he said the police aren’t going to do a damn thing. And you know what, he was right! The police weren’t going to do a damn thing. We went downstairs and the police told me to you know just continue. The next day I find out he was high on cocaine (Max Sparrow, 2017).

I’m not just in danger, everybody here is, due to how they’re being treated (Voices4 allneeds!, 2018c).

These residents expressed understanding that they were disempowered and silenced by the system. YouTube was used to express their silence, demonstrating how YouTube was a tool that empowered their voice as they exercised complete control



over it. While residents expressed the belief of being oppressed by the power structures and powerless in their environment, YouTube was used to break the silence. YouTube allowed residents to break the analogue silence and speak into a digital space.

They call me manipulative and a liar. I think they should look into themselves because that's quite the opposite. I'm fighting for what I know is right and if that's wrong, then they need to suck it up and deal with it and change it then, because I'm fighting for what's right and I deserve to live in a healthy, safe, by the way which means no violent people, no yelling, no assaults, no nothing, but I do not here (Voices4 allneeds!, 2018b).

When violence towards people with disabilities is lawful, it creates a culture of silence and oppression. Oppression is taken for granted and legitimized by the system of restrictive practices, which would otherwise be considered violence under the law. Violence is expected within the group home environment and the use of violence to control people with disabilities, mitigated through restrictive practice legislation. Individuals within group homes used YouTube to break the silence and reveal the injustice they experienced within the group home. YouTube was a tool that empowered their voice in the midst of an environment of oppression and hostility.

### Accessibility as a safeguarding measure

All these things are happening behind closed doors (Jose Baez, 2016).

Violence against people with disabilities is a violation of human rights and is a significant public health issue (Araten-Bergman & Bigby, 2020). This serious issue is often hidden and goes unreported. Group home violence, abuse and neglect occurs within the confines of the group home environment. Dominant disability safeguarding approaches focus primarily on responding to individual cases of maltreatment rather than developing a culture of prevention and protection (S. Robinson & Chenoweth, 2012). These approaches are not focused on solving the problem, but rather reacting to the incident after it has already occurred. Violence prevention in the disability field have policies that are more reactionary rather than preventative (Krug et al., 2002). The violence that men and women with disabilities

experience is further compounded by the multiple intersecting forms of discrimination they experience, based on their impairment and challenging life circumstances (Fraser-Barbour, Crocker, & Walker, 2018). The difficulties associated with reporting abuse, challenges in the justice system, dependence on carers and a greater likelihood of living in supported accommodation, contributes to greater vulnerability of people with disabilities (Beadle-Brown, Mansell, Cambridge, Milne, & Whelton, 2010; Didi, Soldatic, Frohmader, & Dowse, 2016; Hutchison & Kroese, 2015; Sobsey & Doe, 1991). People with disabilities are at risk of harm living in group home environments.

Adult safeguarding refers to “laws and policies that enable protective state responses to situations where particular adults are, for any of a number of reasons, at greater risk of harm than general members of the population” (Chesterman, 2019, p. 361). Adults that are at greater risk of harm from the general population include with cognitive impairments that are isolated from the community. This research demonstrated that YouTube was used effectively by men and women with disabilities, their families and carers, to disclose the experiences of group home violence, abuse and neglect. This counter-attacked the isolating factor of vulnerable groups that are at greater risk of harm. When residents of group homes themselves used YouTube to report malpractice, this itself became a tool for safeguarding the disability sector. Individuals used YouTube to expose to the world outside of the confines of their group home environment that circumstances that were hidden needed to be revealed. Violence, abuse and neglect was occurring in the confines of the group home and out of public view. These harmful experiences threatened the safety of residents trapped within the group home. An understanding that group homes were places where abuse was perpetuated was evidenced in the data set.

Lucy touched my arse and everything so I know that they do things to girls here (Latrice Allen latriceallen@live.com, 2017i).

These people in the group homes have perspectives that are very limited. They're used to abuse (Max Sparrow, 2017).

Residents used YouTube to express care and concern that malpractice was occurring towards other residents within the group home. People within group homes that had been exposed to years of abuse were reported as not knowing any different. They were described as accepting the abuse and maybe not even knowing that they were living in a difficult and unjust situation. Speaking out on YouTube became a safeguarding tool and a means of reporting suspicious and troubling behavior. YouTube was evidenced as a tool which was used by individuals with disability living in the group home to disclose sexual harassment and inappropriate behavior from service providers.

I'm already squealing now so to you out there who works for the Government, please check our Aleanabono Houses (Latrice Allen latriceallen@live.com, 2017h).

Anyone watching who is county or state or government that can and would be willing to help me? Please do! (Voices4 allneeds!, 2018b).

So whoever see this, do something please? Remove me. I'll gladly send you emails. Just ask for it. I have emails and I'm ok to move out again. This is what I live in everyday, all day and I fear for my life, health and safety here. I want to be removed. I have asked to withdraw services and no one does anything. So if anyone's watching from the government, or federal, or state, please help me (Voices4 allneeds!, 2018b).

Something has to be done. I'm going to still fight to make sure all group homes get checked into by state and government officials that run health and safety (Voices4 allneeds!, 2018c).

Residents stated their intention of documenting their experiences of violence, abuse and neglect on YouTube. They were hoping that their video would be viewed by someone that could help them. Men and women with disabilities living in these hidden environments held hope that their stories would reach people in offices of power that could intervene to change their situation. They held hope that YouTube could be used to capture the attention of the world outside the confines of their group home. According to Chesterman (2019), a key core principle that should guide

future adult safeguarding reforms is that a person's wishes must be key to any investigation. The data set captured footage of men and women living in group homes requesting that their experiences be investigated. YouTube as a public platform not only provided hope that individuals were not trapped alone in their distress, but an indication that circumstances needed to be investigated. The content of YouTube videos created by men and women with disabilities revealed information that was serious in nature.

Anyway, just to get funding to keep them going. The sticky part, the part that's funny but not as much, the department doesn't know that there were at least two deaths on the property. One here and one at another house cos if they knew they would have shut it down pronto. Steadfast is covering up a lot of information and a lot of stuff but especially around when people die and pass away (Latrice Allen latriceallen@live.com, 2015a).

It is difficult to determine the accuracy of these incidents, but the information disclosed would warrant further investigation. YouTube, being a public platform, could be accessed from the privacy of a group home. This meant that men and women with disabilities living in these group home environments had access to the outside world even if they could not leave their premises. The videos were sometimes used as a plea for help from anyone watching them.

So whoever sees this, do something please? Remove me. I'll gladly send you emails. Just ask for it. I have emails and I'm ok to move out again. This is what I live in everyday, all day and I fear for my life, health and safety here. I want to be removed. I have asked to withdraw services and no one does anything. So if anyone's watching from the government, or federal, or state, please help me (Voices4 allneeds!, 2018b).

YouTube was used by residents to expose and uncover any hidden workings which the company was hiding. This showed that residents did not trust the organisation and that circumstances and events were being covered up. According to Chesterman (2019), there must be reasonable suspicion that an at-risk adult is facing harm before authorities will force entry into the situation. The content recorded by residents and

then uploaded onto YouTube provided evidence that vulnerable adults were at risk of harm. The YouTube footage could be used to support forced entry and investigation into group homes where there was suspicion of violence, abuse and neglect.

What is it that we can do? What is it that we can change? And I tell you what. I'm not because I'm not going to put them out like that because I'm putting this on Facebook and I hope it goes nationwide (Rapheal Hardwick, 2015).

Men and women may be disempowered in the group home, but social media gave them a sense of power and control over their circumstances. While they may have felt like they were unable to change their situation, having access to a global audience through social media and the internet gave them a sense that they could make change. They held hope that their voices empowered by social media could make a difference to their situation.

I just listen so I can observe what they say every time they ask me something or say something, it is recorded. I have videos, pictures. I started doing a daily blog. In the life of a vulnerable, behind closed doors group home. How are they ok to do this? (Voices4 allneeds!, 2018c).

In the future, if there's something going on, I'll post it up on YouTube because if my rights are violated because I want to tell the truth, there is freedom, the door is open. I'll let the smell get out of the damn house for whatever is happening here (Jose Baez, 2016).

I'll show you the letter so at least I have proof on my daily vlogs of this stuff (Voices4 allneeds!, 2018c).

Hopefully I can provide the evidence that is needed (Jose Baez, 2016).

Residents used disintermediated video to capture evidence to expose the injustice they were experiencing. Sometimes the environment that they were forced to live had impacted their health and caused sickness. It is transparency that provides a safe environment for vulnerable communities. YouTube and internet access – when

aligned - enables transparency and accountability. Power relationships shift and are reconfigured. The 'customer' of disability services can speak.

Resident - (Speaking to staff member – unaware of being recorded) Why can't I sign for and have my money?

Staff (yelling angrily) – I didn't fricken say you couldn't have it, did I? I'm taking my meal break, you've had yours.

Resident – I didn't say it like that. I was just asking nicely.

Staff – No you weren't. Why can't I sign for my money? If you think I'm going to jump up when you say jump, you've got another thing coming.

Resident – Alright then (Trenton Lopez, 2019).

Indisputable evidence of staff speaking aggressively to residents with disability and being unresponsive to requests was captured on film. The public nature of YouTube enabled these injustices to be broadcasted publicly. Staff were recorded using aggression, dominance and hostility. Staff were recorded delaying when asked to meet the needs of individuals with disability. Residents used disintermediated video to show the world that their needs were not being met and that staff were unhelpful in their approach. Other mistakes caused by neglectful practices were disclosed on YouTube.

She was giving meds from an absent patient to a different patient. So she was mixing up people's meds (Vicious x Cycles, 2015c).

Staff making errors with medication was disclosed in the videos. This error could not be covered up when residents were reporting it directly. Staff negligence was documented by individuals using YouTube. The disintermediated videos were used to show the reality of living within the group home.

Why am I still living with toxic by the way, black mould? I have looked up the difference between black mould and toxic black mould. That is why I've been so sick in here. Nasally stuffed up, swollen throat, nausea, severe headache (Voices4 allneeds!, 2018c).

The health and wellbeing of vulnerable community were at risk. Social media provided a way of communicating with the outside world the unsafe reality that residents were subjected to. When health is at risk, social media served as a tool for safeguarding the health and wellbeing of individuals with disability isolated within group home accommodation. They could report the incident freely and on their own terms, without the risk of retaliation. Men and women living in group homes were a vulnerable population. They often needed a guardian to make decision on their behalf and advocate from them. YouTube captured evidence of the difficulty that men and women with disabilities encountered in attempting to engage with their legal guardians.

Let's see, I have debt, civil rights, family law with my guardian because she's been aware of this and in fact has allowed this to happen and what I have researched on reliable government sites and state sites and county sites, a job of a guardian is to protect the vulnerable adults or person. To protect their needs, their wants and safety. She has done none (Voices4 allneeds!, 2018c).

Barriers in accessing the legal guardian increases isolation experienced by men and women with disabilities. This contributes to an environment where violence, abuse and neglect can be perpetrated. Residents within group homes experienced difficulty communicating with their guardians and were therefore left feeling unprotected and unrepresented. This demonstrates the need for further safeguarding measures to be implemented.

I think many laws and rules and regulations are at this home, then why are they still up and running? I know why. The guardians will cover their hiding. I mean see the other clients' guardians are being told something different. But do they know the truth? If they knew the truth, they would be like oh god yeah. They would even, I guarantee you, they would try and help shut down the home (Voices4 allneeds!, 2018c).

Men and women with disabilities believed that their guardians were unhelpful and not privy to the truth about what occurs inside the group home. There was evidence that men and women with disabilities were using YouTube to document evidence

where they did not feel they were being heard elsewhere. The voices of people with disabilities has been missing from the research that is designed to protect them. By using the disintermediated voices of the disability community that disclosed their experiences and thoughts of abuse within the accommodation setting, a better understanding of what constituted violence, abuse and neglect was obtained. By using the visual data collected from men and women living in group homes uploaded onto YouTube, group home violence, abuse and neglect can be conceptualized, theorized, understood and investigated.

In this chapter, I presented the fourth and final main theme to emerge from the data set; that YouTube is used by men and women with disabilities to break silence. An integrated literature review was used to contextualize the findings within the existing parameters of disability theory. Silence was understood to be a predicament of disability, founded on inequality, discrimination and injustice. The impact of marginalization is silence. I argued that social media has been used by the disability community to challenge dominant disability narratives and for this reason, media has the potential to influence. I explained that people with disabilities, their families and carers, have access to and control over media content, and have used YouTube to challenge ableism. I used an integrated literature review to demonstrate that challenging behavior is often a result of men and women with disabilities resisting the ableist ideologies imposed upon in group home living. Further, I went on to explain how restrictive practice is actually lawful violence and therefore a major influencer of group home violence. I demonstrated how individuals often experienced fear from speaking out about their truth. I considered how YouTube was leveraged by the disability community to create online communities for friendship and knowledge sharing. Finally, I argued for the importance of internet accessibility as internet accessibility acts as a safeguarding measure for men and women with disabilities living in group homes. The next and final chapter of this thesis concludes the discussion, providing recommendations for further research and limitations to be acknowledged during this research.



## **CONCLUDING THOUGHTS: HOW THE VOICES OF PEOPLE WITH DISABILITIES CONTRIBUTED TO THE FIELD OF DISABILITY STUDIES AND SOCIAL MEDIA**

As leading disability scholar Shakespeare (2014) has confirmed, disability research does not need more highly theoretical concepts which are untethered to empirical evidence. The field of disability research needs to value the lived experiences of people with disabilities. This research shows that empirical evidence is available on the internet that can be summoned and leveraged in qualitative social research. From the confines of a group home environment, men and women with disabilities have accessed the internet and uploaded their experiences of group home violence, abuse and neglect onto YouTube. This content can be easily summoned by researchers at a low cost from anywhere in the world, regardless of covid19 social distancing measures, where the researcher has internet access. The disability community have demonstrated that they have implemented methods using the public domain of social media to publicly share information, advocate for, and challenge issues that are important to them that is free from censorship. The internet contains a wealth of existing information that is reflective and truthful. Social media data gathering methods need to be recognized and harnessed in disability research and by the social work discipline, social workers being bound by the ethical code to do no harm.

My original contribution to knowledge explored what people with disabilities, their families and carers, disclosed on YouTube about their experiences of living in group homes. This was deployed by using six different search term strategies to summon over one hundred disintermediated videos from the public platform, YouTube. Once videos were summoned and the content of the videos transcribed, a thematic analysis of the data set revealed four overarching themes. The four main themes that emerged from the data set was the neoliberal group home, re-institutionalization of the disability sector, harmful interpersonal experiences and breaking the silence of disability. An integrated literature review and my own personal lived experience of working within the disability sector helped me to make sense of the information and

position the data set within the themes. People with disabilities used YouTube to document their experiences of violence, abuse and neglect and to provide evidence of substandard living conditions that they were subjected to. Men and women were unified in their experiences that group homes were places that perpetrated violence, abuse and neglect. Group homes are dangerous places where people with disabilities feel unsafe and unfairly treated. Group home violence, abuse and neglect transcends national borders just as the internet transcends national boundaries. This research occurs at the intersection of disability and internet studies, to explore a systematic problem that is common across the world. The information summoned from YouTube revealed the frustration and disappointment that the disability community expressed from their experiences within disability group home accommodation.

My original contribution to knowledge investigated and acknowledged the benefits that YouTube offered people with disabilities. YouTube offers connection, community, advocacy and information sharing between the individual, their families and carers, and the world outside of the group home environment. YouTube is a public platform where men and women with disabilities have control over what they post, and therefore can speak about issues that they feel are important to them. As such, YouTube empowers agency. The public interface of YouTube is extremely empowering to a disempowered and vulnerable group of people that are often silenced and forced to fit into ableist systems. Such systems can be intimidating and restrictive. This research extends the current theorization of disability studies and social media. It demonstrated that the disability community are finding creative ways to use the internet to broadcast their truth and advocate for issues pertaining to them. The access to a global audience and the freedom over content posted makes social media, and in particular YouTube, an attractive tool for activism. Content can be used to challenge dominant ideologies and narratives of disability by the disability community themselves. The internet is a gateway to the world, and social media a method to a global audience. This research supports previous research in the field of internet studies that claim the internet has been recognized for its ability to broadcast globally and contribute to the grand disability narratives. This research extended previous research by demonstrating that collecting social media texts that already exists in the public domain is an unobtrusive research method that can be

used as a trauma-sensitive research method, rather than asking people to revisit experiences that were traumatic in nature. Reflective, truthful and explicit information already exists, as people have revealed their stories publicly in their own time, in their own terms. This makes a social media research for researching traumatic and sensitive issues ethically sound.

This research confirmed the strengths that unobtrusive research methods offer research into people with disabilities. This research demonstrated that YouTube as an unobtrusive research method was effective to explore the experiences of disability group home violence, abuse and neglect using the voices of people with a disability themselves. Too often men and women with disabilities are missing from the research that is about them. The videos summoned from YouTube during data collection demonstrated that men and women with disabilities, their families and carers, used multimodal devices and created their own content that disclosed experiences of group home violence, abuse and neglect. Interviews were not required to gather qualitative, information rich data. The data already existed and search term strategies were deployed to gather the data set. The authors of the content chose to disclose their experiences publicly, and this content was public material, proving to be useful for research into this topic area. The disintermediated videos summoned were then uploaded onto public YouTube channels and made available to the online community. Videos summoned from YouTube captured individuals' personal lived experiences. Men and women spoke on their own terms and in their own time about issues that were important to them. Evidence was captured on video of substandard living conditions and maltreatment from staff. This evidence was uploaded to YouTube and made available on the public global domain. This domain transcended national boundaries and could be accessed from anywhere in the world, the determining factor being internet accessibility. Internet accessibility provides vulnerable communities with access to the public outside the confines of their environment. I have recommended internet accessibility as a safe guarding measure to protect against violence, abuse and neglect of people with disabilities. YouTube as a trauma-sensitive research method into the topic of disability group home violence, abuse and neglect. There is a wealth of information about group

home violence, abuse and neglect that is available on YouTube, created by people with disabilities, their families and carers.

Using YouTube in social research has many benefits and advantages compared to other obtrusive research methods. Disintermediated videos uploaded freely by the author of the channel are available in a public domain and therefore, the data is public material. This research demonstrated that rich and reliable information can be sourced from YouTube, but without the downfall of the Hawthorne effect. Content summoned from YouTube was information rich and suitable for qualitative research. Disintermediated videos available on YouTube have the advantage of being cost effective and quick, compared to interviews that can be time consuming and costly. Because the data were public material and able to be summoned from the comforts of the home, the research was exponentially quick and easy. These benefits of using YouTube content in qualitative social research should be taken advantage of.

My original contribution to knowledge assessed how the information that was revealed on YouTube affirmed and extended the existing theorization of disability group home violence, abuse and neglect. The data set already existed. Men and women with disabilities across the world have spoken on their own terms and disclosed their truth regarding their experiences. Their narrative could be trusted. The narrative and personal lived experience of men and women with disabilities was valuable and the use of the content that they have created in this research highlights how valuable it was. The voices in these disintermediated videos stated that they were honest on their channel and felt free to speak their truth. This research demonstrated that the method of disclosing experiences on social media could be more reliable than discussing traumatic experiences in an interview. These are the people who are impacted by the violence, abuse and neglect carried out against them. The information woven amongst existing disability literature affirmed and extended the literature itself by using the voices of individuals with disabilities, their families and carers. Group homes were confirmed to be unsafe places where violence, abuse and neglect was often hidden and perpetrated against the vulnerable living within them. Families were often in a space where they felt powerless to help and turned to YouTube to publicly expose injustices and advocate for help.

Individuals that were trapped within their group home environment were able to access the internet and uploaded content publicly about their group home experiences. Family members used multimodal devices to record their frustrations and uploaded this content to YouTube. According to the information available on the internet and the sheer scope of people with disabilities, their families and carers, contributing their own material on their own terms to public platforms, disability studies cannot ignore the benefits that social media offers research into people with disabilities anymore. For too long the voices of the ones who are impacted have been missing from matters concerning them. This includes the discussion about group home violence, abuse and neglect.

This research demonstrates that there is a large amount of content readily available about disability group home experiences available on YouTube. Powerful representations of disability can occur at the intersection of disability and social media. This research proves that the internet is underutilized in the field of disability studies. The information available on the internet should be summoned for research. This research proves that excluding people with disabilities from the theorization of disability studies is no longer an excuse. Men and women with impairments are finding ways to communicate with people and are creating connection and communities in the online environment. Excluding people because they may have communication difficulties or cognitive impairment is no longer a valid excuse for omitting the voice of people with disability from disability studies. This research demonstrates that the disability community have found creative methods using social media to expose their experiences of injustice and advocate for themselves. This research proves that people with disabilities are capable of challenging dominant narratives that serve to disempower and further oppress them, by sharing their experiences about how the dominant groups have participated in creating disabling environments. Innovation is critical to ensure the most vulnerable communities across the globe are reached.

Chapter 1 highlighted the importance of disability studies incorporating information available on social media into the existing theorization of group home violence, abuse and neglect. The internet matters in social research because the internet has a plethora of information that can be accessed from anywhere in the world with

internet accessibility. The boundaries between the online environment and the real world do not exist and the information available online is a reliable representation of what is occurring offline. Probing the accuracy of data is an opportunity for social researchers to utilize and incorporate it in research. The internet and social media have a global audience, and people from anywhere in the world can contribute information.

Chapter 2 demonstrated the importance of adopting a critical realist approach to disability. The ableism problem mattered because it underpinned the discussion of disability in this research. A theorization of disability must include the history of how disability has been conceptualized, and this is the reason for inclusion of the medical and social model of disability into the discussion. The field of disability studies has evolved over the years, as the importance of including the voices of people with disability in theorizations of disability has been increasingly advocated for and recognized. As the complex experiences and sufferings of the disability community have been valued, the critical realist approach has become more suitable to understand disability.

Chapter 3 argued for unobtrusive research methods to be adopted in the field of disability studies, and more specifically, by social workers. Unobtrusive research methods matter for the social work discipline because of the empowerment and safety that it provides to vulnerable communities. Social workers are bound by the ethical code of conduct to do no harm. If there is a way of conducting research that does not traumatize people, social workers should always give preference to that method. Unobtrusive research methods are underemployed in the field of social work. YouTube especially is an attractive method of contributing information, as users simply record themselves and then upload the content of their choice to a public platform. Their data, once reaching the public, is free from censorship and also free from the Hawthorne effect. Ethics in research can slow down and limit researchers. The benefit of using public information available on social media is that it is considered public material and therefore ethics does not need to be applied for. This makes this style of research incredibly attractive for researchers and is highlighted by the discussion on ethics. In times of coronavirus when social distancing was enforced, this social media research was especially attractive. The research was not

impacted by the global pandemic. The data were simply summoned from the internet.

Chapter 4 highlighted that disintermediated videos are rich sources of information when researching disempowered groups, including the disability community. Disintermediated videos summoned from YouTube matter in social research because the media and able-bodied narratives have dominated social issues. Disintermediated videos remove the power of the dominant group and this needs to be acknowledged and recognized. This research does just that. It acknowledges the power that disintermediated videos offer people that have been dominated by others. This research extends the current theorization of group home violence with the first-hand experiences and narrative of people with disabilities, their families and carers. The unobtrusive aspect of this data collection method makes the data more reliable. Unobtrusive data sets are free from the effects of the interviewer present, therefore free from the Hawthorne effect. When uploading onto YouTube, men and women say freely what they want about their experiences. They are not saying what they think someone might want to hear and they are not refraining for fear of retribution.

Chapter 5 affirmed and extended the current theorization of disability violence, abuse and neglect by acknowledging the impact that neoliberalism has on the wellbeing of people with disabilities and creation of harmful environments. Using content created by men and women with disabilities in the theorization of neoliberalism and the group home environment matters because the disability community has been directly affected by neoliberal policies, and that impact needs to be considered. While neoliberal ideologies guise as a means to empowerment and giving people with disabilities control of their life, the findings reveals that men and women with disabilities are disadvantaged by neoliberal ideologies. Men and women believed service providers to be in the market only for the money, therefore foregoing the caring nature of caring of the service sector. This is a weakness of losing the welfare system and moving disability services into a neoliberal market.

Chapter 6 affirmed and extended the current theorization of disability violence, abuse and neglect by arguing that people with disabilities have been re-

institutionalized by the disability sector during deinstitutionalization. Using content created by men and women with disabilities in the theorization of re-institutionalization matters because the disability community has been directly affected by deinstitutionalization. This impact needs to be considered as dehumanization has destroyed identities, belongings and communities. This research demonstrated that people with disabilities desire autonomy and to be acknowledged for their capacity to make decisions. This strengthens arguments in support of people with disabilities making their own decisions. The notion of normalcy presenting by the dominant ableist narrative was challenged. Dominant ableist discourse was challenged. People with disabilities desired privacy and control of their own affairs. People with disabilities wanted to be supported to achieve their own goals. This is difficult when notions of normalcy are imposed upon them through the group home structure. The findings from this research demonstrated that group home accommodation for people living with disabilities often perpetuate severe human rights injustices. While men and women with disabilities were often forced to share group home accommodation because of poverty and needing extra support, the very structure that was supposed to support and empower the vulnerable individual was the very structure that served to disempower, restrict and violate the individual. These findings matter because they were informed by the disability community themselves and included the uncensored voices of men and women with disabilities themselves. These data demonstrated that men and women with disabilities believed that group homes violated their human rights.

Chapter 7 extended the current theorization of disability violence, abuse and neglect by highlighting that social media research provided a gateway and access point for hard-to-reach environments. The very nature of institutional abuse is that other services are shut out. Social media empowered the voices of victims and gave them a social outlet to raise attention and seek help. Using content created by men and women with disabilities in the theorization of harmful interpersonal relationships matters because the disability community has been directly affected by these harmful relationships and were at the forefront of violence, abuse and neglect. Their lives were oppressed daily within group homes and family members felt powerless to help. Internet accessibility can no longer be thought of as a luxury item. Internet



accessibility for people with disabilities and other vulnerable communities must be acknowledged as a necessity. Accessibility enables communication with others and acts as a safeguarding measure against violence, abuse and neglect. It enables vulnerable communities to signal for help. Group homes are places where harmful interpersonal relationships are provided the opportune environment to breed and further damage people with disabilities. Staff wielded positions of power within the group home structure and this power can be equalized by residents having internet accessibility.

Chapter 8 affirmed and extended the current theorization of disability violence, abuse and neglect, by highlighting that men and women with disabilities are capable of breaking silences and challenging dominant disability narratives. Using content created by the disability community in the theorization of breaking disability silences matters because they have been demonstrated by using YouTube that they are able to challenge dominant disability narratives using social media platforms. People with disabilities are capable of speaking up about issues pertaining to them and have used YouTube to reach a global audience. Men and women with disabilities will not be silenced and access to the internet enables the amplification of their voices to a global audience. Internet accessibility has never been shown to be more important. When the internet is providing a safeguarding measure to individuals living in the group home, internet accessibility should be guaranteed for men and women with disabilities. The findings demonstrate that fear of retribution is a reason for people to remain silent about their experiences of group home violence, abuse and neglect. This finding is very interesting when combined with the data collection method. People with disabilities may refrain from speaking the truth in the presence of an interview. The researcher already holds a significant amount of power and when researching vulnerable communities, this imbalance of power is further exasperated. An unobtrusive research method removes the imbalance of power between the researcher and the researched.

## Recommendations

Men and women with disabilities require internet access and digital literacies as a human right. Individualized poverty means internet access is often denied. But this

research demonstrated the importance of individuals with disabilities and other vulnerable communities having access to the internet. The internet enables access to the outside world. How much different could Ann Marie Smith's case had been had she had accessibility to the internet and social media? Ann Marie Smith could have communicated with the outside world that she needed help. People with disabilities must be encouraged to engage spaces and modalities. Value must be placed on the benefits that social media offer. This research methodology suggests that there are creative ways to engage the existing narrative of people with disabilities in studies that are about them.

Social media must be valued in the field of social work and disability studies. Because of the nature of the work that social workers carry out, social work research is often exploring topics that are traumatic and sensitive in nature. Summoning YouTube videos as a social media interface in place of the time consuming and often re-traumatizing nature of face-to-face interviews, must be harnessed in social work research.

To enhance meaning making, further research into the area of group home violence, abuse and neglect using triangulation is recommended. Triangulating unobtrusive research methods with other methods in a qualitative design enhances meaning making (Auriacombe & Meyer, 2020). Combining data summoned from YouTube and combining it with interviews or surveys would strengthen the meaning making component of the research into this area.

Future work exploring people with disabilities' experiences of disability group home violence, abuse and neglect could be committed to extending the analysis of other social media platforms. Social media platforms such as Facebook and Twitter may be easier to access and require less effort when posting in terms of time and resources. An exploration of experiences of violence, abuse and neglect using a Facebook group should be considered to extend the analysis for further research.

### Limitations of research

Online research has several limitations. A limitation of this research is that YouTube content is constantly being updated. All studies investigating online platforms will

have this issue (Saffi et al., 2020). In 2018, when carrying out the data collection, I recorded the YouTube internet link and transcribed the content of each video. I did not, however, document other details that were needed when referencing the videos in the Bibliography. When writing my thesis at a later date in 2020 and referencing the quotations from the data set, I needed to return to the original YouTube video to gain other information to reference correctly. I discovered that three YouTube videos had been removed by the creator and two channels had changed their settings to private. These videos had to be removed from the data set because of referencing issues. A recommendation when carrying out YouTube for data collection would be to obtain all information required for referencing at the time of transcription.

Another limitation of this research is the search term strategy. The search term, “disability”, does not specify the nature of the disability. Ascertaining whether individuals have an intellectual disability was not possible. The search terms encompassed a wide scope of disabilities. This reflected upon the creator of the channel. This shows that people with disabilities choose what they reveal about themselves and they did not want to identify or define themselves as having a disability.

The research may be limited by digital capacity; that is the ability of people with disability to access and use the internet. Digital capacity contributes to the digital divide and produces a gap between internet users and non-internet users (Ragnedda, 2017). This is a complex phenomenon which is to understand by way of research is beyond the simple yes or no of access (Ragnedda, 2017). This research did not consider to take into consideration digital capacity. It is assumed that the users of YouTube and the group included in this study had access to the internet and possessed digital capacity. A limitation of this study is that participants all had internet access and were able to use YouTube and may be more technically skilled than many people who have disability. This research only captured the experiences of people who had digital capacity and were able to express their feelings and thoughts. While informative, the findings are not generalizable to all people with varying levels of disability.

Regional differences cannot be specified in YouTube. The location of men and women with disabilities could not be specified or targeted in this research. The use of English terms in the search term strategy limited the destination of videos sourced. Furthermore, the destination coverage could not be specified. Fast-moving technological advances have involved only a minority of the world's population (Ragnedda, 2017). Population groups excluded from the advances in technology are those in the developing world and those who are not part of the global economic elite (Ragnedda, 2017). For this reason, the findings are limited to the disability community that live in technologically advanced areas. Group homes that are situated in developing nations are not represented in this data set due to implications attributed to technological capabilities.

The advantages of using YouTube as a trauma-sensitive research method by social workers into issues of a sensitive nature outweigh any limitations that the research poses. The lived experiences captured on disintermediated videos of men and women with disabilities, their families and carers, created by their own free will and uploaded at their discretion into a global public space is valuable and information rich material that is truthful, honest and reliable. Group homes are places that can be hard-to-reach, especially in circumstances where violence, abuse and neglect is fostered by group home staff. This research demonstrates that internet accessibility can be an effective safe guarding measure for vulnerable communities that are isolated from the community and silenced by dominant narratives. YouTube enables agency and empowerment of such vulnerable communities. This research is especially valuable at a time when the safety of people with disabilities is of concern and the provision of disability services has transitioned from the welfare state into the market. As this research demonstrates, neoliberalism disadvantages individuals living with disability. An understanding into the issues impacting the disability community needs to be acknowledged and informed by the voices of men and women with disability themselves.

Not only does this research use the voices of men and women with disabilities, their families and carers, to affirm and extend existing disability literature, this research demonstrates the value that internet accessibility provides people with disabilities. Men and women with disabilities are using the internet and public interfaces such as

YouTube to build online communities and connection with others who may share their same struggles and life experiences. This method of connection has become a space where advocacy and information sharing is enacted. YouTube has been a space where dominant narratives and normalcy has been used to challenge routines, restrictions and injustice. Group home violence, abuse and neglect has been exposed and captured on video. While people's stories can be doubted or disputed, these images captured on video and uploaded onto YouTube provide evidence of the substandard living conditions that people with disabilities living within group homes are subjected to on a daily basis. YouTube enabled empowerment and agency of people with disabilities, their families and carers, to challenge the power and control of those in positions of authority within the home. The value of internet accessibility and the content uploaded by people living with disabilities in group homes must be acknowledged and leveraged in social research, especially by the social work profession.

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