What is disability? It depends whose shoes you are wearing": Parent understandings of the concept of disability

Kathy Cologon Department of Educational Studies, Macquarie University, Sydney Australia Email: kathy.cologon@mq.edu.au

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Abstract

This study investigates parent perspectives on the meaning of 'disability'. One hundred and twenty-one parents in Australia, each of whom have one or more children labelled with impairments, participated in this study. Parent definitions of disability are considered in light of the contrasting dominant deficit discourse involved in the medical model pathologizing of children labelled with impairments, and the social model positioning of disability as oppression of a minority group. Thematic analysis is used to examine parent views and to consider the relevance of social and medical models of disability to families. This study, that forms part of a larger study on family experiences of inclusion and exclusion, contributes to developing a deeper understanding of family experiences and the ways in which parents define disability. Overall, Thomas' social relational model of disability was found to be particularly salient to understanding the experiences of the families participating in this study.

We are all influenced by the context and time within which we exist. Attitudes towards, and understandings of, 'disability' are culturally constructed and embedded and people develop their understandings through a process of enculturation (Cologon & Thomas, 2014). For parents of children who experience disability 1, this is also the case. Parents' views are shaped by context and experience, as they are enculturated into dominant ways of thinking and being.

Thomson (2014, n.p.) writes:

…most disabled people are understood as foreigners within their own families, as an interruption in the continuity of sameness upon which familial solidarity is founded.

The narrative of likeness crucial to group unity fractures critically with the arrival of disability to a family or circle. This does not mean that disabled people are unloved or unaccepted within families or communities, but it suggests another way that congenital or early-onset disability can be understood as some version of wrongness, often a benevolent wrongness, because it violates the anticipated continuity of sameness as nondisabled status within families. In other words, the seeming wrongness of congenital disability lies in the narrative that the family has got the wrong child, a changeling for the nondisabled child who was expected. In such a case, the characteristic identified as disability becomes super salient, overwhelming the child's other characteristics and totalizing the family as nondisabled and the child as disabled.

This notion of an interruption to the "continuity of sameness" (Thomson, 2014, n.p.) points to the impact of the prevailing ableist medical model view of disability, centered on the notion of 'normal' (same) and, therefore, 'abnormal' or 'subnormal' (different or other) (Campbell, 2009). Brett (2002, p. 829) argues "parents can be 'initiated' into 'tragedy talk' from the moment of diagnosis." And yet, parents also frequently resist dominant and disabling discourses regarding their families (Cologon, 2014; Goodley, 2007). Indeed the family experience of disability can lead parents to examine previously unquestioned assumptions and understandings of disability and lead to family advocacy and activism (Carey, 2009; Green, 2003, 2007; Landsman, 2005). As, Thomson (2014, n.p.) goes on to assert, "…the wholeness of the child can fully emerge in family systems that absorb and embrace what once seemed foreign in the child."

How 'disability' is defined is a matter of debate, and varies across time and context (Finkelstein, 1980, 2004; Linton, 1998; Thomson, 2014). There has been discussion within the academy and the disability movement for some time regarding the meaning of the term 'disability', or what constitutes 'disability', who is disabled and how and why, and whether disability identity is helpful or obstructive (e.g. Davis, 2013; Finkelstein, 1980, 2004; Linton, 1998; Siebers, 2013; Thomas, 2004a; Thomson, 2014). Much discussion has centred on the social model of disability, which has been referred to as the 'big idea' of the disability movement (Hasler, 1993). Advocates of the social model have worked hard to redefine disability, and the articulation of the social model has resulted in considerable change in the understanding of disability for many people – with the potential for wider cultural change. At the same time, the medical model has continued to be pervasive at all levels of society. Indeed, it has been argued that the ideas of Disability Studies and the social model are not reflected in the views of many people who experience disability and their families, and thus are of limited use in reality (Shakespeare, 2004; Shakespeare & Watson, 2001). However, there is a need to determine what views

families actually hold and, therefore, whether the social model is of relevance to families. This paper contributes to addressing this gap.

In the present paper 121 Australian parents' understandings of disability, as defined by the parents themselves, are investigated. Of course, considering the perspectives of parents is not intended to infer in any way that the views of children are unimportant. Parents cannot speak for their children and the perspectives of children are of paramount importance in understanding the childhood experience and meaning of disability. However, children experience disability within the context of the family and their communities. Recalling her own family experience, Thomson (2014, n.p.) writes that:

In my own family, not only my disability itself but the very concept of disability went unmentioned, in part because it had become an unremarkable part of how we lived and worked as a family, but also because the matters of the body that feminism and black nationalism eventually liberated us into talking about were still considered faintly inappropriate topics in polite conversation.

Rather than perpetuating this silence, or filling the silence by making assumptions about the views of parents, seeking parent views directly is one important part of coming to understand the lived experience of disability of families. This requires talking to parents about disability.

Brett (2002) argues that no model of disability is adequate unless it takes account of the experiences of parents and children. While many parents may not explicitly state that they hold social or medical model understandings of disability, it is nonetheless possible that – within the diversity of families and family perspectives – parents may express understandings of disability that align with these models.

Parent understandings of disability

There are a plethora of studies conducted with parents of children who experience disability. However, the majority of these studies operate from an assumed understanding of disability (frequently a medical model understanding), rather than examining actual parent understandings of this concept. Nevertheless, there are some exceptions. For example, in research in the UK with 24 parents, Runswick-Cole (2008) explored understandings of disability in relation to an analysis of parent preference for inclusive or segregated education, finding that a social model understanding was more likely to be associated with a preference for inclusive education, while parents holding a medical model understanding were more likely to desire segregated education for their children.

Also in the UK, in qualitative research with four parents of children labelled with 'profound impairment', Brett (2002) found that parents experienced the social imposition of labels and disability on their child and family as a whole. This was experienced through their interactions with professionals and the medicalising approach of 'support services' (Brett, 2002).

Landsman (2005), in a study with 60 mothers in the USA, found that most participants had grown up with the (medical model) view that disability existed within the person, was caused by a mother's 'poor choices' and was undesirable, 'abnormal' and to be avoided. However, this understanding of disability was strongly challenged (or dis-established) by getting to know and living with their children in reality (Landsman, 2005).

This paper builds further on these studies by examining what 121 parents of children who experience disability in Australia understand 'disability' to mean.

The medical and social models

It is important to contextualise parent understandings of disability within the dominant (medical model) and alternative (social model) views of disability. A medical model holds that disability is a problematic within-person characteristic. From a medical model perspective, disability is considered to *be* impairment, thus the role of society in disabling people (and families) is ignored or not seen to exist (French & Swain, 2004; Thomas, 2004b).

At its most fundamental, a medical model view of disability considers disability to be something 'broken' inside a person. From this perspective, the required response is therefore to 'fix' the person, to try to change the person in ways that make it easier to 'fit in' with society, or to seek to eliminate the 'disability'… The medical model is also referred to as a 'tragedy model' or a 'charity model', due to the underlying medical model view of people who experience disability as tragic and in need of charity and pity. (Cologon & Thomas, 2014, p. 29)

From a medical model lens, a person who experiences disability is viewed as in need of 'treatment' for a 'condition' (Runswick-Cole, 2008). This leads to the assumption that a child who experiences disability is a 'burden' upon the family (Llewellyn & Hogan, 2000) and results in the experience of stigma for the person and the family (Green, 2003, 2007; Lilley, 2013).

As French and Swain (2004, p. 38) argue, it is not possible to "predict the amount of tragedy or happiness a person will experience in life." And yet, if a person is labeled with an impairment then people commonly do make such predictions based on the assumption that people who experience disability "want to be other than as they are" (French & Swain, 2004, p. 38). Therefore from a medical model perspective disability is viewed as a tragedy that "is to be avoided, eradicated or 'normalized' by all possible means" (French & Swain, 2004, p. 38).

Directly opposing this deficit based understanding of disability as personal tragedy (Campbell & Oliver, 1996), a social model understanding locates disability within society and recognises disablement as a socially imposed process consisting of barriers encountered by people who are labelled or designated as 'impaired' (Cologon & Thomas, 2014). Hence from a social model perspective disability only exists when these barriers are imposed and, thus, family experience of disability is caused by the social response to an oppressed minority (Llewellyn & Hogan, 2000; Oliver, 2004).

In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, mental or intellectual. The barriers disabled people encounter include inaccessible education systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media – films, television, and newspapers. (Oliver, 2004, p. 21)

A major point of difference between the social and medical models of disability is the separation of impairment from disability within the social model. From a social model perspective disability is imposed upon someone who has been labelled as 'impaired', while a medical model holds that disability is caused by, or equates to, impairment.

Whilst it is a defining distinction between the models, the separation of impairment from disability is also a major point of criticism of the social model (Barnes, Oliver & Barton, 2002; Barnes, 2012; Shakespeare, 2004; Shakespeare & Watson, 2001; Thomas, 1999, 2001, 2004a, 2007; Tremain, 2005). One particularly useful development of the social model that addresses this criticism, is Thomas' (1999, 2001, 2004a, 2004b, 2007, 2010) social relational understanding of disability. Recognising the social construction of disability and the personal experience of impairment, Thomas argues for the need to take account of the lived experience of disability, including the lived experience of impairment. Thus a social relational understanding of disability holds that: disability is defined by, and exists through, the lived experience of the body; that disability is created on the basis of unequal social relationships that undermine the psycho-emotional wellbeing of people labelled or designated as 'impaired' (and their families); and that disability is imposed on the individual through disabling restrictions carried out through social relationships and interactions (Thomas, 1999, 2001). Within a social relational understanding of disability, disablement is understood to occur through barriers to doing, barriers to being and impairment effects.

Barriers to *doing* can be understood as socially imposed environmental or economic barriers (material barriers) that restrict or prevent participation (Cologon & Thomas, 2014). Barriers to *being* constitute inappropriate, hurtful or hostile words or actions (at an individual or institutional/systemic level) that impact negatively on a person's

sense of self, or notions of being (psycho-emotional barriers) (Cologon & Thomas, 2014). Thomas (2007, p. 72) refers to the enacting of barriers to being as a process of psycho-emotional disablism, which "involves the intended or unintended 'hurtful' words and social actions of non-disabled people (parents, professionals, complete strangers, others) in inter-personal engagements with people with impairments." Barriers to being are also evident in images and representations of people who experience disability, or in the absence of representation (Thomas, 2007).

Impairment effects are: "the *direct and unavoidable* impacts that "impairments" (physical, sensory, intellectual, emotional) have on individuals' embodied functioning in the social world. Impairments and impairment effects are always bio-social and culturally constructed in character, and may occur at any stage in the life course" (Thomas, 2010, p. 37, emphasis original).

Barriers to doing, barriers to being and impairment effects are likely to have considerable impacts on the lives of families. The family (in its diverse forms) is the primary context of children who experience disability and, through the exclusionary and stigmatising processes of disablement, families experience disability. "Parents of children with disabilities must raise their children within the context of powerful societal discourse that devalues adults with disabilities and, therefore, holds low expectations for the ultimate 'success' of parenting children with disabilities" (Green, 2007, p. 151). This holds implications for parent understandings of disability and for the lived experience of the family.

The study

In this paper the understandings of 'disability' shared by 121 parents, who are participating in research regarding their experiences and views about inclusion and exclusion, are explored. Families continue to develop their understandings over time and thus the views expressed here are not fixed (Goodley, 2007; Runswick-Cole, 2008). Nonetheless, they provide insight into parent interpretations and experiences of disability.

This paper addresses the following two research questions:

1. What do families in Australia, who have a child labelled 'disabled', understand the concept of 'disability' to mean?
2. What models of disability are reflected in the understandings of disability shared by the participants in this study?

Participants

The families in this study come from diverse cultural and contextual backgrounds and reside in urban and rural settings in Australia, predominantly within New South Wales. One or more child in each family has been labelled with impairments (many children have been given multiple labels). Labels include Down syndrome, Autism spectrum disorder, Attention Deficit Hyperactivity Disorder, cerebral palsy,

intellectual impairment, sensory processing disorder, language disorder, hydrocephalus, Beckwith–Wiedemann syndrome and global developmental delay. The children range in age from 1-17 years (mean age is 8-years-old) and 53% per cent of the children are male. Additionally, six families with adult children (aged 19-28 years) participated in the study. Formal education levels of parents range from completion of grade 10 (two years prior to the end of formal schooling in Australia) through to post-graduate study. The majority of participants were mothers, with 8 fathers participating.

Recruitment

Parents were recruited via community organizations through online advertisements. Additionally, families who had previously participated in research with the study author, and had indicated an interest in further research, were invited to participate. Due to practical constraints, only English speaking parents were invited to participate.

Method

Participants were asked a range of questions relating to inclusion, exclusion and disability. For this paper, responses to the question "how would you define disability?" were analysed.

Participant responses were reviewed in full several times to develop strong familiarity and immersion. Engaging in constant comparison enabled identification of repetitions and patterns emerging from the data as themes (Ryan & Bernard, 2003). Themes and contrasts were repeatedly reviewed, refined and then considered in light of the social and medical models of disability, combining to form a process of inductive and deductive analysis.

Parent perspectives on disability

Analysis of the data revealed diverse understandings of disability as shared by the parent participants in this study. The themes that emerged from the data can be understood through the lenses of the social and medical models of disability. However, some parents' views cannot be simply categorized within one of these models, demonstrating the complexity of family experiences and views and the limitations of models that create a binary. These understandings were not isolated to parents of children diagnosed with any particular impairment labels ('type' or 'level'), rather there was a diversity of views across the sample.

Disability as socially constructed and imposed

Analysis of the data revealed that, consistent with previous research with families (for example, Goodley, 2007; Green, 2003, 2007; Lilley, 2013), the parents in this study face many barriers and oppressive exclusionary or stigmatizing encounters in their everyday experiences. In fact, the family experience of life with a child labelled

'disabled' appears to reveal to parents social and environmental barriers that result in exclusion or oppression.

In understanding disability as socially constructed and imposed through prejudice, exclusion and environmental barriers, the views of many parents in this study reflected a social model of disability. This is consistent with the findings of previous research where parents have identified society – not impairment – as the cause of disability (Brett, 2002).

"Disability is imposed on a person by those around them"

The social relational nature of disability emerged as a key element of understanding disability for parents in this research. Parents identified attitudinal (psycho-emotional) and environmental (material) barriers that produced, and therefore defined for them, disability. Rejecting the able/disabled or normal/abnormal dichotomy, families identified imposed disablement based on social interactions. Consistent with social model thinking (Finkelstein, 2004), the fluctuation possible in the 'degree' of disablement was acknowledged. As such, parents in this study argued that a person may be more or less disabled in any given context or moment in time depending on the responses of, or interactions with, those around and the barriers created through the interpersonal and environmental imposition of disability. For example:

Disability is the degree to which a person, because of environment, prejudices or expectations, is unable to take part in the everyday life of their family and community. Disability is imposed on a person by those around them. (Mother, Family #119)

Parents raised the role and processes of labelling as a powerful aspect of disablement that contributes to negative social constructions of disability. Barriers to being and doing were reflected in parent experiences of the process of labelling. Parents shared that while disability or impairment was for them "simply a label" (Mother, Family #104), they experienced the process of labelling as taking over their child's identity in the eyes of others, and being a determining factor in opportunities and interactions. This is congruent with previous research with parents who have found the process of labelling, or the application of disability or impairment labels, to be disabling in and of itself, and to result in the assumption that all barriers a child encounters are due to the labelled impairment (Brett, 2002; Russell & Norwich, 2012). As Brett (2002, p. 830) argues, "[b]y assuming that all difficulties that a child may demonstrate are solely due to impairment, the child is further disabled". These processes of stigmatization and psycho-emotional disablism (Thomas 1999, 2001, 2007) were experienced as painful and significant barriers to being in the lives of these families.

The role of stereotyping and prejudice in the response to labelling and in the social construction of disability was highlighted by parents. For example:

[Disability is] anything that is an impediment to being able to live a fulfilled life without prejudice. (Mother, Family #71)

Reflecting a high level of awareness, education and orientation towards advocacy and activism on the part of many of the families in this study, some families explicitly expressed a social relational understanding of disability in line with Thomas' concepts of barriers to being and doing. For example:

[Disability is] the experience of barriers to being or doing caused by unaccommodating attitudes, structures or systems. (Mother, Family #121)

Based on this understanding of disability as socially constructed and imposed, rather than focussing on changing or 'fixing' their children, parents focussed on the need for environmental change (removal or reduction of barriers to doing) as the core meaning of disability. For example:

[Disability is] the requirement for some adjustments in order to gain access at the same level as [the] mainstream population. (Mother, Family #73)

"Disability is when people are being excluded"

Consistent with the focus on the social imposition of disability, and the need for environmental and social change, an understanding of disability as exclusion was another theme that emerged. For example:

Disability is when people are being excluded in a society which is not catered for people with different needs. (Mother, Family #95)

Parents shared that being excluded (a process experienced as psycho-emotional disablism) led their children to view themselves as 'disabled' and therefore that exclusion was the cause of disability. This is consistent with a social relational understanding in which exclusion can be understood as a process of psycho-emotional disablism (barriers to being), alongside material barriers to doing (Cologon & Thomas, 2014). Echoing the sentiments of Paul Hunt in the early development of the social model, parents expressed that exclusion through relationships, expressed in words and actions, was a key factor in disablement. For example:

…relatives that buy presents for other children but not him because he 'doesn't know so it won't matter'. (Mother, Family #65 – Cologon, 2014, p. 99)

As Hunt (1966, p. 146) argues, "the problem of disability lies not only in the impairment of function and its effects on us individually but more importantly in our relationship with 'normal' people."

Disability as an individual, tragic difference: A medical model of disability

In stark contrast to parent views of disability as socially constructed, parents within the study also shared understandings of disability that appear consistent with a medical

model view. This is hardly surprising in the face of the dominant medical model discourse of disability.

"To have an impairment that limits your participation"

From a medical model understanding of disability, parents viewed disability *as* impairment and as an undesirable 'difference or 'deviance' from what is considered 'normal.' Parents who defined disability as impairment expressed the view that disability is a disadvantage and that participation limitations are a direct consequence of impairment. From this medical model understanding, disability was viewed as existing within the child, rather than as a socially imposed process of disablement. For example:

[Disability is] physical or intellectual impairment, which restricts or limits a person's ability to perform usual daily activities. (Mother, Family #116)

For some parents the notion of disability (as impairment) was defined simply as physical or intellectual 'challenges' or 'inability', while for others it was defined more broadly. For example, as:

Any mental or physical malfunction that prevents a person from using his or her full faculties. Even a chronic condition … is, in practice, a disability, because it prevents the person from working a full day, doing housework, studying, or in other ways, living life normally. (Father, Family #11)

"Requiring help, support and assistance"

Reflecting the dominant social focus on independence (French & Swain, 2004), parents identified the need of support or assistance as defining of disability. A view from which, by inference, needing support or assistance is essentially considered 'abnormal' or lacking in some sense. For example:

To me a disability means not having full capabilities and requiring help, support and assistance for everyday tasks. (Mother, Family #86)

Challenging this notion, Finkelstein (2004) argues that the natural human need for support has been pathologized and 'dumped' on people with impairments, whereas in reality all humans need support. This is consistent with the views expressed by one parent in this study:

Current societal definition of disability implies dependence on others where I see everyone in society as interdependent on each other, disability or not. (Mother, Family #78)

"Deviance from normal"

Some parents viewed disability as limitations to capability and as "any issue, physical or mental, that prevents a person from living fully in any way" (Mother, Family #63). Within this definition emerged the notion of 'full potential' and 'a valued life.' Consistent with an ableist deficit or tragedy based medical model understanding of disability, a 'valued life' was viewed as being necessarily negatively impacted by impairment.

Ableism is "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human" (Campbell, 2009, p. 9). Ableism is produced through the notion of 'normal' and the division enforced between the concept of 'normal' = human, and the concept of 'abnormal'/aberrant = subhuman (Campbell, 2012, p. 215).

Alongside disability as impairment, in this study, the ableist concept of 'normal' surfaced in defining disability, with disability understood as a person being 'not normal', 'different' or 'abnormal.' For example:

[Disability is a] physical, psychological or medical condition or diagnosis, which imposes a deviance from normal development, abilities or participation in normal life. (Mother, Family #72)

Finkelstein (1980) explores the way in which the categories of 'normal' and 'disabled' emerged through the rise of capitalism. Perhaps reflective of the ongoing insidious creep of the neo-liberal agenda into all aspects of life, the performance of 'normal' and notions of 'normal achievement' were also prevalent in parent accounts of disability. For example:

[Disability is] not being able to learn on a normal pace as others. (Mother, Family #32)

This understanding of disability as meaning a person is 'abnormal' or 'subhuman' is consistent with medical/tragedy model perspectives, from which it is assumed that people who experience disability and their families want to be 'normal' and "are subjected to many disabling expectations, for example, to be 'independent', 'normal', to 'adjust' and 'accept' their situation" (French & Swain, 2004, p. 34). Some parents appeared to have absorbed dominant ableist views of 'normal' or 'typical' and saw disability as the ways in which their child differed from this evidently desired state of being. However, the recognition of 'normal' as a social construction was apparent to some extent. For example:

A student with any medical or mental disability that makes them different from *what is considered to be normal*. (Mother, Family #54)

For some parents being 'not normal' in the view of society was considered a defining characteristic. For others, disability as 'not normal' was viewed as a barrier, but not as defining the person. For example:

A barrier to what is considered normal life, not something that is unsurmountable but something that makes things more difficult. (Mother, Family #84)

Medical model understandings of disability *as* impairment or as being 'abnormal' emerged in the context of care, education and support services that emphasize a medical model understanding of disability, with an emphasis on diagnosis and 'treatment.' Parents experienced their child's impairment label, or the aids that their child used to facilitate participation, as becoming the defining factor in the view of the child from those around, without recognition of the role of social and environmental barriers.

At preschool, the children where told that if our son attempted to hug them that they should high five him. However when the other children tried to hug each other that was allowed. Our son was portrayed by the teachers as 'different' therefore the children did too. (Mother and Father, Family #118)

"I don't define disability"

Some parents actively resisted overt or fixed definitions of disability. These parents rejected the concept of disability and viewed it as not being of value to themselves and their family.

Recognising the variable and socially constructed nature of disability, parents argued that what disability means depends on who, when and under what circumstances it is being defined and the view of humans underpinning the definition. For example:

Disability is a word that boxes indistinctly those people whose abilities fall short of world expectations. It is largely a construct to help understand, help and manage people who are different – What is disability? It depends whose shoes you are wearing. (Mother, Family #80)

For many families, disability was the experience of struggle. This was not necessarily struggle on account of impairment or struggle on account of socially imposed disability, but either or both – with disability defined as "to work harder or differently to achieve the same thing" (Mother and Father, Family #118).

Parents shared ongoing struggles to have their child's needs met, as well as struggles to have their children accepted for who they are – including the experience of psycho-emotional disablism. For example:

At the shops people will come up to me and say 'oh, the poor little thing, you must be so wonderful to look after him', or 'oh, they are such little angels aren't they, always so happy.' They seem to think my boys can't hear them or don't understand them. I find it so hard to know how to respond. How to explain that even though they THINK they are being nice, actually they are being horrible. These are my boys. They are not 'poor little things' or 'little angels', they are people – and they are listening! (Mother, Family #119 – Cologon, 2014, p. 102)

Foucault (1977, p. 151) argues, "whichever group is strongest establishes its own rules on what can be known and how it can be known." For many families in this study, the weight of the dominant medical model and the subsequent view of their child (because of the medical model) played a heavy role in the experience of struggle. Parents reported struggling with the feeling that their child was defined by their impairment/disability by those around them. Parents resisted this notion, arguing that disability – however it is understood – does not define a person, nor their life. For example:

[Disability is] only a part of who a person is and should never be the definition of the person as a whole. (Mother, Family #70)

For some parents within this study this led to a desire to reject the label of disability, and overt definitions of disability, viewing the notion as not having any meaning or value to themselves or their children. These parents preferred to focus on their child as a unique person with his/her own individual strengths and needs. For example:

I don't define disability. I recognise that my daughter has special needs to learn and participate in many activities. (Mother, Family #66)

However, contrary to common assumptions, but consistent with previous research (Runswick-Cole, 2008), none of the parents in this study appeared to be 'in denial' about their child's 'needs' or 'difficulties.' Instead, parents found disability labels and common concepts of disability to carry frequent negative associations that were not reflective of the experience of their family lives, nor the views they held of their children, and therefore not helpful. Whilst rejecting the negative connotations of disability as not being meaningful or useful, consistent with a social relational understanding of disability, parents acknowledged both the psycho-emotional disablism experienced through socially imposed responses to their child (social relational experiences), and the effects of impairment at an everyday level.

Conclusion

This paper considered what 121 Australian parents, who have a child labelled 'disabled', define as 'disability', and what models of disability are reflected in these understandings. In analysing the data, a range of understandings of disability emerged.

In the face of the dominant discourse of disability that commonly pervades the 'helping professions' and the processes of support within education systems, unsurprisingly, a medical model understanding of disability emerged as the view held by some families in this research. From this understanding, some parents viewed disability as impairment (with variations in what constitutes impairment) and as an undesirable 'difference' or 'deviance' from what is considered 'normal'. Within this understanding, some parents articulated the social construction of the concept of 'normal', while others appeared to absorb dominant ableist views of 'normal' or

'typical' and saw their child's disability as the ways in which they differed from this evidently desired state of being.

However, contrary to the suggestion that a social model is not relevant to the everyday reality of families who experience disability, in emphasising an understanding of disability as socially constructed and imposed through prejudice, exclusion and environmental barriers, the views of many parents in this study reflected a social model understanding of disability. This is consistent with the findings of previous research where parents have identified society – and not impairment – as the cause of disability (Brett, 2002). The family experience of life with a child labelled 'disabled' appears to reveal to parents disabling social and environmental barriers.

While many parents in this study demonstrated a social rather than a medical model view of disability, within the social model view it was clear that the individual experience of impairments was also an important part of understanding disability. Exploring family experiences more deeply – beyond the social/medical model binary – consistent with Thomas' social relational understanding of disability, parents identified barriers to doing (material), barriers to being (psycho-emotional) and the effects of impairment (bio-social) as creating the experience of disability.

A clear limitation of the study is that it does not consider the views of the children who experience disability themselves. The child's perspective is critical to understanding the lived experience of disability and to future developments of theories or models of disability. Interviewing the children in these families is an important next step for this research.

Nonetheless, it is also important to understand parent definitions. The bulk of research with families who experience disability assumes, rather than investigates, parent understandings of this concept. Frequently research with families is premised on a medical model view. The present study contributes to the finding that these medical model assumptions are inadequate or incorrect as many parents do not hold a medical model view and that the social model is directly relevant to parent understandings. Additionally, the acknowledgement of impairment within social model understandings appears important to many families in this research, thus highlighting the contribution of a social relational model of disability. This needs to be taken into account in future research with families.

In going forward, questioning the frequently negative assumptions regarding parent views of their children who experience disability is important. At the same time, the experience of struggle was very present in the accounts of the parents in this study. This has wide reaching implications for supports and 'service delivery', social awareness and research. Greater efforts are clearly required to break down the disabling barriers that families who experience disability encounter.

A genuine understanding of a social model of disability is essential for service providers and educators to create a space within which support services and

educational approaches can align with the views, needs and priorities of families, and to avoid the 'initiation' of parents into 'tragedy talk' that Brett (2002) outlines. While the need for a social model underpinning to 'support services' is certainly not a new suggestion (e.g. see Finkelstein, 1980), the focus on social model views of parents in this study contributes to the further development of this argument. Not only do some parents hold social model views, but the negative social relational experiences shared by the parents in this study highlight the ongoing need for a genuine engagement with the social model at the *core* of education and support services. This is not to transgress into what Gibbs (2004) refers to as the 'oxymoron' of 'social model services', but rather to engage with a social model understanding of disability as the foundation for the development of all processes of support.

While parent understandings of the concept of disability were considered in this study, the implications of these understandings for other parent beliefs or choices, and for the forms of support received (or not received), were not explored. Further research, including further analysis of parent responses in the broader study, is needed to address these implications. Additionally, given that the majority of participants were mothers, further research to investigate fathers' perspectives is needed.

The formal education levels of the participants ranged fairly widely (grade 10 through to postgraduate study). However, the considered and eloquent responses of many participants indicate that the level of education and awareness in regards to disability may be quite high in this sample. While some families shared experiences aligned with disability activism, this was not directly explored in this research. Further research could shed light on how common these high levels of disability awareness may be in this population of families and could explore family engagement in disability activism. Restricting the participant group to English-speaking families is also a limitation of this study that could be addressed through further research.

Drawing from the participants in this study, 'disability' can be understood as a complex combination of social and environmental barriers, as well as bio-social 'differences' or 'impairments.' While some parents in this study clearly held medical model views of disability, even in the face of the highly medicalized discourse families encounter in everyday experiences, many parents in this research demonstrate resistance to this tragedy perspective.

Parents acknowledged both the psycho-emotional disablism experienced through socially imposed responses to their child (social relational experiences), and the effects of impairment at an everyday level. These parent views do not always 'neatly fit' within either a medical, nor a "strong social model" (Shakespeare, 2004). However, the recognition of the social relational barriers – even in the rejection of the notion of disability – and individual impairment effects can be viewed as consistent with Thomas' social relational understanding of disability. Consequently, a social relational model of disability holds particular promise for understanding family experiences.

It is clear from the responses of parents in this study that the experience of disability creates many struggles – particularly on account of negative social responses that families encounter. However, the parents in this study resist the notion that *their children* are a tragedy or necessarily a burden. Parents in this study shared that their children are highly valued family members who contribute much to their families and to the community.

Sincere thanks to the parents who shared of themselves, their time and their family journeys in order to facilitate deeper understanding of parent perspectives and family experiences through this research.

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Endnotes

1. In writing this paper, I acknowledge that 'disabled person' is the commonly used term within Disability Studies. However, in reality in many contexts (including Australia), use of the term 'disabled person' commonly involves a negation or diminution of personhood rather than an acknowledgement of the social construction and imposition of disability. Furthermore, as this paper explores the views of parents of children who experience disability, rather than the views of people who experience disability themselves, it seems inappropriate to assign 'disabled person' as an identity marker. Consequently, the term 'person who experiences disability' is used throughout the paper to both acknowledge personhood and agency, as well as to highlight the social construction and lived experience of disability.