Department of Child Studies (Tema Barn)

Linköping University

Doing disability online: Young people's negotiations of disability labels and identities

First Year MA Thesis (736A31)
15 ECTS

Sarah Mitchell

LIU-TEMAB/MPCS-A--15/004—SE

ACKNOWLEDGEMENTS

ABSTRACT

Historically, there has been little theoretically-informed research which focuses on the voices and experiences of young, disabled people without making use of adult proxies. The current study sought to address this gap in the literature by taking an inductive, constructionist approach to exploring how young people negotiate their disability labels and identities on an online forum called *Teenhelp.* I focused upon the Disabilities Forum of the website, using thematic analysis to analyse posts made between April 2012 and April 2015. From there, I selected ten posts for in-depth analysis. Some posters resisted disability labels while others actively sought them out and adapted them to their needs. The question of legitimacy was also significant, with some posters being unsure whether they really 'qualify' as disabled, while other posters policed the use of disability labels. The data also highlighted important identity questions relating to disability. For example, the extent to which a disability label influences a person's self-concept and what they believe themselves to be capable of. The theme of 'visibility' also came through in relation to disability identities. One of the posters had an invisible disability and used the forum to make her disability 'visible' to others. In contrast to this, a poster with a visible disability described how she sometimes tried to 'pass' as a non-disabled person (thus making her disability temporarily invisible). Overall, this research highlights the complex identity work involved with being a young, disabled person. It also shows that computer-mediated communication can provide a valuable virtual platform where such work can be performed with support and input from peers. Although disability labels have often been seen as harmful, this research shows that they can also give young people a sense of commonality and connectedness which can allow them access to a positive group identity and a potentially supportive community.

Keywords: *disability; youth; identity; labelling; social constructionism*

TABLE OF CONTENTS

INTRODUCTION

In this study, I use data from the *Teenhelp* Forum in order to explore the ways in which young people negotiate their disability identities online. Historically, the World Health Organization (WHO) defined disability using a three-fold distinction between 'impairment', 'disability' and 'handicap' as follows: "An impairment is any loss or abnormality of psychological, physiological or anatomical structure or function; a disability is any restriction or lack (resulting form an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being; a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that prevents the fulfillment of a role that is considered normal (depending on age, sex and social and cultural factors) for that individual" (WHO, 1976).

These definitions were highly problematic, and activists in the disability movement argued that the WHO had misunderstood the difference between 'impairment' and 'disability'. Instead, they proposed a 'social model of disability'. According to this model, impairment includes physical and sensory impairments and more recently, learning difficulties and mental health problems (Barnes, 1996 cited in Riddell and Watson, 2003, p. 3). In contrast to impairment, disability refers to the disadvantage and restrictions caused by the organization of contemporary society which takes no or little account of people who have impairments (Oliver, 1996, p. 22 cited in Riddell and Watson, 2003, p. 3). As McLaughlin and Coleman-Fountain (2014) put it, impairment is of the body, while disability reflects the social dynamics *around* disability.

The approach taken in the current study is that disability cannot be reduced to a health problem residing in the individual, but nor is it simply the result of oppressive practices and discourses (Shakespeare, 2006). Rather, disability arises due to the complex interactions between the person with the impairment, and their physical and social environment (Birkenbach et al., 1999). It is these 'complex interactions' which are of interest here. The study focuses on posts from an online forum which deals with a broad range of impairments. These impairments include physical impairments (such as blindness, deafness and paralysis), learning disabilities (such as ADHD and dyslexia) as well as conditions such as Asperger's Syndrome and other Autism Spectrum Disorders (ASD). What is important in this study is

not so much the impairments themselves, but rather the social dynamics around them and the ways in which these impairments come to be seen or framed as disabilities on the forum. In other words, the focus of the study is upon the ways in which young people *construct* notions of disability based on their perception of impairment and the ways in which they draw upon disability discourses to do so. At times, they may reproduce social norms, while at other times they may resist or reformulate them. The ways in which their impairment contributes towards their self-concept or a 'disability identity' is also a key focus of the study.

Research Aim and Questions

This study aims to explore the following how young people negotiate their disability experience and identity in online forum. As Watson (2012, p. 200) emphasizes, there is a strong need to explore the category of disability and how it impacts on children's lives in different ways. Following on from this objective, the study seeks to address the following two research questions:

1. How do young people respond to and negotiate disability labels?
2. How do young people negotiate their disability identities?

Theoretical Approach

In this study, I take an inductive, social constructivist approach. As Conrad and Barker (2010: S67) note, social constructivists believe that cultural and social factors influence the meaning and experience of illness. Conrad and Barker (2010) define social constructionism as "a conceptual framework that emphasizes the cultural and historical aspects of phenomena widely believed to be exclusively natural" (S67). While the study focuses upon the ways in which notions of disability are socially constructed, it also recognizes disability as an embodied experience. Since the data for the study are limited to what is available on the online forum, it is impossible to know the biological 'reality' behind the posts. However, what is of interest is the ways in which those biological 'realities' are constructed and presented in the online forum. The theoretical approach taken in this study allowed me to explore the layers of subjective, qualitative meaning expressed in the posts.

Rationale

The WHO estimates that there are between 93 and 150 million disabled children in the world (WHO, 2011), with 36% of all recorded disease and injury involving children under the age of 15 (World Health Organization/World Bank, 2008). Young people with disabilities often experience a dual form of marginalization – firstly on the basis of being young and secondly on the basis of their disability. The *New Sociology of Childhood* calls for a greater recognition of children and young people as social actors who deserve to have their views and perspectives heard (James and James, 2012, pp. 24-25). Similarly, *Critical Disability Studies* has highlighted that young, disabled people have often been excluded from being involved in decisions that affect them (Tisdall, 2003, p. 19). While research on children's gender, ethnicity and social class has become mainstreamed, research on disabled children remains marginalized (Watson, 2012, pp. 192-193). Studies which have looked at issues of children with disabilities have often included the voices of adults (such as parents and medical professionals) as proxies for the voices of the children themselves (Stalker, 2012, p. 173). There is also a lack of research which focuses on the social experiences of disabled children (Watson, 2012, p. 193) and on how impairments impact on individual children's lives (ibid, p. 195). The research in this field has also tended to be a-theoretical (Stalker, 2012, p. 174). There is thus an important need for theoretically-informed research which focuses on the voices and experiences of young people with disabilities.

Data and Methods

This study sought to access the voices of young, disabled people as directly as possible. Data from a website called *Teenhelp* were used, with a focus on the Disabilities Forum. Young people who are living with either physical or mental disabilities can post their questions and discussions on this forum[1]. These data were selected as an effective means of accessing young people's voices for several reasons. Firstly, the data are unsolicited and naturally-occurring. This means that the young people were genuinely able to express the issues and concerns which were on their minds rather than being guided or constrained by questions being posed by a researcher. Secondly, the data are completely anonymous. This means that people were able to express themselves without being influenced by 'social desirability bias' or concerns about their reputation. Thirdly, the data were communicated through typed text as opposed to relying on verbal communication. This point was particularly significant in cases

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[1] http://www.teenhelp.org/forums/ accessed 09.06.15

of, for example, Asperger's Syndrome where people may have found it difficult to express themselves in face-to-face interactions. Finally, the data come from young people from different social, cultural and geographic backgrounds and with different types of physical, mental and sensory disabilities. Thus, the study was able to draw on a broad and heterogeneous sample while looking for common points of interest.

This chapter has highlighted the research aims, questions and rationale of the study. The following chapter will provide an outline of previous research which has been conducted in this field, as well as outlining the theoretical concepts which the research draws upon.

LITERATURE REVIEW

Introduction

This literature review provides an overview of how childhood disability has been researched in the past, as well as highlighting more contemporary approaches to this topic. The notion of the 'social model of disability' is explained, and critiques of the model are discussed. The term 'identity' is then described using more precise terminology. The idea of 'disability identity' is then explored and linked to the idea of 'stigma' and 'disability community'. From there, the impact of 'disability labelling' is discussed. Finally, the notion of 'computer-mediated communication' (CMC) is explored, with particular focus on the impact of such interactions on children and childhood.

The recent history of Childhood Disability Research

Watson (2012) provides an informative summary of the recent history of research which focuses on children with disabilities. In the 1980s, such research tended to focus on the views and perceptions of adults (such as parents, carers and professionals) about children with disabilities rather than the voices of children themselves (p. 193). Disabled children were portrayed as being passive and vulnerable, and the research was mostly concerned with issues pertaining to service provision and quality of care (ibid). In the 1990s, two new research paradigms emerged – *the social studies of childhood* and *disability studies*. The research agenda began to shift from focusing upon children's impairments to trying to challenge the disadvantages faced by disabled children (ibid). Researchers began to focus upon the voices of disabled children, drawing upon participatory methods in order to allow them to express themselves as social agents (p. 194).

The Social Model of Disability

The 'social model of disability' emerged in the 1970s as a response to the medicalized conception of disability (Tremain, 2005, p. 9). The model was largely part of a political project initiated by the *Disabled People's Movement* in the UK which focused upon anti-discrimination legislation for disabled people (Watson, 2012, p. 1994). According to the social model, disability arises as a result of the way in which society is organized rather than being inherently due to a biological impairment on the part of the individual (Watson, 2012,

p. 194). Thus, the focus is upon addressing the social and environmental barriers faced by disabled people. Proponents of the social model of disability argue that 1) disablement is not a necessary consequence of impairment; and 2) impairment is not a sufficient condition for disability (Tremain, 2005, pp. 9).

Contemporary perspective on Childhood Disability Research

Today's research on disabled children takes the social model of disability into consideration, but also seeks to move beyond it. The model has been criticized for its failure to recognize that aside from social and environmental barriers, impairments themselves can be limiting (Thomas, 1999). The model also focuses on the social to the extent that it overlooks how impairments impact upon individual children's lives (Watson, 2012, p. 195). It also failed to acknowledge how disability intersects with other identities. Today there is an increasing recognition that disabled children are not a homogenous, cohesive group with a common identity and interests (Corker, 1999). Disability intersects with many other identities which impact upon the disability experience. For example, ethnicity (Hussain et al., 2002); social class (Emerson & Hatton, 2007) and gender (Emerson, 2003). The current study recognizes these intersections, while seeking to explore the notion of 'disability identity' as it is navigated and negotiated by young people online.

Disability Labels and Stigma

Many studies have indicated that being identified as having a disability is an important psychological experience (Fewster, 2002; Prowse, 2009; McDonald, 2009). Fewster (2002) critiques the *Diagnostic and Statistical Manual IV* (DSM-IV) arguing that disability labels are based on modernist assumptions, and that these labels are controlled by the powerful elite in order to maintain social and moral order. Savaria and colleagues (2011) also make the connection between disability labels and power structures, highlighting the "long-term implications of disability labeling" (p. 93). Research by Ingesson (2007) found that disability labeling had a significant impact on children's trajectory within the education system. Research by Higgins and colleagues (2002) also found that disability labeling can be detrimental to children. However, some studies have also alluded to advantages being associated with receiving a diagnosis. For example, Oleny and Kim (2001) found that their participants' label or diagnosis "legitimised functional or social limitations for which there

had formerly been no explanation" (p. 578). However, they also noted that labels could be associated with social stigma.

According to Goffman (1963), stigma refers to "an attribute that is deeply discrediting" (p. 13). Goffman (1963) distinguishes between people who are "discredited" and those who are "discreditable". The former refers to people whose stigmatized status is already known, while that latter refers to people whose stigmatized status is not yet known to the people involved in an interaction (p. 14). Goffman (1963) also distinguishes between three different types of stigma. Firstly, there are "abominations of the body – the various physical deformities" (p. 14). Secondly, there are "blemishes of individual character" (p. 14), including mental disorders. Finally, there are "the tribal stigma of race, nation, and religion" (p. 14). Those who do not possess the stigmatizing characteristic in a certain situation are the "normals" (p. 15). Goffman (1963) describes how the "normals" often discriminate against stigmatized individuals and often unthinkingly reduce their life chances (p. 15). The current study seeks to explore how young people relate to their disability labels and questions whether such labels necessarily have a harmful impact. The impact of such labels on young people's identities is also an important focus of the study.

Identity Terminology

In the past, identity has been seen as something that is fixed and singular, but today it is increasingly recognized as something that is "multiple, fragmented and fluid" (Brubaker & Cooper, 2000, p. 6). Brubaker and Cooper (2000) argue that identity has become an ambiguous term since it is torn between essentialist connotations and constructivist qualifiers (p. 2). It is for this reason that they propose a new set of terminology that allows us to separate analytically the various meanings denoted by the term identity. These are: 1) identification and categorization, 2) self-understanding and social location, 3) commonality, connectedness and groupness. *Identification* is an active process that implies agency on the part of the individual and that varies according to context. This identification may be self-identification or identification imposed by external, authoritative institutions e.g. the state. Where identity may be seen as a condition, identification is seen as a process (*ibid*, p. 17). *Categorization*, on the other hand, refers to the process of "locating oneself vis-à-vis others" (*ibid,* p. 14). The second set of terms is *self-understanding and self-location. Self-understanding* "is a dispositional term that designates what might be called 'situated

subjectivity': one's sense of who one is, of one's social location, and of how (given the first two) one is prepared to act" (*ibid*, p. 17). Finally, they propose the terms *commonality, connectedness and groupness*. These collective identities refer to "the emotionally laden sense of belonging to a distinctive bounded group, involving both a felt solidarity or oneness with fellow group members and a felt difference from or even antipathy to specific outsiders" (*ibid*, p. 19). "'Commonality' denotes the sharing of some common attribute, 'connectedness' the relational ties that link people" and "'groupness' – the sense of belonging to a distinctive, bounded, solidarity group" (*ibid*, p. 20). In this study, I attempt to apply some of this terminology in the context of disability identities.

Disability Identities

In psychology, identity refers to "conceptions of the self, expressions of individuality, and accounts of group affiliation" (Dunn & Burcaw, 2013, p. 149). Identities help people make sense of different aspects of their self-concept (Oyserman, Elmore & Smith, 2012). Disability is an identity in the sense that it "clearly marks individuals as part of a group and as members of a minority sometimes subject to prejudice and discrimination" (*ibid*). Dunn and Burcaw (2013, p. 149) emphasize that disability identity does not necessarily supersede other identities and that it may stand out more or less as an identity depending on the situation. As they put it, disability identity may be "activated" by certain situations or experiences (p. 149). However, Dunn and Burcaw (2013) argue that disability identity can have positive qualities in that it creates a connection between the self and other people with disabilities. In this way, disability identity can be a means through which disabled people are better able to cope with challenges in their everyday lives (Gill, 1997; Hahn & Belt, 2004).

Disability Community

According to Dunn and Burcaw (2013) the notion of 'disability identity' is strongly connected to the idea of a 'disability community'. Such a community allows people with disabilities to engage with their peers due to common experiences (Dunn & Burcaw, 2013, p. 149). According to Olkin (1999), disability identities should be considered on a continuum. Olkin (1999) distinguishes between three disability-identity groups. The first includes individuals with some functional limitation who self-identify as a person with disabilities, but who could "pass" as non-disabled due to their disability not being severe (or perhaps, not

being visible). The second group is made up of people whose self-concept is linked to disability and who feel part of the disabled community. The third group is made up of disability rights activists who see disability as a social construct and a human rights issue. For the purposes of the current study, the first two groups of disabled people are of particular interest. The current study considers how and to what extent the *Teenhelp* website may serve as a platform for a virtual disability community. The fact that their interactions are mediated by computers is significant, and shall be expanded upon below.

Computer-Mediated Communication and Discourse

Computer-mediated communication (CMC) is an interdisciplinary field which focuses on language and language use in computer networked environments (Herring, 2004, p. 1). Computer-mediated discourse (CDM) is a specialization within the field of CMC, which focuses on the communication produced when people interact with each other by sending messages through networked computers (*ibid*). Most CMC is text-based as messages are typed on computers and read as text on computer screens (or other devices such as smart phones or tablets). CMC takes a variety of forms, such as email; discussion groups, real-time chat and role-play games. The focus in the current study is upon an online forum. CMD exchanges are generally faster than other forms of written exchanges (such as letters), and yet they are significantly slower than spoken exchanges because typing is slower than speaking (*ibid).* Text-based CMD is also a surprisingly effective way of 'doing' interactional work because it allows users the time to choose their words with greater care than spontaneous speech would allow (Sproull & Kiesler, 1991). CMD also allows messages to be shared with an unseen (and often unknown) audience, while at the same time creating a feeling of personal and even 'private' exchanges (King, 1996). Although CMD is sometimes considered a 'lean' medium in comparison to the 'richness' of face-to-face communication, users often compensate textually for missing auditory and gestural cues which mean that CMD can become richly expressive (Herring, 2004, p. 3). CMD often contains a unique linguistic structure which may be less correct, complex and coherent than standard written language (*ibid,* p. 5). Although CMC often contains non-standard features, only a relatively small percentage of such features are caused by errors. The majority of such features are intentional choices made by users to reduce typing time and effort, to mimic features of spoken language or to find creative means of self-expression (*ibid).* The ways in which young people make use

of an online forum as a means of communication, self-expression and self-exploration is one of the focuses of this study.

Children, the Internet and New Social Media

James and James (2012) include "Internet and New Social Media" as a Key Concept in the field of Childhood Studies (pp. 70-72). They define this concept as including "Children's engagement with electronic media of all kinds" (p. 70). They note that as new forms of electronic media have developed during the 21ˢᵗ century, they have offered both adults and children new forms of communication and interaction. However, this has not always been seen as something that is good for children, and some have seen it as a threat to childhood innocence (Postman, 1983). Concerns around children's use of social media generally relate to two main issues; firstly that children need protection from the 'adult world' and secondly that electronic media will necessarily have a negative effect on children (James & James, 2012, p. 71). However, as Buckingham (2000) argues, children are not passive in the face of social media, but rather are social actors who are able to respond reasonably and selectively in their interactions with these media (p. 38). Buckingham (2000) argues that rather than restricting children's access to social media, they should receive education on how to use such media productively and safely. Livingstone (2009) found that there are both opportunities and risks in children's use of the internet. Although there are risks, such as cyber-bullying, the internet allows children to participate in the global peer culture of contemporary childhood (Livingstone, 2009). It is important to recognize that it is not the technology per se which is the risky. The level of 'risk' is affected by the social context in which the technology is being used (Livingstone, 2009).

Having highlighted previous research in the field and key theoretical concepts, I shall now move on to discuss the methods used in this study.

METHODS AND METHODOLOGY

Data Source

The data for this study comes from a website called *Teenhelp.* I came across this website, as I was interested in doing research on teenagers and was looking for information online. There are many other websites which provide help and support for teenagers, such as *Teenline*[2] (a teen-to-teen hotline with community outreach services); *TeenAdvisor*[3] (a website offering information and support to teenager) and *The Teen Centre*[4] (an online forum dealing with drugs, sex, puberty, LGBT issues and health questions) to name only a few. I decided to go with *Teenhelp* for several reasons. Firstly, it is easily accessible without one having to register as a member or requiring any special plug-ins or software. Most websites only allow limited access to 'guests', whereas *Teenhelp* allows full access. Secondly, it offers extremely rich data over a relatively long period of time. Thirdly, it has a special *Disabilities Forum* which was the area I was interested in researching.

Teenhelp is an "international, not-for-profit organisation which provides anonymous support and advice to anybody who needs it[5]". The website defines itself as "an online community created to afford young people a safe haven on the internet[6]". *Teenhelp* provides a space for adolescents to express themselves and discuss issues with their peers, while also having adult moderators to intervene where it is deemed necessary. The service is provided completely by volunteer staff of various ages, who work under the direction of the Project Coordinators[7]. The website does not indicate any connections or affiliations to other organizations, although the website is sponsored by "B2 Net Solutions" – a company involved with web design and server hosting. According to the website's mission statement, the purpose of the site is to provide support and advice to anybody in need. They aim to treat all *Teenhelp* users with "kindness, compassion and respect[8]". Although they encourage people to make use of *their* services, they also recommend the support and advice of professionals where necessary. Users who want to be able to start threads or reply to existing threads need to register on the

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[2] https://teenlineonline.org/about-us/ accessed 11 June 2015
[3] http://www.teensadvisor.com/aboutus.html accessed 11 June 2015
[4] http://www.theteencentre.com/forums/ accessed 11 June 2015
[5] www.teenhelp.org accessed 9 June 2015
[6] http://www.teenhelp.org/mission/ accessed 19 April 2015
[7] http://www.teenhelp.org/terms/ accessed 28 April 2015
[8] http://www.teenhelp.org/mission/ accessed 19 April 2015

website. When they do so, they create a profile which is linked to their chosen alias. They are able to choose how much information they share about themselves, e.g. their country, age, sex, gender etc. (they are able to leave these fields blank if they choose to). They can also include a profile image, but this is not allowed to be an actual photograph of them selves. Whenever a user starts a thread or posts a reply, their alias, profile image and basic demographic information appears alongside their post. In the analysis section of this report, I have included this basic information so as to contextualize the post.

Following the example of Lindgren and Sparrman (2014), the current study takes the form of a virtual ethnography. According to Silverman (2011), words which have been recorded without the intervention of a researcher can be considered as "text" (p. 153). I treat the threads and posts on the forum as text – thus resulting in a form of unsolicited naturalistic data. As Bryman (1984) notes, an advantage of qualitative research is that it provides rich data, or data which offers depth (p. 79). Through a close reading of the texts, I analyze the ways in which the posters negotiate the meaning of disability as a socially-constructed label or identity.

Using this online data has both advantages and disadvantages. One advantage is that the data are 'naturally occurring' which adds a greater sense of authenticity compared to solicited data. It is also freely available and easily accessible – an important practical consideration. However, there are also some disadvantages. For example, there is a huge corpus of data available. As of 1 April 2015, there were 263 threads and 1953 posts in the *Disabilities Forum.* Thus, I have had to be selective in choosing which posts to include in my analysis. I allowed my selection process to be guided by my research question and selected posts which illustrated the themes I was interested in. I also focused on posts which had high levels of interaction – i.e. where there were many 'replies' or comments on the thread. This allowed me to analyze the interactions between adolescents as well as the interactions between the adolescents and moderators with a focus on the "co-constructed" nature of their talk (see Danby, 2011, p. 75). Another limitation of the data was that the posts came predominantly from young people in the 'minority world'. However, since this is a qualitative study with a relatively small sample, the aim is not to provide representative, generalizable findings but rather to provide greater insights into the experiences of young people with disabilities.

Data Analysis Methods

According to Braun and Clarke (2006), thematic analysis is "a method for identifying, analyzing and reporting patterns (themes) within data" (p. 79). Some of the key advantages of thematic analysis are that it is a flexible method that does not require a specific theoretical, epistemological or ontological approach (Braun and Clark, 2006). I took a semantic approach to the data whereby I provide a detailed account of a relatively limited number of posts (*ibid*, p. 83). The reason for this choice was that the purpose of this study is to address a specific research question rather than to describe themes across the entire data corpus. The analysis is theoretical in nature, and uses an inductive rather than a deductive approach (*ibid*, pp. 83-84). I sought to identify latent themes, since I was working within the constructivist paradigm and seeking to examine the "underlying ideas, assumptions, and conceptualizations" that I identified within the dataset (*ibid*, p. 84). While conducting the data analysis, I also consulted the literature in order to get ideas for themes I may have missed in the data as well as to see if the themes I had identified had emerged in other studies. Thus, I worked iteratively between the literature and the data during the analysis process.

Selection of Posts

For this research, I decided to analyze posts which were made over a three year period, between 1 April 2012 and 1 April 2015. Over this time period, there were 114 threads in the Disabilities Forum and there were 561 replies to these threads. I began by reading through all of these threads and replies, and sorting them into initial, preliminary themes. When an initial thread is started, the poster provides a title to the thread. This title then becomes a marker which comes up every time someone comments on the thread or replies to the initial post. Thus, I used these titles (in addition to the date and time the post was made) in order to sort the posts into preliminary themes. This process yielded the following broad themes: 1) Do I have a disability? 2) Medicalization of disability (where posters described their experiences with medical or pharmaceutical treatment or recommended or warned others against such treatments); 3) Disability and identity; 4) Parental attitudes towards disability (acknowledgement or denial of disability as well as providing or denying support in accessing treatment); 5) Reasonable accommodation of disabilities (especially at school, college or university); 6) Rare and contested illnesses; 7) Disability and sexuality; 8) Disability and embodiment; 9) Disability and affect (dealing with feelings of depression and low self-

esteem). These were themes which I found to recur within the data, however I acknowledge that these themes were strongly influenced by my theoretical interests and research questions.

Initially, I was interested in the identity and labelling aspects related to disability in addition to questions relating to medicalization and embodiment. However, I realized that the scope of the study was too broad, and decided to focus only upon disability labelling and identity. I also decided to select ten posts (from seven different threads[9]) which I would then analyze in detail. I decided to do this so that I could include the original post as it was written rather than providing a summary several posts in my own words. This allowed me to stay close to the data and to convey the young person's voice in a more direct (although still 'mediated') fashion. In selecting these ten posts, I tried to find posts which were particularly rich and well suited to analysis. I also tried to find posts which captured the essence of the themes which I had chosen to focus upon and which conveyed sentiments which I had found to re-occur on the forum. However, as the posts were chosen based on my research question and theoretical interests, I cannot claim that they are representative of the entire data corpus. Rather, the posts provide snapshots into the types of things that young people with disabilities chose to post about on this forum which were relevant to questions of identity and labelling.

Methodological Questions

As mentioned earlier, this study takes a social constructivist approach. James and James (2012) define social construction as "a theoretical perspective that explores the ways in which 'reality' is negotiated in everyday life through people's interactions and through sets of discourses" (p. 116). This study raises some important epistemological questions. For example, how can I be sure that what people are posting on this forum is 'true'? The simple answer to this question is that I cannot be sure – it is not even possible for me to know if the people using the forum are even young or disabled when they claim to be. However, I argue that the 'truth' is not the most important consideration in a study which draws on the social constructivist perspective. What is important in such a study is what is *presented* as being true and the ways in which these *truths* are constructed by different social actors. What is of interest here is what people have chosen to post under the *Disabilities Forum* of this website and what these posts can tell us about disability, childhood and how young people experience and make sense of their disabilities. Following the example of Osvaldsson (2011), the unit of

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[9] Note that four posts came from the same thread, as indicated by the title of the thread in the analysis section.

analysis for this study is the posted texts (or "postings") as opposed to the individuals who posted them. This also reduces the significance of the *true* identities of the people who post on the forum.

Ethical Considerations

On the one hand, this online data has the advantage of being "naturally occurring" (Silverman, 2011, p. 201) which means that it was not produced for the explicit purpose of answering interview questions. On the other hand, it raises ethical concerns for precisely this reason. Indeed, when dealing with CMC, there are certain unique ethical considerations. One key question is the extent to which Internet sites can be seen to be public or private spaces (Berry, 2004; Mann and Steward, 2006). These data are freely available and technically within the public domain since they are accessible to anyone online. The *Teenhelp's* Code of Conduct[10] explicitly states their approach to research and data collection. It is clear that if one is conducting research for a publication, it is necessary to seek the explicit approval of a Project Coordinator. However, since the current research is not intended for publication, the study is in line with the terms of conduct of the website. Should the research be considered for publication at a later stage, the Project Coordinators at *Teenhelp* will be approached for their permission to use the data.

Aside from the consent of the website, the question of the children's consent still remains. Children's competence is a complex and contentious point. In the twentieth century, children were theorized as "pre-competent people who one day may become adult humans" (Farrell, 2005, p. 6). From this followed the idea that children are not competent to consent to participate in research (Abramovitch et al. 1991 cited in Farell, 2005, p. 6). More recently, researchers in the field of Childhood Sociology have argued that children are "already competent participants in their everyday worlds" (Mackay, 1991 cited in Farell, 2005, p. 6). Following from this, it may be argued that children may be considered to be competent to give consent. The young people posting on the *Teenhelp* website made their posts with full knowledge that their content is within the public domain. Thus, they implicitly consented to it being accessed by the public. The terms and conditions of the website advise users against using their real names (and especially against providing their full names) or photographs. In this way, the participants are afforded a relatively high degree of anonymity and protection.

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[10] http://www.teenhelp.org/terms/conduct/ accessed 28 April 2015

According to the principles of beneficence and non-maleficence, researchers should aim to maximize possible benefits and to minimize possible harm to participants (Farell, 2005, p. 4). In the case of the proposed study, the foreseeable risks to participants are fairly minimal. The most harmful scenario would be the inclusion of personally identifying data (such as real names, photographs etc.) in the research. However, even in such a case (which I will strive by all means to avoid), the data is already technically in the public domain, so there would be no 'new' risk. It is possible that participants could indirectly benefit from the research, which seeks to explore the ways in which disability is constructed and experienced by young people online. Such knowledge could contribute towards improving the quality of life of young people with disabilities. For example, it could provide health-care practitioners who work with young disabled people with valuable insights into how they experience and make sense of their disability.

In order to be an ethical researcher, it is important to be self-reflexive. Many of the posts on the website convey high levels of emotional distress and are written by young people who feel quite desperate and alone. At times, I felt tempted to reply to posts or to offer advice. However, I personally believed that it was not my place as a researcher to intervene in such a fashion. As a compromise, I decided that if there were cases where someone's life could be at risk (e.g. a suicidal post), that I would contact the website moderators rather than intervening myself. Fortunately, the moderators seemed to be very active and alert and had already responded to all the distressing posts that I came across.

This chapter has described the data source, as well as the methods used in analyzing the data. Ethical considerations were also highlighted and addressed. The following chapter will present the results of the data analysis process.

DATA ANALYSIS

Introduction

The data selection method described in the previous chapter allowed me to draw on a broad and heterogeneous sample while looking for common points of interest. In this section of the report, I display the results of the data analysis. I begin by presenting the post and then go on to provide a thematic analysis of it. I have numbered the lines of the post for ease of reference. The analysis is organized into six main themes. The first theme deals with labelling and how some young disabled people are looking for a fixed label with which to identify. The second theme follows on the topic of labels, but this time emphasizing how one needn't be limited or restricted by one's disability label. The third theme deals with the question of the legitimate use of disability labels. The fourth theme follows on the notion of legitimacy, but this time focusing upon disability identities. The fifth them deals with identity and 'normality' – emphasizing that just because a person has a disability does not mean there is 'something wrong' with them. The sixth and final theme deals with the question of visibility and invisibility in these young people's lives. Although these themes have been separated for analytical convenience, many of them are related to each other and may cut across a single post.

"I wish I could get a label written in stone"

As discussed in the literature review, disability labelling is often considered to be something negative. However, it is not always so simple. In the above post from *Ihea*, *Catharsis* described how he found it useful to have a diagnosis of Asperger's Syndrome, as it helped him to understand how his mind works and to be able to access help and support. Here is another later post from *Ihea* (approximately three weeks after the post presented in the above section) where he continues to express uncertainty over whether or not he has Asperger's Syndrome (or "Aspie" as he calls it):

> **Conflict over Aspie label (rant-y) -** March 12th 2014, 02:31 AM
> 1 I just don't know if I'm really "allowed" to be an Aspie or not. I'm kind of
> 2 strict on the whole label thing and I'm just super worried that I'm misusing
> 3 the title and claiming to have something I'm not and I would talk about it but

4 my mom won't hear it and I haven't seen the psychologist in a while. I

5 honestly don't know if I genuinely have a problem or I'm super super good at

6 lying and pretending to myself because sometimes I think this whole thing is

7 an awful mistake but then other times I acknowledge I act like an Aspie and

8 think it fits. And I'm just so worried about this and I've become obsessed with

9 just researching and researching and making sure I still add up with

10 symptoms and testing my empathy and emotional intelligence and I wish

11 my mom would just take me to like a place that could really set these things

12 in stone but she just drills into my head, "You're not an Aspie."

13 No one can just explain my behavior, and that's all I want. I *want* labels

14 because I'm just really uncomfortable with myself. I don't know if I'm just

15 high-functioning or an accident and I'm really bothered by this whole thing.

While the literature tends to emphasize the negative aspects of labelling young people with disability, this post illustrates that some people actively seek out labels in order to feel legitimate in what they are experiencing, to understand their condition better and in order to be able to receive appropriate treatment. In this post, *Ihea* says emphatically that "I wish my mom would just take me to like a place that could really set these things in stone" (l. 11-12). Here *Ihea* is seeking a form of 'identification' and 'categorization' (Brubaker & Cooper, 2000) that would be imposed from the outside. *Ihea*'s discomfort appears to be caused by his lack of 'self-understanding' (Brubaker & Cooper, 2000), which he believes would be relieved if he were to be categorized and labelled. *Ihea's* reference to getting things "set in stone" implies that he is searching for something definitive and fixed – a label that will give him something solid and concrete in a world that otherwise seems perhaps fluid and unstable. Since his mother will not take him to an expert to be tested, *Ihea* has resorted to testing himself. He notes that he has been doing research and tests (likely online) in order to test his empathy and emotional intelligence (which may be lower in a person with Asperger's Syndrome than in other people). He says that he is "making sure I still add up" (l. 9). This is an interesting choice of phrasing – it implies that the label or identity of "Asperger's" is only legitimate if one gets the right "score". Perhaps some of the tests *Ihea* was doing did in fact work this way – using some kind of scoring system to calculate whether one fell within the Autism Spectrum or if one specifically could be considered to have Asperger's Syndrome. Once again, the question of legitimacy is central to adopting a disability identity.

Being (more than) the label

In contrast to *Ihea's* strong desire for a label, some posters emphasized that one needn't be defined by a label. For example, *Average Joe* (a female from the UK) posted the following reply to a question. The question came from a person with Asperger's who was worried that he would never be able to have a successful romantic relationship because of his disability:

> **Re: i think aspergers is gonna ruin my life -** October 17th 2012, 04:43 PM
> 1 Hey there.
>
> 2 I will start by saying that I too have Asperger Syndrome, and have had a diagnosis
> 3 since 14 (I am now 20). & Sometimes, I feel the same way you do; but not as often
> 4 as I used to. I went to a college for people with Autism/Aspergers and related
> 5 things... so many of them have come so far, you'd be surprised... I was. I used to
> 6 think a person with it was just the exact definition of what their label/diagnosis
> 7 was, but I was wrong. You can become so so much, just like people without an
> 8 Autistic Spectrum diagnosis. It doesn't define you in the way you think... that's
> 9 what I'm starting to realise.

Average Joe begins her post by stating that she too has been diagnosed with Asperger's Syndrome and that she received the diagnosis six years ago. She can relate to the way the original poster feels and says that she sometimes feels the same way. Although she has Asperger's herself and went to a special college for people with Autism, she refers to people with Autism as "them" (l. 5) indicating that she was almost making her observations from an outsider's perspective. She notes her surprise at how far many of "them" have come. She describe the evolution in her thinking from assuming that people with "it" (Asperger's Syndrome) were "just the exact definition of what their label/diagnosis was" (l. 6-7) but notes that she later realized she was wrong. Her reference to "the exact definition" of a label may link to something like the *Diagnostic and Statistical Manual* (American Psychiatric Association, 2013)[11] which is a tool used for defining, classifying and diagnosing psychiatric disorders.

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[11] The DSM is published by the American Psychiatric Association. The DSM is now in its 5th Edition, which was published in May 2013. While it has been praised for standardizing psychiatric diagnostic criteria, it has also been criticized for being unscientific and for producing artificial categories of 'normality' which have become medically regulated and policed.

Negotiating disability identity claims

Following on the theme of legitimacy, *Lelola* (a female from Ohio) expressed outrage when a friend of hers made what she perceived to be an *illegitimate* disability claim:

> **Claiming to be physically disabled -** September 19th 2013, 08:30 PM
>
> 1 Does anyone else get annoyed when people you know in real life are
> 2 convinced they are disabled? Especially when she is doctor shopping for
> 3 disability payments? So far, 3 will not sign her paperwork.
>
> 4 Oh, and I have most of what she claims to have in the physical ailments and
> 5 they are not disabling.
>
> 6 She has mental issues which may be causing her to feel that she has those
> 7 physical complaints.
>
> 8 Oh and she trained her own service dog. She's wanted one since she was a
> 9 little kid but never qualified for one through an agency so she went and
> 10 picked a breed that is not traditionally a good service dog because she
> 11 wanted that breed as a pet.
>
> 12 Not to mention recently she was in a wheelchair because supposedly she
> 13 dislocated her hip/was too tired to move. Her story changed multiple times.
>
> 14 I am really close to telling her that real people have issues. I see people who
> 15 are actually sick all the time. She does need help, but not physically. It
> 16 doesn't help if you don't seek the proper help.
>
> 17 I am more pissed that she is trying to draw a disability check when she can
> 18 work, but chooses not to. She has stated to me before she'll only work at (a
> 19 video game chain store). She also is trying to train service animals. Being
> 20 disabled means you cannot work, not that you don't want to.

Here we see that *Lelola* is undermining the legitimacy of her friend's claim at being disabled and is actually policing the use of the 'disability' label. Again, this is a question of 'identification' and 'categorization' (Brubaker & Cooper, 2000). She does this in several ways. Firstly, she notes that the claim is not recognized as legitimate by experts (three doctors

have refused to sign her paperwork) (l. 2-3). Secondly, the symptoms she experiences are not disabling in *Lelola*'s opinion (l. 5). Thirdly, *Lelola* suggests that the symptoms themselves are psycho-somatic ("mental issues", l. 6) and thus not legitimate within the bio-medical health model. Towards the end of the post she acknowledges that "She does need help, but not physically" (l. 15) – perhaps implying that she needs psychological help. Fourth, *Lelola* notes that her friend wants to have some of the privileges which are reserved for people with legitimate disabilities (such as a guide dog for blind people or a wheelchair for people who are unable to walk). The wheel-chair and the guide-dog are iconic symbols of disability which are visible to others and mark the person as a disabled person. Thus, by wanting to make use of these symbolic markers, *Lelola*'s friend is trying to access a disability identity which *Lelola* feels she should not have the right to do (since she does not believe that she is legitimately disabled.) *Lelola* also questions the legitimacy of her friend's claim because her story is inconsistent ("Her story changed multiple times", l. 13). Finally, and most distressing to *Lelola*, her friend is trying to draw a disability check (l. 17). Since *Lelola* considers her friend to have no legitimate claim to the disability identity, she feels that there is no basis for her to make a legitimate claim to accessing a disability check. She believes that her friend does not *want* to work, rather than being *unable* to work due to her disability (l. 20).

To be or not to be?

Beyond the disability label is the disability identity. For the purposes of this study, I distinguish between a label (which e.g. a medical professional may apply to a patient) and an identity (whereby an individual may choose to accept or reject certain labels through how they *choose* to identify themselves). For example, here is a post by *SoftShh* (a 19 year old male) who is unsure whether he identifies himself as 'disabled' or not:

> **Unsure about being disabled or not.** - November 8th 2014, 10:51 AM
>
> 1 Hey. Like the title says, I'm unsure about whether I should be considered
>
> 2 disabled or not. I'm legally half-blind, but I've never felt like a disabled
>
> 3 person before. I don't feel like someone with special needs, and it's actually a
>
> 4 very uncomfortable position.
>
> 5 I've lived a pretty normal life, by which I mean I've never needed special
>
> 6 drugs, or assistance, or support in school, or anything like that. No one even
>
> 7 says or notices most of the time. Not even I do.

8 But recently someone said to me that I should be getting benefits and treated

9 like any other disabled person, and it made me feel really awkward, and,

10 honestly, guilty. Like I was faking, or something. Because to me, seeing out

11 of only one eye is normal.

12 When I asked my cousin, with whom I am close, and have lived with for

13 years, they said they had always thought I was disabled, and saw me that

14 way. Now I feel so uncertain and doubtful.

15 Should I be considered disabled, or what?

SoftShh distinguishes between his impairment (he is legally half-blind) and the "disability" label and identity (l. 2). He notes that he has never *felt* like a disabled person before (l. 2-3) – indicating that the notion of being disabled was not part of his self-concept or his 'self-understanding' (Brubaker & Cooper, 2000). He justifies this lack of 'identification' (Brubaker & Cooper, 2000) with the fact that he doesn't feel like he has special needs (l. 5-6). He also says it's a "very uncomfortable position" (l. 4), although it is not clear what he is referring to here. Perhaps the position of having impairment but not feeling like a disabled person is uncomfortable. Perhaps the thought of identifying with the 'disabled' label at all is what makes him feel uncomfortable.

SoftShh also goes on to note that he has a lived "a pretty normal life" (l. 5) which he defines as not needing special drugs (medication) or assistance (l. 5-6). Here disability is positioned as the antithesis of normality – thus if he has lived a 'normal' life, he is not really disabled. The theme of disability vs. normality comes up again later in the post where *SoftShh* says that for him, seeing out of one eye is normal (l. 10-11). This illustrates just how problematic it is to define disability in relation to what is 'normal' because what is normal for one person may be abnormal for another, i.e. there is no consensus on what is normal. *SoftShh's* lack of identification with the disability label appears to stem from his lack of sense of 'commonality' (Brubaker & Cooper, 2000) with disabled people. He believes that disabled people require special drugs and assistance and that they cannot live a normal life. Since these things do not apply to him, he does not believe that he shares the common attributes necessary for accessing a disability identity.

SoftShh notes that someone recently said that he should be receiving disability benefits and should "be treated like any other disabled person" (l. 8-9). This makes *SoftShh* very uncomfortable in two ways. Firstly, he is uncomfortable because someone is applying a label to him which he does not personally identify with. This creates a kind of 'identity crisis' for him as he is beginning to question whether he has misunderstood his own identity. This identity crisis is reinforced by the fact that his cousin (who he notes he is close to, i.e. someone who knows him well) said he had always seen him as a disabled person (l. 12-13). The second reason that these comments make him feel uncomfortable is because he does not want to make false claims to the disability identity. Here the question of legitimacy is central. *SoftShh* does not identify as a disabled person and by his definition, he does not qualify as a disabled person. Thus, he feels that if he was to claim disability benefits etc., he would be "faking" (l. 10) i.e. pretending to be a disabled person when in fact he is not.

Of some relevance here is Charles Cooley's (1902) notion of the "looking glass self". According to this theory, the self-concept has three main elements: "the imagination of our appearance to the other person; the imagination of his judgement of that appearance; and some sort of self-feeling, such as pride or mortification" (Cooley, 1983, p. 126). In the case of *SoftShh,* he does not see himself as disabled. However, he has now come to imagine (based on what people have said to him) that those around him *do* see him as disabled. Although he does not say anything about people judging him negatively on this basis, this is perhaps what he imagines their judgement to be. He is now in the process of trying to decide whether or not it would be legitimate for him to incorporate disability into his self-concept, and also perhaps whether it is desirable to do so.

Following on the theme of disability identity, here is a post from *Ihea* (transmasculine from Kansas). He made a post regarding his recent diagnosis of Asperger's Syndrome. After receiving an encouraging response, the following interactions took place between *Ihea* and *Catharsis* (an 18-year old male from Ireland):

> **Re: Asperger's? -** February 22nd 2014, 05:22 AM [*Ihea*]
> 1 Thanks for that response. The psychologist was reassuring me that I can still
> 2 be successful when he told me, and I know there are a lot of people with
> 3 Asperger's that do great things, but it's still weird to think that hey, I'm one of
> 4 them.

Re: Asperger's? - February 22nd 2014, 04:52 PM [*Catharsis*]

5 I also have Asperger's, and I share some of the same qualities as you. I think

6 social anxiety is experienced by most people with Asperger's. Other anxiety

7 disorders and OCD are also more likely to be exhibited by Aspies than other

8 people. I personally feel having a diagnosis is good, as you understand how

9 your mind works. It's useful for getting support and help with the disorder.

10 Also, I'm gifted and on the spectrum. It's more common than you'd think to

11 be both, and there are some very famous people who have had Asperger's or

12 are speculated to have it [...]

Re: Asperger's? - February 23rd 2014, 12:55 AM [*Ihea*]

13 Thanks for all your support. It's still a bit confusing, because I don't seem

14 like an Aspie all the time. Like, I can handle some social interaction and I

15 pick up on some cues, and I think that maybe that un-qualifies me, but at the

16 same time I still have a lot of problems with that, haha.

In this post, the question of 'categorization' (Brubaker & Cooper, 2000) comes up again for *Ihea* as he considers himself in relation to others, e.g. "I know there are a lot of people with Asperger's that do great things" (l. 2-3). *Ihea* is also wrestling with the idea of being "one of them" (l. 3-4). Here he is using distancing language, presenting people with Asperger's as "others" with whom he must now begin to identify. In the following message, *Catharsis* says that he found the diagnosis of Asperger's Syndrome to be useful because it helps you to "understand how your mind works" (l. 8-9). *Ihea*'s last post in this thread emphasizes that he still feels confused about the label and expresses some concerns over legitimacy. He states that he is able to pick up on some social cues and wonders if this "unqualifies" him from having Asperger's Syndrome (l. 15). At this point, it is unclear whether he is worried about making an illegitimate claim to having Asperger's Syndrome or whether he is trying to avoid the label because he does not want to be identified with "them" in the first place. Interestingly, *Ihea* ends his post with the word "haha". Herring (2004, p. 5) notes that one of the features of computer-mediated language is the textual representation of auditory

information, such as prosody or laughter. Thus, 'haha' is used to mimic the sound of laughter in a verbal interaction. Perhaps *Ihea* is using this 'laugh' at the end of the post to lighten the mood on an otherwise serious topic. Another possible explanation is that he is aware of the irony that he is wrestling with his 'Aspie label' but that he also has characteristics which he thinks may 'unqualify' him.

Ihea's use of the word "Aspie" (l. 7 and l. 14) is also interesting. He is certainly not the only person on the forum to make use of this term – it is actually quite commonly used. There may be several possible reasons for the evolution of this term and for its common usage on the forum. For example, saying that one is an 'Aspie' is less formal and less intimidating than saying that one has 'Asperger's Syndrome'. It also removes the medical connotations from the term. While a 'syndrome' is necessarily a condition and a diagnosis, being an 'Aspie' is more like an identity. Note that the way that these two terms are used is also different. For example, one is *diagnosed* with Asperger's Syndrome but one *is* an Aspie. Thus, Asperger's Syndrome is a label which a doctor or medical professional applies to an individual, whereas being an Aspie seems more like a matter of personal 'identification' (Brubaker & Cooper, 2000). The term 'Aspie' also implies a kind of group membership or community – being 'one of them'. Here, Brubaker and Cooper's (2000) term's 'connectedness' (i.e. having ties or links to others) and 'groupness' (having a feeling of belonging and group solidarity) seem particularly relevant. Feeling part of a community may be particularly valuable and significant to young people with Asperger's Syndrome, who often find social interactions challenging and may feel isolated in other aspects of their lives.

"There's nothing WRONG with the individual"

Lugez (a 25-year old male from New Jersey) posted the following comment in response to a question about how disabled people react when someone asks them about their disability:

> **Re: People with disabilities, do you get offended when people ask? -** June 25th
> 2012, 07:10 AM
>
> 1 Diagnosed with autism (high functioning) here. Here's my two cents.
>
> 2 I don't mind people asking as a curiosity. I think the issue is *how* it's asked.

3 To my understanding, people sometimes ask about disabilities with a tone similar

4 to "why isn't he/she normal?" or "is something wrong with him/her?" These types

5 of questions can easily offend, because more often NOTHING is wrong with the

6 individual. These people are born the way they are. Some are actually quite happy

7 with it. I am.

8 So when you ask about disabilities, ask about the disability itself. Don't ask the

9 question as if you're implying the person is made the wrong way.

Lugez's comment emphasizes the importance of *how* people ask about a disability. He begins by stating his diagnosis as "autism", although he qualifies that it he is "high functioning" (l. 1). He then goes on to share his "two cents" (l. 1) – implying that it is just his opinion and not a definitive answer to the question being asked. He notes that what is offensive is if people ask about disability in a way that implies a value judgement – i.e. that the disabled person is not "normal". He emphasizes that there is "NOTHING" (l. 5) wrong with the person with the disability – his use of all-capital letters emphasizes the strong feeling behind this statement. He then goes on to say that "people are born the way they are" (l. 6) – a point which emphasizes *naturalness* and a *lack of responsibility* on the part of the person with the disability (although obviously not all people with disabilities were born with their disability – a point he fails to acknowledge). In other words, *Lugez* is highlighting that it was not their *choice* to be born with what is considered a disability and that it is not their *fault* either. However, because it is natural it should also be accepted. *Lugez* also distinguished between asking about the disability itself (which he considers acceptable) and asking about *what's wrong with the person* with the disability (which he indicates is unacceptable). This draws a subtle distinction between the physiological body and the phenomenological body of the person with the disability. While the body may have an impairment, this does not mean that the *person* is abnormal. It also highlights that although people with disabilities may be different from others in some ways, this does not mean that there is something *wrong* with them. In other words, their identity need not be 'spoiled' by their disability (see Goffman, 1963).

Lugez also notes that some disabled people are "quite happy with" their disability, and that he is happy with his (l. 6-7). This indicates a level of self-acceptance, and also challenges the assumption that people with disabilities resent their disability. This is what has been

described in the literature as 'affirmation of disability' – when a person with a disability views their experience as something positive and not necessarily something which they want to have changed or corrected. For example, a study by Hahn and Belt (2004) found that some disability activists saw their disability as "a positive source of personal and political identity" (p. 453) and they were strongly opposed to receiving treatment for it.

The original question posted on the forum asked how disabled people feel when *children* ask them about their disability. *The Bat Queen* (a female, *Teenhelp* mentor) posted the following reply:

> **Re: People with disabilities, do you get offended when people ask? -** June 27th 2012, 04:34 AM
>
> 1 I actually love the curiosity of children and do not get offended when they ask
> 2 about my disability.
> […] 5 lines delete
> 8 I will mention it if people ask me a question or are curious about something, or if I
> 9 am having trouble understanding something but usually I do not talk about it unless
> 10 I have to or want to.
> 11 Back to the topic of children and disabilities:
> 12 It is not the children asking questions like "Mommy, why does she have that
> 13 stick?" or "Mommy, why do her eyes move like that?" or "Why are your eyes
> 14 different colored?" that bother me because children are just not educated and most
> 15 who ask those questions have never seen people with a disability, or with certain
> 16 disabilities.
> 17 What really annoys the heck out of me are the parents that are like "Shhhh, don't
> 18 ask questions like that." or "Be quiet, you shouldn't ask things like that." or the
> 19 parents that yell at their children as if they did something wrong.
> 20 It is not the child's fault that they do not know about the differences of people and
> 21 it is not their fault they want to learn, that is how children are and no one should
> 22 tell them that they are wrong and that they shouldn't be curious. Parents need to
> 23 understand that teaching their children at a young age about the differences in
> 24 people and what abilities, not inabilities people with disabilities have will help out
> 25 a lot with how their children respect other people and treat their classmates
> 26 through school

The Bat Queen says that she actually appreciates children's curiosity about her disability. She

gives examples of children's questions which she finds innocent, curious and inoffensive. *The Bat Queen* notes that she doesn't really "like talking about [her] disability all of the time" (l. 7). Perhaps people assume that her disability is her defining characteristic and that conversations tend to revolve around this subject – something which bothers her. She notes that she usually doesn't talk about it, "unless I have to or want to" (l. 9-10). Thus, there are certain circumstances where she may *want* to talk about it (i.e. she has a choice) and other cases where she feels she *has* to talk about it (i.e. she feels that she does not have a choice). Since she has a physical disability, talking about it may either be a form of explanation (in cases where someone can see her disability) or disclosure (in cases where someone has not seen her disability).

However, she then describes the part of the situation that bothers her – when parents react to their children's questions in an embarrassed fashion. Perhaps they are embarrassed because the disabled person heard the child's question and they are worried about offending the disabled person? *The Bat Queen* is describing typical parental responses as implying that it is inappropriate or rude to ask "things like that" (l. 18) – i.e. questions that draw attention to the disability which most adults pretend or prefer to ignore. *The Bat Queen* goes on to make the point that it is valuable to explain to their children about differences between people and that people with disabilities also have *abilities*. She also emphasizes that such education helps to build a more tolerant and less prejudiced society, which could benefit other disabled young people. *The Bat Queen's* comments illustrate that it may be okay to ask a disabled person about their disability in an inoffensive way, and that this can even be a valuable means of educating the public about disabilities. However, her comment also implies that while it can be useful and important to talk about disabilities, it should be the disabled person's choice *when* and *how* they choose to talk about it.

Making the invisible visible

One of the central themes on the forum is the question of visibility – a theme which had not been anticipated at the beginning of this study. In the following post, *Astar* (female, age 15 from England) uses the post itself to make her invisible disability visible to others:

learning disability?? - March 1st 2015, 09:08 PM

1 😵 is it likely I have a learning disability like dyslexia.. I've look symptoms

2 up and they don't all agree, but want to see what people think.. So basically

3 my spelling is pretty bad (it took me a while to spell this message), I can't and

4 never have been able to read an ordinary clock, I have no sense of direction

5 nor can I read maps, I struggle to tell my left from right, and am terrible at

6 readinng aloud.. Is this signs of disability or is it ordinary I haven't been told I

7 have a problem but its becoming more noticable.. Any advice would be

8 useful 🙂

In this post, *Astar* begins by asking her main question: she wants to find out whether or not she has a learning disability, such as dyslexia. She then goes on to justify why she is asking this question here when she could simply look up the symptoms of dyslexia online and self-diagnose. However, she explains that she has done this already and has found that "they don't all agree", i.e. there have been contradictions and inconsistencies in the information she has found. This is the reason she has turned to the online forum "to see what other people think". She then goes on to list what she considers to be her potential "symptoms" and then asks the reader if these symptoms could be "signs of disability" or if they are "ordinary" . Here, disability is clearly defines as something that falls outside the "ordinary". *Astar* also notes that she has *not* been told that she has a problem. This perhaps refers to teachers who would be expected to pick up if a student had a learning disability. However, *Astar* does not consider this to be sufficient evidence that she does not have a disability and justifies her concern based on the fact that "its becoming more noticable". She does not say whether it is becoming more noticeable to her or to others, but in either case, it seems to be something that she feels needs attention.

This post serves a dual function. Firstly, it has the explicit intention of requesting information. *Astar* is trying to figure out if she has dyslexia (or another learning disability) and has turned to the online forum for help in this regard. However, the post also serves a second, less obvious purpose. Through making this post online, *Astar* is attempting to 'make the invisible visible'. If she does in fact suffer from a learning disability, then it is possible that no one may have noticed (in fact, she says that this is the case since she hasn't been told that it's a "problem"). Thus, something that is visible to her (in that it is a manifest part of her experience, affecting her daily life in a concrete way e.g. inability to tell the time etc.) yet it remains invisible to others. Through making this very public post, *Astar* is trying to make visible something which has been invisible to others.

Following on the theme of visibility, *Siren* (a female from the UK) described her opinion as a person with an invisible disability:

> **Re: People with disabilities, do you get offended when people ask? -** July 1st 2012, 12:25 PM
>
> 1 I have Aspergers, meaning obviously no one can see my disability as it's a mental one,
> 2 apparently. Occasionally people may notice I'm a bit odd, but they never seem to ask me
> 3 'ARE YOU IN ANY WAY AUTISTIC' because that'd be rude (I kinda agree). When I tell
> 4 people they do act quite shocked and surprised; but occasionally get the 'OH I SEE' kind of
> 5 reaction, haha. Most people do notice my oddness sooner or later, they just don't question
> 6 it, I guess.

Here, *Siren* begins by stating that she has Asperger's syndrome. She notes that no one can *see* her disability because it's a mental one ("apparently"). However, her later comments actually indicate that her ability is not completely invisible, because "people may notice I'm a bit odd" (l. 2). Thus, although the disability may be considered as invisible because it is mental as opposed to physical, it does manifest itself in a concrete way in that *Siren* is aware that she sometimes comes across as being "a bit odd". However, people don't really ask her if she is autistic. She attributes this to it being considered rude to ask and she agrees that it would indeed be rude to ask. When she does volunteer to tell people that she has Asperger's syndrome, some people appear to be surprised (which they are either feigning or they generally had not anticipated that this may be the case). Some people respond by saying "OH I SEE" (l. 4), which would indicate that this somehow explains something about *Siren* – perhaps they had found her "a bit odd" and now understand the cause of this oddness? She concludes her post by saying that most people notice her "oddness" sooner or later but that they "don't question it". This may indicate that they accept it as part of her personality or character rather than looking for a diagnosis or label to explain or justify it. Thus, although *Siren*'s disability is technically invisible, she sometimes finds it useful to tell people about her disability as it helps them to understand why she may come across as "a bit odd".

Making the visible invisible

The following post comes from *The Bat Queen* who is a female, *Teenhelp* mentor who is blind (note the comical link between her pseudonym and her disability, which implies that she is 'blind as a bat'). Her post also deals with the issue of visibility, but in quite a different way

from the previous two posts:

The Bat Queen notes that her disability is "pretty noticeable" because she is blind and uses a cane (l. 3). However, she also remarks that there are times when she does not use her cane and she does "her best to fit in with other people around" her (l. 6). Her reference to "fitting in" coupled with not using her cane (which is usually an easily identifiable, visible disability marker) could be interpreted as her making an effort to 'pass' as a non-disabled person (see Goffman, 1963). Here, the theme of visibility/invisibility re-appears. In contrast to earlier posts from *Astar* and *Siren* which served to make *invisible* disabilities *visible*, here *The Bat Queen* is attempting to make her *visible* disability *invisible* by passing as a non-disabled person. She also notes that she doesn't really like talking about her disability "all of the time" (l. 7). Perhaps she gets tired of explaining it to people or perhaps she simply does not want it to be such a focus when she interacts with people. Again, this is in line with the notion of passing – wanting to be seen and treated just like everyone else without being marked or considered as different.

This chapter has highlighted the various themes relating to disability identities and labelling that were found in the data. The following chapter will provide a discussion of these findings in relation to the original research questions, as well as drawing relevant conclusions.

CONCLUDING DISCUSSION

This study set out to answer two main research questions. The first question dealt with disability labels and the second dealt with disability identities. The data analysed in the previous chapter indicated that young disabled people had many different ways of dealing with disability labels. There were cases where disability labels were resisted while some poster's actually found the labels or diagnoses quite useful and even sought them out and embraced them. Such posters found that having a diagnosis helped them to understand how their minds/bodies worked and also helped them to get help and support with their condition. People also adapted their disability labels to suit their needs – for example by using the term "Aspie" to refer to people with Asperger's Syndrome. Thus, the data showed that young people sometimes resist disability labels but at other times, they seek them out, embrace them and even adapt them to their own needs.

The second research question in this study dealt with disability identities. Researchers such as Thomas (2007) distinguish between 'barriers to doing' and 'barriers to being' when studying disability. Applying Thomas's concepts, Connors and Stalker (2007) found that disabled children face greater 'barriers to being' than 'barriers to doing' and that these barriers may be particularly important to young people who are in the important stages of identity formation. This appeared to be the case in the posts analyzed here, with identity questions playing a fundamental role in many of the poster's discussions. These young people were trying to figure out firstly, whether the disability label did legitimately apply to them and then secondly, to figure out the identity implications if it did apply to them. Although adopting a disability identity could be stigmatizing, it could also offer them the advantage of having access to membership within the broader disability community (and in this case, having access to the *Teenhelp* Disabilities Forum community).

The question of visibility of disabilities also had important identity implications. The fact that one young person with an 'invisible disability' sought to make her disability more 'visible' to others by telling them about it indicated that she found some value in accessing a disability identity. In this case, making an invisible disability 'visible' could allow posters to become members of an online community of young people with disabilities. This could provide a

basis for self-identification and could also provide social, emotional and practical support and advice. Seeking out visibility (and also labels, as mentioned earlier) could be an indicator that the levels of stigma associated with disability may be decreasing in some contexts. On the other hand, there was a case where a young person with a visible disability actually attempted to make her disability invisible at times by attempting to 'pass' as a non-disabled person. Such strategies appeared to provide the disabled person with a greater sense of fitting in and reduced their feeling of being different from others. This may indicate that there is indeed still some stigma surrounding disabilities if there are cases where people may prefer to pass as being non-disabled. These findings also highlight the flexibility of the notion of identity in contemporary society – where people are able to adopt, adapt, use or even discard different labels and identities depending on the situation and context.

Following on from these findings, I believe it is essential that medical professionals and health-care providers understand the significant identity implications that labels and diagnoses can have. This is likely the case for people of all ages; however, it is particularly important when dealing with young people and adolescents who are at a significant stage of life when it comes to identity formation. Their bodies and lives are changing rapidly and they are trying to figure out who they are in relation to the people and world around them. Having a disability label added to this can cause a great deal of stress and anxiety. It is important that health-care providers be sensitive to such issues. It may even be useful for them to receive training that would allow them to have discussions with newly diagnosed young people so that they are able to provide a degree of emotional support at the diagnosis stage so that these young people are able to incorporate their disability label into their self-concept, should they choose to do so. They may even wish to refer them to websites such as *Teenhelp*, to allow them to have access to peer support. However, further research is required on the topic of identity and labelling in young disabled people. For example, it would be interesting to to focus upon a specific disability, such as Asperger's Syndrome, in order to explore in greater depth how this particular disability label affects young people's identity and self-concept.

Overall, the findings of this study challenge the common assumption found in the literature that disability labels are generally harmful to young people. Rather, this study has shown that some young people actively seek out labels and diagnoses in order to gain a greater

understanding of themselves and their experiences and also to enable them to seek appropriate help, support and treatment (where necessary). Although labels can be stigmatizing, they offer the potential benefit of allowing a young person to gain membership in a new group or community which may provide them with a valuable sense of identity and belonging. Indeed, this research also highlights the complex identity work involved with being a young, disabled person, and the ways in which identity issues relating to adolescence intersect with identity issues relating to disability. This research has also shown that computer-mediated communication can provide a valuable virtual platform where such identity work can be performed while providing the aforementioned sense of group membership and belonging. Virtual communities like *Teenhelp* can potentially provide a safe space for young people to meet, share, discuss and be open about the challenges they face while also enjoying the protection of anonymity.

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