Exclusion, positive identities and tricksters: perspectives from members of a wheelchair sports club

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"So have the academics agreed on what disability is yet?"

Clair Lewis, (2000)
ABSTRACT

Using a concept driven narrative enquiry the objective of this study was to gain an insight into young wheelchair user’s experiences and understanding of disability and normalcy.

In line with the affirmation model of disability, this research looked for positive experiences, which reject the normalising discourses of disabled identities following a constructivist position and guided by a critical realist perspective.

This work follows on from Ryan and Runswick-Cole (2008) and others, who use the narratives of parents of disabled children to indicate how such parents question concepts of normalcy. Also, research by Singh and Ghai (2009), and Traustadóttir (2009), which reflects the lived reality of children and youths with disabilities. This research recognises the importance of representing voices and experiences particularly in the planning and implementation of policy and service provision.

Participants were a purposeful sample of young wheelchair users aged 12-20, N=3 and a snowball sample of adult wheelchair users, N=4, all members of a wheelchair sports club. One of the younger participants acted as a co-researcher and collected narratives from other participants.

A thematic analysis identified three broad themes: examples of everyday exclusion, a collective positive disabled identity and tricksters: examples of reactions against nominative discourses.
Introduction: Background to Research

This paper will explore the social model of disability, which considers disability to be a social, cultural, economic and political phenomena. The use of a constructivist theoretical framework assumes the epistemological position in which meaning is constituted through social and historical influences. The following definition of disability reflects a social constructivist perspective:

“Neither a medical nor a health question, it is a policy or political issue. A disability comes not from the existence of an impairment, but from the reality of building codes, educational practices, stereotypes, prejudicial public officials... ignorance, and oppression which results in some people facing discrimination while others benefit from those acts of discrimination” (Pfeiffer,1999 p.106)

This definition reflects disability studies’ understanding, which opposes the individual/medical model by recognising the societal roles that create disability whilst also acknowledging impairment. The model does not see impairment itself as being disabling; rather it is created through disablement in all areas of life such as work, leisure, education and social opportunities. Goodley and Lawthom (2006) describe this form of disablement as “a form of apartheid of the 21st century” (p.3)

The emergence of emancipatory research, influenced through a socio political understanding of disability perceives disability as occurring through socially constructed barriers. This is opposed to the medical models assumption that the cause is individual impairment. This social model of disability described by Olkin (2009) as a paradigmatic leap has caused much debate, still ongoing among disability theorists.

Criticism of the social model of disability comes from Swain and French (2000) who also reject the medical model view of disability but argue that the social model still upholds a tragedy viewpoint. This is because it describes people who are oppressed or marginalised by society and they also suggest that by separating impairment from disability, impairment can still be viewed as a personal tragedy. They argue towards an affirmation model of disability, which considers disability as a form of human diversity and a positive form of social identity. This model moves beyond what Swain and French describe as the tragedy model of disability and impairment by offering “a perspective on life that is both interesting and affirmative and can be used positively” (p.576) They
acknowledge that disabled people reject normalising ideologies and oppose the dominant medical model “within which their experiences are denied, distorted or re-interpreted” (p.578). They give examples where having a disabled identity is a positive, life affirming and beneficial experience. Sociocultural discourses, which shape meaning can be subjugating when values, which are pertinent to a particular culture are used to evaluate what is considered to be normal (normalisation).

Goddard, Lehr and Lapadat (2000) uphold the affirmation model, arguing that traditional research into disability has contributed to a set of culturally derived subjugating discourses which White (1991) describes as “problem saturated narratives” (p.274). They argue for a more critical approach, which challenges the negative, tragic discourses on disability that help maintain the cultural narratives about difference and perceptions of normality. Sunderland, Catalano and Kendall (2009) also suggest policy frameworks and policy documents regarding access and equity for disabled people that embody values which:

“Exclude people with disability from broader discussions on human health, well-being and flourishing. The political and discursive segregation of people with disability into a negative axis of evaluation inadvertently reproduces popular misconceptions that a life lived by someone with a disability is a bad, sad or inferior life” (Sunderland, Catalano and Kendall, 2009, p.711)

By comparing official texts regarding disability to focus group discussions using narrative enquiry, they argue that official Australian policy discourses do not reflect the full range of positive and negative or empowering discourses. Additionally such literature exhibits predominantly negative discursive patterns. They attempted to identify “the presence or absence of discourses of happiness and joy in the contexts analysed”, (p.703), and concluded that research can be structured in a way to uncover these hidden discourses.

In examining how the construction of dominant discourses or tragedy model impact on parenting a child with a disability, Goddard, Lehr and Lapadat (2000), describe humour from a deconstructive perspective as “laughing at assumptions about what is supposed to be the correct response to a given situation” (p.281). They argue that stereotypes of disability and parenting can be reconstructed through examples of parents positively reframing their experiences. By exploring the way cultural narratives shape individual experience, this paper follows a critical realist perspective implying that parenting a child with a disability causes such parents to naturally question hegemonic discourses about disability. Ryan
and Runswick-Cole (2008) also argue that it is time to move beyond the stereotypical representations of parents and disabled children suggesting that the ablest assumptions of being such a parent are misinterpreted “within a disabling set of practices”. They describe the processes of parenting a disabled child as a way of developing considerable skills through a non-traditional mothering role. Describing such parents as developing a “special competence” when that family’s experience of normal can challenge the “dominant social order”, (p.201).

Similarly, Landsman (2005) suggests such parents interact with the competing models of disability though their own experiences and insights and she describes them as being at an “intersection of competing discourses” (p. 121). She indicates such experiences enable mothers to react against the dominant discourse i.e. that of the medical (tragedy) model as such parents interpret their own child’s identity. She argues this type of interaction between competing models could enable insights into modelling disability. This research offers insights of everyday lived experiences where normalcy is regarded as an arbitrary construct highlighting how, as the mother of a child with a disability, the abnormal/normal dichotomy becomes blurred. Goddard, Lehr and Lapadat (2000) used thematic analysis to deconstruct the narratives of parents of children with disabilities. By focusing on the meanings parents give to their experiences, they concluded that such parents “exist at a crossroad of discourses” by challenging the dominant medical discourse, and they highlight a “newer more critical discourse of acceptance and empowerment of people with disabilities”, (p.284).

It is well documented that research into childhood and disability has compounded a negative view of disability, whilst excluding the voices of the children themselves: Watson et al (1999), Goodley and Lawthom (2006), Traustadóttir (2009). Traustadóttir recognises the importance of reflecting the voices and experiences of disabled children. She explores how disabled children and youth negotiate spaces for themselves in today’s society and how the normalising discourses of childhood impact on their everyday experiences and self-understanding. The study aims to explore the lived experience of growing up with a disability by gaining an understanding of the barriers created through social, environmental and cultural processes. This research also identifies the voices of such children as under-represented in research, which tends to focus on adults perspectives, i.e. parents and professionals. Traustadóttir argues that services have been developed without input from disabled children and youth who have important opinions about the services they receive.

Acknowledging that the social, political, economic context is what shapes the individual who, is then the embodiment of these experiences; Diamond (2008) calls for critical thinking as a way to
tolerate “uncertainty and ambiguity” (p. 186). This in turn enables different perspectives to be taken into account and Parker (1999) also suggests that critical enquiry needs to look at problems such as narrative constructions which “are embedded in discursive practices” (p.2). This is further highlighted by Goddard, Lehr and Lapadat (2000) who argue that by challenging the dominant social and professional discourses, parents of children who have disabilities “subvert taken for granted realities and practices” (p. 285).

Similarly, White (2006) calls for a need “to be anthropological about ones presuppositions” accepting the need for critical reflexive practice to examine “taken for granted distinctions” (p.24). These presuppositions are culture bound and meaning is created and upheld through established formats of thought and language and White invokes the notion of “trickster” described by Hyde (1998 p. 76). Culture upholds prejudices and presuppositions and White describes the trickster as a boundary crosser, someone open to multiple possibilities and “the other” (p.25), who questions taken for granted cultural distinctions. White’s paper celebrates the need to critically reflect on the constructed nature of what is considered to be normal and this resonates strongly with the experiences of the parents of children with disabilities in previously mentioned studies. This notion of trickster is described in many cultures, associated with rule breaking and crossing boundaries and “rituals that turn reality upside down,” Jung (1956 p.5). White argues that professional based practice’s use of explicit formal knowledge needs to be critically examined. She uses the trickster metaphor to open up spaces to question established knowledge bases and taken for granted distinctions suggesting such dominant knowledge bases can obscure a practitioner from critical engagement. Formal knowledge can be used to create certainty from ambiguity, indicating that the vocabulary of professionals upholds the dominant viewpoint. White argues that it is essential to question such assumptions through critical engagement. She calls for a need to “make the familiar strange and make language lively” (p. 20). In a similar way, Wyatt (2005) also calls for the need to invoke this trickster notion into the research process:

“a touch of the trickster gives us a way of loosening the grip of control orientated research paradigms and bringing more vitality and delight to our research” (Wyatt, 2005, p.6)

Afuape (2006) also indicates that those professionals in positions of power maintain the dominant discourses and describes the “quietened voices of the subjugated minority” (p.189). This highlights the importance of opening up to such voices, which then in turn, can enable the development of new knowledge. This is also reflected by Parker (1999) who suggests that to take a critical
standpoint means accepting that meanings are embedded in cultural practices arguing,

“it is only by working through the spaces of resistance opened out by competing accounts and alternative practices that it is possible to find a lever for change.” (Parker, 1999, P3)

In researching the lived realities of children with disabilities, Sing and Ghai (2008) illustrate that children do respond to dominant discourses. These can often create negative and discriminatory social reactions, which are crucial to a child’s identity formation. They also suggest there is fluidity in children’s identification with disability arguing that this type of research, which explores children’s perceptions and experiences, offers a unique perspective. Their paper explicates the fact that disabled children’s voices need to be heard calling for a “critical need to disrupt the hegemonic discourses of normality” (p.143).

Research does suggest that children with disabilities and their parents do question every construct of normality. Goodley and Tregaskis (2006) collected narratives about family life and uncovered a “range of themes that challenged the personal tragedy approach” (p.630), it could be suggested that such persons adopt the trickster role as a part of everyday experience. In addition, it could be argued that to enable the voices of young people with disabilities to be heard, it offers a chance to give voice to people under represented in research who naturally question cultural distinctions of normalcy.

Research Question

This study was designed to address the research question: How do young wheelchair users conceptualise disability and self-identity in the presence of normalising discourses? The theoretical approaches underpinning this research are disability studies and the affirmation model of disability forwarded by Swain and French (2000). The research epistemology is also guided by a critical realist perspective, which aims to reflect how individuals make meaning of their experiences.

The rationale for this study originated from personal experience as the parent of a child who uses a wheelchair who is a member of a wheelchair sports club. This perspective offered me a unique opportunity to be able to talk to participants (friends) during everyday conversations, which then enabled me as a researcher to explore the socio-cultural aspects and discourses, which informed the individual accounts.
Aims and Objectives

By using a concept driven narrative enquiry the objective of this study was to gain an insight into young wheelchair user's experiences and understanding of disability and normalcy. The study aimed to explore examples where disabled youth challenge the dominant, tragedy model of disability and to seek out positive experiences and personal anecdotes, which reject the normalising discourses of disabled identities. In the light of previous research, the study aimed to look for alternative interpretations of normality expressed through the experiential knowledge of the participants in line with the affirmation model of disability.

This work follows on from, Fisher (2007), Ryan and Runswick-Cole (2008), and Goddard (2000), who use the narratives of parents of disabled children to indicate how such parents question concepts of normalcy and research by Singh and Ghai (2009), Salmon (2010) and Traustadóttir (2009) who reflect the lived reality and experiences of children and youth with disabilities. This type of research recognises the importance of reflecting voices and experiences.

Reflexivity

Although qualitative methodologies attempt to gain an emic understanding to a phenomenon where the researcher is the instrument, research findings are inevitably translated via the researcher's subjective experience and interpretative stance. Parker argues that qualitative research is “always carried out from a particular standpoint” (Parker 1994, p.13). When speaking for others, their stories are retold through qualitative research to represent the theories and methodologies of the researcher. Awareness that this interpretive lens can influence aspects of the research process demonstrates how reflexivity is required when representing another in the research process, described by Fine (2002) as “working the hyphen”. This “hyphen of self other”, describes the researcher as involved in a negotiated process of “who’s story is being told, why, to whom and with what interpretation”. (p.131)

Position Statement

The rationale for this research is grounded in my own theoretical perspective as a researcher, which is influenced by my own perspective as a parent of a child with a disability. The study was driven by concepts derived through literature, which resounded
strongly with my own experiences. Firstly, the literature regarding how parents of disabled children question normalising concepts of their child, personally, socially and in reaction to the many institutional and medical settings they have to endure. In addition, literature suggests that the dominant knowledge making processes do not represent the voices of the people they represent which has important implications for policy planning and service provision. The metaphor of trickster was chosen specifically because of the trickster characteristics, which I hoped would emerge during the analysis of the data reflected in the participants' stories. The trickster metaphor is used to describe the questioning of dominant knowledge bases both in research and professional practice as research indicates that such dominant discourses contribute to maintain negative discourses surrounding disability. Therefore the analysis of both theory and data within this research is not from a neutral perspective.

**Methodology**

This research collected narratives from young members of a wheelchair sports club and used a theoretical thematic analysis to identify emerging themes within the data. Participants were selected from a purposeful sample of members of a wheelchair sports club, aged 12-20 and were specifically chosen to reflect on their own insights and experiences within the research question and could therefore be described as an expert sample, N=3. Other members of the club who are over the age of 20 have been included in the analysis, N=4. All participants are known to the researcher and each other one participant agreed to act as a co-researcher to collect data. Davis (1999) argues that children should be active participants in the research process and this is an empowering process allowing children the maximum opportunity to express their views. It is in this spirit that Y1 was asked to act as co-researcher to conduct individual interviews with the younger participants. This could also aid his role as young persons representative for the sports club as an opportunity to gain feedback about the club.

The research used a semi-structured approach to interviewing to explore the participants lived experiences. The interviews became very informal, group discussions, which often included other club members joining in the conversation, these included wheelchair users not in the target age group including parents, carers and siblings. These were given the following labels to remain anonymous and indicate the age group of the participant. Young wheelchair users: (Y1), (Y2), (Y3) - adult wheelchair users: (P1), (P2), (P3), (P4). Researcher: (R). Sibling: (S1).

Initially the interviews were centred on five broad questions, which aimed to give the participants a chance to talk about experiences and understandings of disability (Shown in Appendix B).
This type of research values experiential knowledge and research into the lived experiences of disabled children is arguably limited. Watson et al (1999) highlight this, describing the young people involved in their research as “experts on their lives” (p.6), suggesting we should challenge the traditional roles of researcher and researched.

The choice of a group discussion gives the opportunity for shared or divergent stories, which Goddard, Lehr and Lapadat (2000) suggest can achieve a “richer and more dynamic context for discussion” (p.276). It was this suggestion that the sharing of stories can initiate a critical dialogue among the participants that led the researcher to recruit a participant as co-researcher as part of the project to collect narratives from other participants.

Although the research question had been decided by the researcher and therefore influenced through academic paradigms, the data collection aimed to be participant driven. The co-researcher and participants are all friends through membership of a wheelchair sports club, which enabled the research to be participant led and therefore has the potential to be emancipatory as described by Barnes:

“emancipatory research is about the demystification of the structures and processes which create disability, and the establishment of a workable dialogue between the research community and disabled people. To do this, researchers must put their knowledge and skills at the disposal of disabled people.” (Barnes, 1992, p.122)

Furthermore, the research question underpinning this study was generated through literature. The use of open-ended questions generated discussions on broad topic areas, which enabled the analysis to focus on the participants' meanings and perspectives rather than attempting to impose an interpretative framework. This enabled the content of the discussion to be determined by the participants and Burman (1994) suggests this type of research can be empowering by offering the potential to “document perspectives not usually represented or even envisaged by researchers” (p.51).

Previous research by Sunderland, Catalano and Kendall (2009) indicate data collection methods which “has implications for researchers”. The inclusion of humour uncovered hidden discourses, which offered a way to “finding ways to access hidden or silenced discourses of joy and happiness” (p.712). In the light of previous research, the questions for the semi-structured interview were chosen to facilitate discussion, which aimed to highlight the positive benefits of having a disabled identity described by the affirmation model of disability:
Example questions:
1. What is the best thing about being a wheelchair user?
2. Who are your heroes?
3. What do you like about Wheelies Sports Club?
4. Define disability.
5. Define normality.

Watson et al (1999) used interviewing and other qualitative methods to reflect the experiences of young people and highlight the importance of developing research relationships on the participants’ own terms. In doing this, they accepted that their own assumptions and frameworks would be challenged. However, they demonstrated how being flexible and sensitive during the research process facilitated the exploration of very diverse views and experiences.

Methods of text creation can be facilitated to uncover hidden discourses. This is highlighted by Sunderland, Catalano and Kendall (2009) who argued that the structure of their research i.e. informal focus groups, had a significant influence on the inclusion of humour in the discussions.

**Ethics**

Davis (1998) divides the ethics of children’s research into three groups: informed consent, confidentiality and protection. Firstly, informed consent refers to the protection and confidentiality of all participants. Participants were asked verbally if they would like to take part in this study and were given the opportunity to decide how and when the interviews took place. They were given a letter explaining the nature of the study and consent form adapted from Salmon (2010), (shown in appendix A). Confidentiality - the data collection aimed to be an open, ongoing process within a group of friends who meet regularly for a variety of sporting and social activities. Some interviews take the form of joint interviews and group discussions, therefore confidentiality cannot be guaranteed in the data collection process. Because the research will be conducted within a group of friends, there has been much opportunity in the past to discuss negative interpretations and experiences of being a wheelchair user between both adults and youths who are members of the club.

The research question was designed to look for positive affirmations of disability, highlighted by the choice of questions and the participants will only be asked to answer questions or talk about areas they are comfortable with. Pseudonyms were used and any quotations used in the final report will be discussed with the participant and only used with signed consent. Protection - the study was designed to lead the participants into discussions about their own concepts of disability whilst being active participants in the research process. This research was undertaken by a member of
the club and parent of a young member following the club's child protection policy guidelines.

**Methodological Issues**

The initial conversations used the questions I had naively thought would create discussions around the positive aspects of a disabled identity, e.g. the question, what is the best thing about being a wheelchair user? This tended to cause a stunned silence, or answers from some older members, which indicated the anserine nature of the question.

**P1:** Being a wheelchair user.. it saves so much leather on my shoes, but unfortunately tyres and inner tubes cost about sixty quid a pair..... Do you know what I did last year, I went to France,… I went to Lourdes and there's this cave in the middle of no-where and I got there and these to nuns got me out of my wheelchair and chucked me in this water, said a load of words to me, splashed some water on me hair, picked me up and I got back in the wheelchair,…… and guess what…

**S1:** what

**P1:** I got a new pair of tyres and innertubes.

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**R:** What do you think the best thing about being a wheelchair user is Y3?

**Y3:** Errrr.............Pity sex ?

I can't actually bring myself to add the one about involuntary arm movements to an academic text, although these types of conversations created a lot of laughter they also demonstrated some methodological issues which led to some changes to the method of data collection. The relationship as a researcher to the participants was not considered in the design of the study but was highlighted by the above examples. When designing the research, the questions were chosen specifically to tie in with previous research and specific theoretical perspectives such as, the affirmation model. In reality, it soon turned out that these questions, which aimed to generate a specific discussion, were actually quite strange questions to ask a group of friends who soon brought my epistemological position back down to earth.

The use of a narrative enquiry enabled the research to be flexible and also enabled the research to be participant driven in the sense that much of the data transcribed comes from general conversation of a group of friends. (General conversation, from the perspective of this research, offers very rich, descriptive data which ties in with the research question). Braun and Clarke (2006) indicate that projects are guided by the research question but they may also be refined as the research progresses.
As the thematic analysis was driven by both the research question and the content of the transcripts, it enabled the research to be participatory. This type of analysis is driven by the researcher’s analytic interest but it is recognised that the research question can evolve through the coding process. The analysis reflects the views of other members of the club, who were not in the target population who became involved with the discussions.

**Data Analysis**

This analysis followed the six basic steps described by Braun and Clarke (2006), and this approach was chosen because it can be applied flexibly to fit the research question and data. (Shown in Appendix C)

Braun and Clarke describe the “keyness of a theme” (p. 82). Themes were not identified in terms of prevalence but rather pertinence to the research question. The analysis identified latent themes that go beyond the explicit level of the data. Identifying underlying assumptions and ideologies within the data required interpretative work and latent thematic analysis is compatible with a constructivist framework, whereby experiences and meanings are arguably the affects of societal discourses. The thematic map was created and reviewed and three main themes were identified during an ongoing analysis. (Shown in Appendix D)

**Analysis and Discussion of Results**

The aim of this research was to reflect disabled youth’s experiences and understanding of concepts of disability and normalcy. This was done by highlighting examples where disabled young wheelchair users challenge the dominant, tragedy model of disability. By seeking out positive experiences and personal anecdotes, which reject the normalising discourses of disabled identities and exploring the socio-cultural aspects, which inform individual accounts.

Three broad themes were identified on analysis of the data:

1. Examples of everyday exclusion
2. A collective positive disabled identity among the members of the sports club.
3. Tricksters i.e. examples of rejecting normalising discourses.

1: Exclusion

Focusing on accounts of disabled children and their families, Goodley and Runswick-Cole (2011) uphold their viewpoint that “disablism is rife in our sociocultural context” (p.4) and although this
study did not aim to uncover everyday experiences of disablism, many such examples were cited indicating examples of institutional, societal and personal exclusion.

As a member of this club, and a parent I have heard many of these types of conversations, which often occur due to so many similar, shared, everyday experiences. Prior to recording some of the transcripts, whilst waiting for the sports hall to become available, the general conversation centred on how many cars had taken up the disabled parking spaces. It occurred to me that this was such an everyday conversation for anyone who uses a blue badge, particularly wheelchair users. Personally, to an extent that is so familiar to me it is like talking about the rain in Manchester. This kind of narrative becomes such a part of normal conversation among a group of wheelchair users, parents and carers that although it may appear to reflect negative values that uphold the tragedy view of impairment, it is just reflecting reality.

“Cultural, social and psychological forms of violence against disabled people reflect often subtle, mundane and everyday encounters with disablism” (Goodley and Runswick-Cole, 2011, p.5).

One frequent experience for wheelchair users is to be stared at and this form of cultural violence is so common an experience as to appear mundane. Being stared at often is a constant cultural disavowal, and as such is an example of a very easily identifiable everyday encounter with disablism.

P3 I used to get that a lot when I was young……I still do.
R Does it upset you
P3 Winds me up…… I stare back.
R I do………..Y2 does now, we’ve got a trainee haven’t we.
P3 Yeah, oh yeah, you’ve got to harden to it.

Another common shared experience is that of being talked over, when a person addresses the carer rather than the person in the wheelchair.

R: That’s the classic one, talking over you, does anyone do that to you.
P4: Well not often
Y1: But you’re an adult, people actually see you and think, Oh I might bite back whereas you know, people look at people, you know… I was in …. Oh gosh…. British Homestores, you know… buying a gift with alcohol at Christmas you know, eighteen, perfectly fine, perfectly legal and I was with my support worker and the checkout assistant said, “he is old enough to buy alcohol isn’t he?” anyone else would have been just asked for ID.
“Disabled people are far less likely to be in employment. Although there have been significant improvements in the employment rates of disabled people in the last decade, the employment rates of disabled people are around 48 per cent, compared with around 78 per cent of non-disabled people.” (Source: Labour Force Survey, Quarter 2, 2010)

One of the members of wheelies has been unable to return to work for over a year after a car accident, which has left her unable to use stairs. Of all the adult members of the sports club, only one is in full time employment.

P4 That’s why I’m not allowed back to work, because I’m a fire hazard.
Y1: WHAT, they can’t tell you that!!!!!
P4: Because I work in a mill in ******** and there’s only one, there’s a lift and only one staircase, so you can’t use the lift in a fire. So…… if everyone’s got to go down the stairs, I’d have to go last.
Y1: You do not have to go last.
R: Have they got an evac chair?
P4: A what?
Y1: An Evac chair.
P4: A what………………no, well I’ve not gone back anyway so.
P4’s MUM They’ve been a fabulous company to work for.
P4: They’ve been brilliant; they’re still paying me full pay, well seventy-five percent of full pay, to not work.
R: Oh, alright, let’s not take them to court then
P4: No, no way

Structural disability is another common experience for wheelchair users and many public buildings such as shops, restaurants, public transport etc are physically inaccessible. Kitchin (1998) describes “landscapes of exclusion” (p.351).

Y1: Another good one, going to the bank and they had a push button for the door and we had……push button for the door… wonderful. Push button for the door, look inside the bank and you could see the lowered counter and everything………Big step
R: What a push button next to a step
General laughter
Y1: Wait till I tell you the rest of the story, so I thought they may have a ramp inside, so I sent someone in blah blah blah and they said oh I’m very sorry we haven’t got a ramp. They haven’t got a ramp, no.
R: What, they’ve got a lowered counter and no ramp?

Institutional exclusion often occurs in schools where the pupils are ‘integrated’. Murray (2006) described a universal theme from talking
to young people in mainstream education as ‘being present but not belonging’ (p. 36).

**Y3:** Err… I always used to get put in the Lancaster suite (laughter), because they thought I wasn’t capable of pushing up the ramps, I used to ignore them because, why should you be separated from your friends, just because it snows.

These examples included do reflect the everyday cultural disablism and the aim of this research was to seek out positive experiences in line with the affirmation model. Sunderland, Catalano and Kendall, (2009), indicate that methods of text creation can access “silent discourses” (p.704) including shared meanings and understandings that go beyond the dialogue recorded. This research noted that humour played a significant part in the focus groups:

“In many cases the stories were accompanied by collective nods of agreement, smiles and laughter during the focus group sessions”  

The stories about exclusion on a personal, institutional and societal level reflect everyday reality and in the initial coding of the data there were many sub themes which emerged and developed into the main theme of exclusion. Examples included stories about shops, school, work, the media and participants’ reactions and attitudes. It is difficult to translate the silent discourses that underlie the transcribed text and as with the Sunderland, Catalana and Kendall (2009) study, there is a lot of laughter, humour and sarcasm when these tales of everyday exclusion occur. Furthermore, these conversations highlighted a strong awareness and reaction to everyday exclusion and disablism. There became a strong sense of ‘them’ in describing such experiences, the word ‘they’ is often used to describe the perpetrators of disablism in an extremely derisory manner. For example, when Y1 could not access the bank, and described how, after he refused their offer to lift him up the step, he was offered the opportunity to make his transactions in the street, the effect was a lot of laughter and incredulous head shaking.

The narratives used here are examples demonstrating the frequent barriers and obstacles wheelchair users face. Discussing such subjugating barriers could be considered to be upholding the tragedy viewpoint of disability. Therefore, this does not seem to offer insight into how disabled youth reject the normalising discourses of disabled identities in line with the affirmation model. Furthermore, this transcribed data does not reflect positive experiences, which this research aimed to uncover. Alternatively, it could be argued that this data does reflect the affirmation model of disability. Swain and French (2000) argue that “personal tragedy” from the
perspective of some who see barriers as socially constructed are understood through a discourse of “frustration and anger in the face of marginalisation and institutional discrimination” (p. 577), due to a shared understanding of discrimination and rejection of normality.

Susinos (2007) follows the social model of disability in studying the social constructions of exclusion by using a narrative technique that enables the perspective of the people involved to be heard and, additionally investigating the barriers that the young people involved found most significant. This paper highlights the importance of studying exclusion “from the inside” or “giving voice” (p.122) arguing that these voices are all too often not heard in the policy planning. The wheelchair users in this present research do react against ableist assumptions and what emerges through the retelling of these stories indicates a group dynamic that is an empowering, positive discourse.

Swain and French (2000) argue that a collective identity is actually a benefit to being disabled. It is very apparent, although difficult to translate across transcribed data, that members of this sports club have formed a very strong collective group identity. This is across a wide range of ages and different levels of ability.

2: Collective positive Disabled Identity

This study was designed to find examples where disabled youth reject the normalising discourses of disabled identities and the following definitions of disability offer different insights into how people construct disability. One noticeable similarity between them all is they all contain the word different.

P1: Disability………………. Well.. it’s a matter of…… it affects people differently, but ... if you can accept a disability when you’ve got one.. it’s lot easier, a lot of people can’t accept little disabilities and ......mines quite a big disability and I just get on with it....

P2: Disability is different to every individual.....the way I would define it for meself.. iiisss if I physically can’t do something then I would call that.. to me it’s a disability.

Y2: Disability is when you’ve got to do things differently to get around the way you are and it’s not necessarily bad it just means it’s different to the way lot’s of people live. It’s when you’ve got to do things differently in your daily lives maybe.

Y1: If you look at the legislation.. it talks about how it impacts detrimentally on life and well, disability isn’t necessarily disability.. it’s different levels of ability.
Watson (2002) suggests that the way disabled identities are represented by disability studies is problematic, arguing that an identity based on a disabled/non-disabled dichotomy reinforces the notion of difference upholding normative assumptions. Some of Watson’s participants’ questioned normality and he argues against a collective identity of disabled people because it highlights difference and therefore othering people on the basis of impairment. None of the data within this present research referred to specific impairments. Watson argues against a common identity based on impairment suggesting that “difference between themselves and non-disabled people was simply the result of discrimination and prejudice” (p.514). From this perspective, it could be argued that the participants in this study were reacting to normative assumptions by highlighting difference. Conversely, the use of the word difference seems to indicate that this paper does agree with the affirmation model. Swain and French (2000) suggest that a shared experience and understanding of the barriers experienced by disabled people has helped build a “collective identity” (p.577). They call for a “celebration of difference” (p.578) arguing that the re-definition of disability as being in terms of socially constructed barriers has altered the understanding from an individual tragedy to one that becomes a shared experience.

Davis (2002) questions postmodernism offering the concept of a disabled identity which is not fixed, calling for a “malleable view of the human body and identity” (p26). This “dismodern” concept is what Davis uses to suggest the one thing we all have in common is difference. This dismodernist ethic, whilst suggesting we are all non-standard, questions how some people are oppressed by their disability because of normalising concepts which occur when using dichotomies as methods of categorisation.

In the following extract Y1 defines normality as difference, “being different is what makes us the same”

R: So in that case how would you define normality?
Y1: Variance, being different, you know, being different is what makes us the same. The fact that we are all different and all doing different things, is the norm, if you see what I mean, just one minute.....If you look at something as simple as..... If we all had blonde hair, how boring would we be. It’s that we are all different, we all like different things and we all need different things that, that makes the world go round.

This insight by an eighteen year old into dismodernism supports the idea that a disabled person’s collective identity is problematic. The data presented in this paper does not indicate a common identity based on impairment. Nevertheless, the data presented does indicate a commonality based on experience, this does not necessarily mean rejecting a disabled identity. Davis calls for
cosmopolitanism whilst challenging dominant narratives towards the
disabled body and disabled identity. The nature of the disability as
an unstable category enables a broader understanding of
oppressive systems highlighted by the statement “Impairment is the
rule and normalcy the fantasy” (Davis, 2002, p.31)

Y1: As part of my perception it’s .. you know, obviously we all
have different levels of ability, different things, but I don’t come
because we’re an accessible group, I come because I come to see
my friends. It is a club for wheelchair users but everyone’s so
different….

During many of the conversations the word ‘they’ was often used to
describe members of the public, health professionals, schools and
systems and this strong theme of us and them became very
apparent. Goodley and Runswick-Cole describe a dominant culture
of disablism in which these cultural discourses are “viciously
othering” disabled people (p. 8). Furthermore, the group in this
present research, when discussing such experiences, accepted
themselves as the other and re-otherised the perpetrators of such
experiences in a very disdainful way. A lot of humour, laughter and
reactions against cultural discourses occurred when sharing
experiences of these everyday examples of disablism as a group.

Y1: The best one was, have you heard of ?????? a children’s
rights organisation, well I did some training for them…..and the lady
at the start says stand up if you agree, you know sit down if you
agree, so me being on the front row went, excuse me….. Hiiiiiiiiii,
made a right show of her, I thought
Much laughter
Y1: How am I supposed to stand up, and at the end she
comes…she comes and says, are you Y1 and I thought, patronising
cow, and I said yes I’m Y1, yes I have a brain, and she went, I’m
sorry about before…..

Y2: The thing that annoys me is…. They want us to be
independent, but not to a certain extent……not to a extent to where
they’ve actually got to do something
R: What do you mean?
Y2: Well... Not to the extent where they’ve actually leave us for 2
seconds to do something on our own, they want us to be
independent…but with someone else.
R: Is that independence?
P3: No
Y2: No it’s not

Y1: Because they won’t, they won’t admit that they’ve cocked up
up to anyone.
Y1: A prime example, at a school in Cheshire. A young gentleman who’s got autism, he kept running off…. and the, the schools solution, to stop him running off and everything….. was to put him in a red top. Right so they can see him when he runs. The schools uniform is blue right, so he’s autistic and he’s going to want to wear blue, he going to want to be part of the routine, their compromise was…… we’ll put him in a blue top with a red cross on the back, just get me crossbow and shoot him shall I.

These particular anecdotes appear not to challenge traditional disability discourses. Through highlighting the cultural otherness that occurs through living in an ableist society, they are reinforcing the normative notion of difference. But in the collective retelling of these stories, the other became them and us became the group of people reacting against the normative assumptions of this other, in a sense the collective sharing of these experiences precipitated a re-othering of the otherisers.

This is highlighted by Reid, Stoughton and Smith (2006) who recognise how the “us them dichotomy” in disabling humour can uphold stereotypical representations of disabled people. They also suggest that disabled humour can promote solidarity through an understanding of shared experience: “Insider jokes highlight the common experience of being disabled” Reid, Stoughton and Smith, 2006, (p. 635), suggest this type of humour challenges accepted thinking, offering alternative perspectives or counter narratives:

“*This comedy is emancipatory. Sharing their lived experiences, revealing their multidimensionality and humanity, makes disabled comedians seem more Us than Them.*”
(Reid, Stoughton and Smith, 2006, p. 638)

In agreement, Shakespeare (1999) argues that in opposition to disabling, which occurs through mainstream assumptions, laughing about impairment focuses on shared assumptions and group identity and this offers alternative social assumptions.

Y1: Just out of interest, you use the term minority……. but obviously at wheelies, your in a majority, you’re on the flip side of it, so if you’re in a minority, who do you think puts you in that minority, do you put yourself in that minority or is it the way people look at you that puts you in that minority.

Y2: You don’t have to be in that minority, I go to a club where I’m not in a minority.

A criticism of the social model of disability is the maintenance of the disabled/non disabled dichotomy, but Reid, Stoughton and Smith
(2006) argue towards a positive disabled identity indicating the educational properties of comedy which “re-presents” disability in an alternative way to dominant discourses. This research does point towards a group identity based on collective experience. A disabled identity does not necessarily maintain the binary opposites, which uphold ableist assumptions because disability is only a small part of a person’s identity and not the sole identifier. Braidotti (2006) argues that nomadism is a form of critical consciousness and a way of resisting socially prescribed modes of behaviour and this relinquishing of a fixed identity can therefore be a way of subverting conventions. Nomadism offers new subjectivity and a way of negotiating the blurred boundaries between constructed categories and thus navigating multiple selves in response to life experience.

“Disabled people, perhaps nomads par excellence, are faced with the need to creatively re-configure and re-invent themselves to resist (professional) control, voyeurism, bio-power, existential challenges and oppressions that they have to face in their everyday lives” (Goodley and Roets 2008 p. 103).

A strong sense of group solidarity emerges in conversations amongst members of the club; this in itself is a positive affirming experience. Swain and French (2000) suggest that disabled peoples experiences can enable them to “have a heightened understanding of the oppression other people endure” (p.575). These conversations occurred when I asked Y3 and Y1 to give Y2 some advice about school:

R: I don’t think they even do that at your school do they, you tell
Y1: What happened when it snowed.
Y2: Oh well… I had to like sit in the physio room and like… do the work.
R: It was unsafe to get around the school.
Y1: You had to DO WHAT!!!!!!!, sorry?
Y2: To sit in the physio room and do my lessons.
Y1: I’ll tell you about the legality of that in a minute. That’s completely wrong, utterly and totally.
R: Not just Y2, all the other wheelchair children, but..
Y1: Was there anybody else in your class, was your class sitting in the physio room?
Y2: No
Y1: OK so, ok, yes the ramps are frozen, so yes it is dangerous to go on them, but shouldn’t your whole class sit somewhere else instead of just you.
R1: Yes that really annoys you doesn’t it.
Y1: If the areas aren’t accessible and….. the ramps are dangerous, aren’t the steps dangerous to use as well?
S1: Everybody should be safe.
Y1: Exactly, and legally, that’s defined as indirect discrimination, your school are trying to keep you safe, but you know…. If the ramps are dangerous then the steps are dangerous and no-one should be going into that dangerous area. And in terms of the law….. you could take your school to tribunal.

Y3 went to the same mainstream school, which Y2 attends, and both Y1 were shocked that Y2 is not allowed to use the lifts on her own. Between them, they gave her a bit of a grilling and became almost like a double act, to the point where they both spoke simultaneously:

Y2: Well yeah, they showed me.
Y3: So what’s stopping you....
Y1: Doing it on your own.
Y3: Doing it on your own.
Y2: I’m not allowed.
Y1: Why not?
Y3: Why not?
Y2: I don’t know, I just don’t challenge it.
Y1: Yeah but who’s is it saying you can’t do it, is it your TA’s, your teacher.
Y3: Have they still got the key code, you have to punch in a code to get the key.
Y2: No…. the teacher has the key.
Y3: So you can’t go up on your own then.
Y1: And would the teacher, if you said Miss or Mr, I’ve got wherever, wherever….. yeah I’ve got science or… but I need to go in the lift to get there,
Y1: would they give you the key
Y3: simultaneously: would they give you the key. (Y2 giggling)
Y1: Would they give you the key? Or would they say, no, no ******, you can’t go in the lift on your own.

In calling for a positive collective disabled identity, Swain and French (2000) highlight the politicising of disability issues through the Disabled Peoples Movement for example in the area of disability arts Shakespeare, Barton and Oliver state:

“Drama, cabaret writing and visual arts have been harnessed to challenge negative images and harness a sense of unity” (Shakespeare, Barton and Oliver, 1996, p. 186)

3: Tricksters

The theme of exclusion indicated examples where individuals react against normalising discourses of an ableist society. Conversations about such shared experiences offered insight into alternative perspectives and challenges to the dominant sociocultural and
institutional discourses. Some of the previous examples revealed normalising discourses that are rejected, even ridiculed and these texts highlighted challenges to the disabled/non-disabled dichotomy and assumptions of difference. The trickster metaphor is used to indicate a critical reflection of taken for granted assumptions of normality, and to White (2006) the trickster is someone who is open to multiple possibilities. The trickster is a lively character who defamiliarizes everyday norms. The following extracts indicate examples where people have reacted against the dominant knowledge bases, particularly in educational settings in ways, which arguably indicate trickster-like properties.

Y2 particularly finds risk assessments a waste of time:

Y2: Well if they don’t put down a hazard it doesn’t look like it’s painstakingly dangerous”

More advice about the lifts:
Y3: They tried the same with me and, and I couldn’t go up in the lift
S1: So what did you do?
Y3: I just went up in the lift, the ones that had key codes on.
Y1: Just go and climb the stairs shall you.
Y3: I was just er….
S1: You got your TA to tell you the keycode
Y3: Yeah, just ask and ask and ask them and…..I’d just ask them and eventually, they’d either give up..or
Y1: Make yourself a nuisance, make yourself a pain.
Y3: If they gave the key code out, what we used to do was…jam up the locks, so when they put it back on it wouldn’t actually lock

Y3: Moral of the story is……. Don’t let your classroom and teaching assistant tell you what to do, you tell them what you want to do.

On a discussion about classrooms:

R: Do you ever get a choice to where you sit?
Y2: No, not really
Y3: I was always at the front, but I don’t think it was because of the chair.

Y3 is proud of the fact that he was one of the only three pupils at his school to be given an award for special achievement when leaving school. Proud of the fact he refused to go to the ceremony to collect the award because two of the three recipients were wheelchair users. The ‘trickster’ metaphor is used to describe someone who crosses boundaries and breaks rules, and Wyatt (2006) and White (2005) use this metaphor to call for critical thinking within research and health practices and to question formal knowledge bases. White
calls for an “Academy of Trickster Excellence, (ATE) to train people to eat hubris” (p. 30) which is summed up by Y1’s advice to Y2 to “make yourself a nuisance, make yourself a pain”.

Baswell (2006) agrees with Sunderland, Catalano and Kendall (2009) regarding official and professional discourses, which uphold the negative perspective. He argues against disability as a category that he describes as a “monolith” rejecting the idea of a stable, individual condition. The TAB acronym highlights the division reflected by the term disability which he describes as “the rainbow of impairments” Baswell (2006) argues that disability equality schemes issued in line with the Disability Discrimination Act 2005 uphold the us/them, dis/abled dichotomy. He calls for disability equality schemes to change the concept of disability to one that recognises the “variety and ultimate universality of impairments.”

As with research about parents of disabled children, Singh and Ghai (2009), Salmon (2010), Traustadóttir (2009) and Watson et al (1999) all reflect that the voices of disabled children are under-represented in research, voices that could offer a unique perspective and could potentially question established knowledge bases. This type of research values experiential knowledge; Watson et al (1999) and White (2006) both suggest we should challenge the traditional roles of researcher/researched, and question established forms of thought and knowledge hierarchies. We should celebrate the need to question taken for granted rules and this is also reflected by Fisher (2007) who argues that parental reflections question the hegemonic understanding of what it is to be normal. She argues that services overlook the “expertise that disabled people and their parents acquire in the home environment” (p.285). Suggesting from the narratives in her studies that parents find ‘space’ to question pre-given prescriptions of normality enabling them to “embrace an alternative way of being” (p.294). Traustadóttir also argues that understanding different perspectives has important implications for the development of policy and practices and the provision of services.

There are many limitations to this paper as it only offers a few examples from a very small sample of wheelchair users, but this type of research is important as it opens up to the “rich contextual nature of individual lived experience” (Traustadóttir, 2008, p.6). Furthermore, it cannot be used to reflect on general attitudes and concepts of disabled people, whom, as this present paper signifies, cannot be represented as one homogeneous group. However, it does offer an insight to how people react to normative standards when they recognise themselves as other within a ableist society. Additionally this paper suggests that the recognition of other as a reaction against the tragedy model of disability can lead to a collective group identity, which is not centred on impairment but on common life experiences. In addition, reaction against societal
discourses can open up a space to question taken for granted knowledge. This process can be used “to find a lever for change,” (Parker, 1999, P3) enabling the voices of young people with disabilities to be heard who arguably naturally question cultural distinctions of normalcy. This type of research has the potential to gain insights into disability via the first hand experience of people who deconstruct such discourses through everyday normality.

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