The impact of disablism on the psycho-emotional well-being of families with a child with impairment

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According to Carol Thomas, individuals with impairment are subjected to disablism. They are disadvantaged in material areas of life and also in the non-material domain of psycho-emotional well-being, by the impact of negative ideas, images and stereotypes about impairment and disability. Families with children with impairment have also been described as disadvantaged. Whether this disadvantage is the result of disablism is unknown. This study explored how disadvantage affects families with a child with impairment using Thomas’ iteration of the social model of disability. Twelve mothers were interviewed to understand their everyday routines and the influence of impairment in their family life. Family members did encounter prejudice associated with impairment, however, the mothers were able to ‘stand aside’ from this such that their psycho-emotional well-being was not harmed as Thomas describes for individuals with impairment. These families are nevertheless disadvantaged in that they do not enter social interactions on an equal footing with others. This paper describes the ways in which the mothers resisted prejudice. It also suggests that Thomas’ model may benefit from considering the harms of disablism from this perspective.

Keywords: families; disability; social model of disability; disabled children; prejudice

Introduction

The psycho-emotional well-being of individuals with impairment

Modern understanding of disability, spearheaded by social modellists, rejects the notion that disability is best understood as ‘owned’ by the individual and as a personal tragedy. Oliver (1990), for example, argued that disability as tragedy is a limited and distorted representation created by non-disabled others and imposed on disabled people. Instead, the disadvantage experienced by individuals with impairment is now understood as the result of social structures and practices failing to take into account the needs of individuals with impairment (Oliver 1990). Taking this viewpoint, scholars have highlighted the harm done to identity when disability is understood as an individual’s inherent lack or inability. When impairment resides within, people with impairment are understood as suffering the consequences of their unfortunate lack or incapacity.

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Ubiquitous cultural messages about impairment as tragedy, deficiency, lack, incompetence or aberrance negatively influence the identities of people with impairment (Abberley 1987; Hughes 2007; Shakespeare 2006; Thomas 1999; Watson 2002). As Abberley (2002) has noted, the understanding of impairment as inability and incompetence is an assault on the dignity and worth of people with impairment.

Thomas’ (1999, 2004) version of the social model gives equal place to the restrictive impact of disablism on non-material dimensions of life such as identity along with material dimensions. Thomas (1999) noted how negative and stereotyped meanings of impairment and disability can infiltrate the consciousness of disabled women and undermine their psycho-emotional well-being. She gave the following examples of the undermining of psycho-emotional well-being: ‘feeling “hurt” by the reactions and behaviours of those around us, being made to feel worthless, of lesser value, unattractive, hopeless, stressed or insecure’ (47). She suggested that these negative ideas about impairment gain their power to seriously harm when they are taken in and become an internal barrier to how one thinks and feels about oneself: ‘prejudicial meanings, ideas, discourses, images and stereotypes impact upon disabled people in diverse ways and can lodge themselves in their subjectivities, sometimes with profoundly exclusionary consequences by working on their sense of personhood and self-esteem’ (47–48). For Thomas, prejudice restricts the potential of people with impairment and acts as a barrier to realization of being – that is, negative ideas, images and stereotypes about impairment and disability, when internalized, become ‘barriers to being’. Thomas’ concept of ‘barriers to being’ has been taken as the psychological impact of prejudice broadly (e.g. Reeve 2004). For the purposes of this study, we understood ‘barriers to being’ to be when prejudice profoundly undermines personhood and self-esteem.

This is not to suggest that people (and women more particularly) with impairment are hapless victims of disablism. Indeed, for Thomas as well as other scholars who themselves have disabilities (e.g. Asch and Fine 1988) people with impairment resist and act against disablism in their lives, and can develop a strong sense of self-worth. For Thomas, however, resistance is always necessary to address the damage done by the material and non-material dimensions of disablism.

The psychological well-being of families with children with impairment

There is considerable evidence that families with a child with impairment experience disadvantage and that disadvantage for these families may extend to non-material areas of family life. For example, maternal well-being is lower in families with children with impairment (e.g. Blacher, Neece, and Paczkowski 2005; Emerson and Hatton 2007; Emerson, Robertson, and Wood 2004). Little is known, however, about harms experienced by families from a social model perspective.

How the psychological well-being of families of children with impairment is understood has changed over time. According to Ferguson (2001), in the period after the Second World War, the presence of a child with impairment was thought to be harmful for the family. Mothers received particular attention. They were thought to be psychologically damaged by their mourning the loss of the imagined, wished-for ‘normal’ child (Solnit and Stark 1961, 533). A related view at this time was that parents with children with impairment experienced ‘chronic sorrow’ (Olshansky 1962). As Olshansky noted, parent sorrow is the ‘natural response to a tragic fact’ (193), and if, on occasion, a parent denies the ‘reality of the child’s defectiveness’ (191), this is because denial ‘may help the parent to tolerate better the terrible reality that confronts him each day’ (191). From this chronic
sorrow perspective, tragedy is intrinsic to impairment. Summers, Behr, and Turnbull (1989) suggest that the concept of chronic sorrow has an enduring appeal because it accords with the popular belief that having a child with impairment is inevitably a tragedy.

The devaluing of a person, adult or child, with impairment might then ‘spread’ to those around them, such as their family members and associates. When dominant norms call into question the personhood of the person with impairment (Landsman 2005), especially for those with intellectual impairment (Parmenter 2001), this may also affect the personhood of family members. Such a notion is not new. Goffman (1963) used the term ‘courtesy stigma’ to describe the spread of stigma from the stigmatized person to those close to them. For children with impairment, stigma can extend to their parents (Birenbaum 1992; Darling 1979; Green et al. 2005). For example, Darling (1979) described parents as achieving a positive view of their child with impairment despite the stigma they experienced in particular in their interactions with medical services. According to Gray (1993), parents of children with autism view themselves as stigmatized by their child’s ‘disorder’.

Landsman (1998) suggested a different effect, that is, that mothers may take on socially derived guilt and blame for failing to successfully reproduce. However, they also resisted the socially ascribed notion as a producer of ‘damaged goods’ through their affirmations of themselves as ‘real mothers’. Like the parents in Darling’s (1979) study, this was particularly pertinent in the way they challenged medical professionals who held little hope for their children. As ‘real mothers’ these women assumed they knew best about their children.

Green et al. (2005) questioned the direct and vicarious experiences of stigma according to five dimensions of stigma: labelling, stereotyping, separation, status loss and discrimination. These authors conducted interviews with seven mothers of children with varying impairments from preschool to high school age as well as eight adults with various impairments. They concluded that stigma as acts of separation, that is, hostile or even violent acts of social shunning, was most damaging. It was then that participants experienced profound feelings of ‘otherness’ and this form of stigma was the most difficult to resist.

Green, in other work (2003, 2007), has suggested that stigma has a negative emotional impact on mothers of children with impairment. In her 2003 study, and on the basis of survey questionnaire responses from a group of 81 mothers of children with impairment in Florida, and qualitative interviews with a small subgroup of these mothers, she found that stigma added to the burden of care for mothers. She drew attention to the negative attitudes of others but did not suggest that mothers internalized these negative attitudes, nor did they constitute a threat to their sense of self-worth as women and mothers.

McKeever and Miller (2004) suggested that mothers of young children with impairment become marginalized and stigmatized along with their children. From interviews with Canadian mothers of children with impairment they reported that mothers overcame the devaluing stigma and presented their child and themselves as capable, co-operative or dignified to others in the fields of medical care and education. Neely-Barnes and colleagues (2010) noted various parent responses to negative attitudes about their child with impairment. They described some parents as advocating and informing others on behalf of their child with impairment, with others working to hide their child’s impairment so as to avoid having to challenge the disablism they were experiencing. They suggested that some parents held negative attitudes and thus were less able to resist disabling prejudice.
Voysey Paun (2006), in a classic study of the experience of families with a child with severe impairment, suggested that families were constrained to present themselves as competent and normal because of the challenge to their identity posed by the presence of a child with impairment. Todd and Jones (2003) echoed Voysey Paun’s finding when they described how mothers of children with intellectual impairment struggled to have their view of themselves and their families as ordinary people confirmed by professionals. They interviewed 30 mothers of young people with intellectual disabilities in Wales about their perceptions of their dealings with professionals. The mothers resisted the professional-derived identity as ‘special’ parents because it threatened to overshadow any other aspect of their identity. Shearn and Todd (2000) had earlier described how some mothers of children with impairment faced a particular challenge in being seen by others as a person in their own right rather than only as a mother to a child with impairment.

The studies described so far suggest that the social responses to families of children with impairment can add to the burden of care, stigmatize non-disabled family members and impact families’ ability to present themselves as ‘normal’ or ‘competent’. It appears that this has some parallels to the social response to individuals with impairment, in that both groups are perceived as harmed by the presence of impairment, and both groups resist social responses to build a strong sense of self. The process involved in resisting social responses and the impact this has upon the well-being of family members, who are not themselves impaired, is not yet understood.

The social model of disability
The social model offers a particular explanation of why the disadvantage associated with impairment arises and is perpetuated. However, the social model was developed to understand and improve the situation of people with impairment rather than their family members. The social model’s uncoupling of impairment and disability in understanding disadvantage has led to deeper insights about societal processes of disablism (Thomas 2004). Perhaps this social model perspective and understanding of disablism can help in understanding and explaining the stigmatizing effects of child impairment on family members.

Dowling and Dolan (2001), using the social model, explicitly advanced the argument that families are disabled along with their children. Their study is based on interviews with 22 parents of children aged 0–18, as well as with children and service providers. They observed that caring for a child with impairment could harm the mental health of carers, linking this to what they saw as a ‘sense of isolation for the disabled child and the parents’ (30). And, they argued that this exclusion is not inherent to impairment but rather is ‘social in nature’. In so doing, they point to the prejudiced responses of others playing a role in harming the well-being of families with a child with impairment.

The current study builds upon the studies briefly described earlier that suggest that the identity of family members and mothers in particular, is negatively affected by having a child with impairment. The aim of the study reported here was to explore whether Thomas’ concept of barriers to being as a manifestation of disablism applies to families with children with impairment, and if so, in what way.

The social model offers a particular perspective on the reasons that people with impairment experience social disadvantage and challenges the idea that impairment is the cause of social disadvantage. Thomas’ social model was chosen because it opens up investigation of the potential impact of non-material factors, such as stereotyping, on family identity.
Revealing whether barriers to being operate in family life has the potential to inform and change the way families with a child with impairment are understood. Importantly, and consistent with the social model’s concern for advocacy, using the social model to understand the experience of families might suggest how families with a child with impairment could be supported to overcome the disablism they encounter. Families may have the potential to mediate and reduce the harmful effects of disablism on their child with impairment. Family members, in particular mothers, can create opportunities for their child with impairment which can reduce and even overcome the disabling barriers that their child faces (Ryan and Runswick-Cole 2008). If families are disabled by barriers to being, this may impinge on their ability to promote the well-being of their child, and therefore further add to the harms of disablism. The social model proposes that for individuals with impairment, changes are required to the social fabric that produces prejudice, not to the individual’s psychological adjustment (Thomas 1999). If the psycho-emotional well-being of family members is also undermined by disablism, then social change is required to address this harm along with the other harms of disablism.

Method

Interviews were conducted with 12 mothers of children with impairment, focusing on their family’s everyday routines. This approach comes from eco-cultural theory, which was developed to study families with children with developmental delay within their sociocultural context (Gallimore et al. 1989). Eco-cultural theory proposes that the core challenge for all families is to create and maintain a sustainable and meaningful routine of daily life. The pattern of families’ daily lives depends on their understanding of both the challenges they face and the resources available to them to meet those challenges. This understanding of family life provides an alternative to the ‘family stress’ model of family life, in which impairment is understood as a possible source of stress to families (Blacher, Neece, and Paczkowski 2005). Eco-cultural theory proposes that the everyday routine of family life reveals the social and cultural structures and processes within which individual families construct their routine. The method derived from eco-cultural theory to capture the family’s daily life is the eco-cultural interview (Gallimore et al. 1989). Importantly, eco-cultural theory and the method that derives from it, the eco-cultural interview, accords strongly with Thomas’ method for understanding the lives of individuals with impairment.

To understand family routine the family perspective is obtained from the point of view of the primary caregiver, the person who ‘orchestrates’ the family’s daily life. In all cases in this study, it happens that the primary carer of the child with impairment was the mother.

This study was part of a larger study reported elsewhere (reference withheld), which developed a tool to measure the sustainability of the routines of family life in families with children with impairments. All 12 participating mothers were those interviewed by the first author and agreed to their interview data being used for this smaller study. No mother interviewed by the first author refused participation in the current study. All had children who were clients of the specialist government disability service in New South Wales (NSW), Australia. To be a client of this service, the child was either under 6 years of age with a developmental delay in at least two areas of functioning, or 6 years or above with an intellectual impairment and ‘significant deficits in adaptive functioning’ (DADHC 2004). Families recruited to the study had a child aged 0–6, 10–14 or 16–21, and all spoke English at a level not requiring an interpreter.
While the families in this study have in common that they used services for which their child’s impairment was sufficiently severe to qualify, the children in the sample of 12 families experienced a broad range of impairments. Some have severe physical impairment, while others were physically active and independently mobile. The behaviour of some of the children was challenging. Three mothers were from non-English speaking backgrounds. Family income and socio-economic background varied; some families had sufficient income whereas others, including two primary carers who were single mothers on government benefits, struggled financially.

Interviews were audio-recorded and transcribed. Interviews were semi-structured and explored the eco-cultural domains of family life: accessing special services, financial resources, home and neighbourhood, sharing workload and responsibility, balancing needs and demands and the extent to which the child was integrated into the everyday world. Thus, mothers were not asked directly about their encounters with prejudice or negative experiences. Their experiences of the non-material disadvantage of impairment and disability were ‘read’ from their accounts of their daily lives of living with impairment and disability.

Analysis proceeded in three stages. Open coding was conducted to compare the family narratives of their lives and develop an understanding of family life that was grounded in the family’s experiences (Richards 2005; Strauss and Corbin 1998). Second, following open coding, instances suggestive of the presence of disablism in the form of barriers to being were grouped together. Disablism was not presumed to exist; it was treated as a ‘sensitizing’ concept that earned its way into analysis through the data (Glaser 1978). Thomas’ (1999, 47) description of the psycho-emotional dimension of disablism as the result of negative images, ideas and stereotypes was used as an organizing guide: so, for example, where a mother described an encounter with a person holding negative attitudes about disability or impairment, this was selected as a potential instance of disablism in the form of barriers to being.

Finally, codes were analyzed utilizing Thomas’ definition of the undermining of psycho-emotional well-being. According to Thomas, barriers to being result from the negative impact of prejudice on psycho-emotional well-being. Encounters with prejudice do not necessarily negatively impact well-being. Many of the women of Thomas’ study resisted and continually renewed their resistance to negative social messages regarding impairment to develop strong senses of self-worth. Resistance could take the form of personal development efforts, artistic work or activism. For Thomas, however, the work involved in such resistance was necessary in order to resist the undermining of psycho-emotional well-being.

Instances where parents described encountering prejudice to do with their child’s impairment or disability were examined for the impact on family members, and scrutinized to determine whether there was evidence of Thomas’ concept of barriers to being. Thomas’ proposed mechanism by which negative ideas, stereotypes and images about impairment cause harm was used to guide analysis of the extent to which encounters with prejudice experienced by families resulted in barriers to being. In what follows, pseudonyms are used to protect participant confidentiality.

Results

Encountering prejudice

Mothers described many encounters with others who held negative views about their child with impairment. For example, Trudy, the mother of a 12-year-old with severe
intellectual and physical impairment, described feeling angry when a stranger advised her to institutionalize her child. As Trudy understood this, the stranger had felt entitled to share her views and did not seem to sense that they were offensive to her. The stranger’s views appear to stem from thinking about a child with severe impairment as obviously inferior to other children, and to the point where that child could be removed from their family and ‘discarded’. The impairment of the child was paramount, overriding any other considerations to justify the child being treated very differently from other children. Although this attitude may not be widespread, with Trudy reporting that for every unpleasant encounter she experienced other people wanting to be kind and generous to her and her son, the existence of this negative and prejudiced view nevertheless demonstrated for Trudy the way in which her son was seen by some as defective.

Negative prejudicial judgement about a child with impairment may also contain implicitly or explicitly a negative judgement about the family as well. In the instance suggesting Trudy to institutionalize her child that there was something wrong with Trudy’s judgement for keeping such a child was also implied. Other mothers also reported that their child and they as a family were judged as wanting or as damaged by having a child with impairment. For example, Maureen said that one of the hardest things about her 4-year-old son Danny was going down the street to do her shopping and being asked by strangers what is ‘wrong’ with him. When she told them about his chromosomal disorder, ‘they immediately jump on the pity bandwagon’. Maureen rejects their pity because, for her it is based on the misguided idea that it must be terrible to have a child who is not normal. She explains her situation and how she corrects misperceptions as follows:

A lot of people will come up and ask you about it and you sort of, you know, you’ll launch into your whole pre-prepared speech pretty much of, you know, of well this is what he has, and this is how it affects him, and all that sort of stuff and, ‘oh you know, you poor thing’. And I’m like, ‘Well don’t feel sorry for me! You know don’t, please don’t’. He is – like and I’ve sat there in the middle of a shopping centre or supermarket or whatever and given people a lecture on you know, ‘don’t feel sorry for me’, because, you know, my son is beautiful no matter how he is, you know, and people’s perceptions of it are really hurtful sometimes, you know, and that’s what makes it hard a lot of the time because, you know, people say ‘Oh well how do you cope not having a normal child?’

Belinda’s reflections below contrast with the experience of Maureen above.

[Others express to me] ‘I kind of feel for you, yeah, I understand what you might be going through, I’m a mother myself, I’d hate to be in that boat’. …I think 10 or 15 years ago there was a lot of finger pointing, a lot of giggling and a lot of; and I think it’s to do with the way society is now accepting children out. And I think it’s, like 20 years ago facilities weren’t around, and I’m thinking as time’s going on, community are accepting children. Like now Leo is at the mainstream preschool. He is inputted on all those children at school that are normal. So that is starting their life already beginning to understand that other people are different.

Maureen reacted angrily to the pity of others who judged her child and therefore her own lot as inferior because her child was not ‘normal’. Belinda on the other hand thought it understandable that another mother would not want to be in her position.

Families also encounter service providers who hold negative views about people with impairment and their families. Mothers frequently have to rely on services so they are not as free to avoid whatever prejudice they experience through contact with service
providers. Jean, who has a 16-year-old son with autism, described how she felt criticized by some of the respite carers who were, in her words, ‘looking down on you. And you already feel put down enough when you have children like that anyway, don’t you?’

Some parents commented that they had held negative views about impairment, or had not thought about impairment, before they had their child. For Trudy, she had no contact with disabled people previously and had not really thought about disability before having her son. Belinda also recalled that when she was pregnant with her son, who has severe developmental delay, she met a friend who had a daughter with severe cerebral palsy. She remembers thinking at the time that she would not cope with that.

**Responding to prejudice**

Families have to at least respond to negative attitudes, beliefs or ideas when encountered. Such encounters reveal the disrespectful nature of the ideas held about their child and their family. The child is seen as in some way less than a normal child, and the family viewed as damaged. Family members do not necessarily agree with these prejudiced ideas. Trudy, for example, dismissed the advice about institutionalizing her child as ignorant. Despite the offensive nature of this advice, her sense of identity and the value of her son were not threatened. Maureen understands that she receives pity because her child is seen by others as a ‘problem’ for her, and so she rejects that pity. As described earlier, she explains her situation to others and corrects their misperceptions. When Laura’s daughter is teased by another child at the park unchecked by their mother, Laura tells the mother to ‘wake up to herself’. Janice worried that any difficulties experienced by her other children would be attributed by others to their having a brother with impairment, so she takes care to give her other children attention.

Belinda puts a lot of effort into proactively countering prejudice by educating other children about her son Leo and ensuring he is well known in his local community. She actively works to counteract the prejudice that she knows Leo and his siblings are likely to encounter because of his impairment. She thinks that ‘there will always be someone who doesn’t understand’, and this sharpens her desire to protect all of her children. She sets about actively educating other people, especially other children, to include and value Leo. She wants them to learn that even though he cannot walk or talk, Leo is fun to be with. Consequently, she has ‘pushed’ to get him into regular preschool so that he is known and accepted by his peers. She shows Leo’s feeding equipment to other children who visit their home so that they will not be alarmed at his different way of eating. She also coaches her other sons not to react angrily if they are teased about Leo. Belinda is concerned that prejudice exists and will be experienced by all her children, so she takes steps to create a valued place for Leo. She worries that prejudice could harm her son’s acceptance in the community, however this does not, from her perspective, threaten the family’s sense of worth or value.

So far, the actions of mothers that have been described are actions in response to prejudice that influence others, through correcting, explaining and teaching. These activities have external objects, and do not appear to be focused on bolstering mothers’ views of themselves. Mothers did, however, report feeling negative emotion in response to prejudice. They may feel hurt or angry because they feel that they and their child are not understood, appreciated or accepted by others as they would like. Mothers also may feel that they are not seen as they would like to be. Diane, for example, works hard to care for her son, but she thinks very few people value her for this. She feels that her family is devalued and that social values need to change so as ‘to get that compassion and
respect back’. Diane is angry that others do not value her or her family as she feels they ought, but she also asserts the value of herself and her family. Diane’s family surround themselves with other families who also have children with impairments, whereas Belinda’s family are building networks with other local families in order to integrate their son into the non-disabled world. Both families have a strong sense of the value of their child and feel that they have to work to build the valuing of their child by others.

Understanding impairment and family life

Whatever prejudices they might have held prior to becoming a family the mothers of children with impairment in this study had overcome these through the experience of caring for their child. For them, the difference of impairment has become a fact of life, rather than, as they may have understood previously, an exception. Their experience of caring for their child seems to have developed in them a resistance to disablist ideas about impairment. Mothers may describe routine aspects of their family life that to an outsider might seem distinctly unusual. Trudy describes her daily family routine as like any other, even though some of the things she has to do are not typically done by other mothers of 12-year-olds:

It’s no real difference to any other family routine, except that it’s more hands on and more intensive. That’s basically it. I mean, you still have to get up in the morning, have a shower, clean your teeth, get dressed, have your breakfast, get his schoolbag packed, go off to school. I mean with Matthew it’s a little bit more intensive than that because he’s not able to do anything for himself. So he needs someone to do everything like that for him.

For Trudy, the difference of impairment is and has become a normal part of family life. Janice described the good relationship between her son Stephen who has severe physical and intellectual impairment and his siblings as really good and that ‘we’re all quite stupid with him, “cause he laughs at us”’. Even though Stephen cannot talk, Janice’s description of the quality of his relationships with his siblings emphasized the normality of those relationships rather than his atypical communication skills.

Mothers described their child with impairment in ways that present their child in a positive light, or in a way that challenges the idea that the impairment is their child’s defining feature. For example, Belinda compares understanding her son’s impairment to understanding the dietary preferences of children:

Consideration, but you do that with any siblings, you teach them to be considerate for other family members. Every family member has a different need. Some like tomatoes, some don’t. Like I’m saying everyone is different. So in our case, Leo’s different, but to us, it’s not…

By making such a comparison, Belinda is suggesting that having an impairment is not so different or unusual and belongs in the normal realm of children being fussy about their food. She emphasizes his capacities and talents rather than his deficits or problems.

There are aspects of impairment that are less than endearing for families, and are hard to live with, such as difficult, aggressive or destructive behaviour. Mothers can nevertheless describe their child without presenting those aspects of impairment that disrupt family life as their child’s defining feature. Laura described her daughter with impairment whose behaviour has autistic features as being like a much younger child, in order to explain why she is difficult to manage sometimes: ‘in her head she’s a baby’.
Maureen challenged the validity of the distinction between ‘normal’ and ‘abnormal’ altogether:

People say ‘Oh well how do you cope not having a normal child?’ and you know, what’s a normal child? Who’s to say what’s normal? You know, so that’s what makes it really hard, not so much that you’ve got a child with a disability because you love them regardless, and you know, it’s just people’s perception, I think.

Mothers in this study noted that gains and benefits for their family in having a child with impairment. Some of the gains mothers reported were the joys and rewards of parenting in general, while other gains were specific to raising a child with impairment. For example, siblings learn that not everyone can walk and talk, and they are more independent. Mothers also talked about the personal gains for themselves, such as becoming more patient, learning particular skills in caring for their child with impairment, becoming more assertive, feeling capable or feeling that they have a clear purpose in their life. Belinda says that her marriage has improved because her husband has become more involved in caring for the other children, and this has made him more ‘in touch’ with her as well.

Supporting children with impairment can have particular rewards. Because their developmental progress is slower, their achievements, being long awaited and worked hard for, can be very rewarding. For example, when Leo first climbed onto the coffee table, the whole family went crazy with excitement about his achievement. Diane’s young adult son William is starting to use single words. She said: ‘He’s doing things that nobody ever thought he would, and he’s a person that nobody ever thought he would be’. Diane feels a particular satisfaction that her child has exceeded expectations and shows a certain defiance of medical authority that predicted so little for her child.

An encounter with negative attitudes about impairment can be an opportunity for family members to affirm their values and beliefs about the family and affirm their commitment to their child. Maureen dislikes going to the shops where people make comments about her child or herself, but at the same time, she takes this opportunity to explain to others that her son is beautiful and that he is a person worthy of respect even though he is not like other children. Diane objects to the ongoing restrictions in her life that she experiences because of her caring role but at the same time she believes that she and her husband have grown through having their son:

I just think some people have this perspective of perfection, you know what I mean, and I don’t believe any of us are perfect, you know. The only difference is you can see William’s, you can’t see mine. I do have faults, but mine aren’t obvious, and I don’t think any of us are perfect, because really, I, I have learnt so much from having him. I’m a heaps, heaps better person for having him and I wouldn’t give him away, change him, or do anything with him, because, … to me, I mean, George and I don’t even think about his disability. We work, we know what we have to do, we do it.

In sum, when these mothers described their lives bringing up a child with impairment, they seemed to be working hard to create a valued place for their child, and saw their work in so doing as valuable.

Discussion

Similar to the findings of others (including Darling 1979; Green 2003, 2007; Landsman 1998; McKeever and Miller 2004), the mothers in this study encountered the prejudicial
and hurtful attitudes of others. They reported feeling misunderstood or devalued. These women, however, do not appear to experience the undermining of psycho-emotional well-being in the same way as individuals with impairment. For individuals with impairment, according to Thomas, barriers to being work to corrode belief in the value of the self and create internal barriers that inhibit action. Thomas suggests that prejudice exerts its harms when negative stereotypes are internalized, and when such views lodge themselves within (Thomas 1999). In this instance, individuals with impairment experience the destructive potency of barriers to being. Resisting such undermining of self-worth involves significant internal work (Thomas 1999).

This process does not seem to occur for families, or at least not for the mothers who were interviewed for this study. Where Thomas described women being made to feel devalued or worthless (1999), each mother in this study had a sense of the value of her child and of herself, and was likely to assert the value of their child, themselves or their family when they encountered prejudicial attitudes. Mothers such as Diane or Trudy might feel hurt in response to the prejudicial attitudes and ideas of others, but they were not internalizing the prejudices of others that they encountered. Indeed, the work they did to counter prejudice focused on others. They did not appear to take in negative attitudes about their child or themselves, and so their sense of their worth was not shaken or challenged in the profound way that Thomas described for individuals with impairment. As a result, mothers’ sense of the value or worth of themselves as parents and of their family as a whole was not damaged or diminished because of their encounters with negative attitudes or stereotyped views. Their understanding of impairment was not consistent with prejudicial stereotypes which denote a child with impairment as of lesser value or with impairment being the dominant attribute of the child or the family. Mothers worked hard to create a valued space for their child in the world and did not seem to doubt their value. Their resistance seemed engaged in work in the outside world rather than their interior world.

Indeed, the challenges of having a child with impairment reinforced for these mothers their worth and value. Mothers worked to articulate their values and advocate on behalf of their child in a way that could strengthen their family. How the families in this study were able to protect themselves from prejudice provides insight into how families promote their well-being and that of their child with impairment. Having a sense of the value or worth of the family in the face of prejudice about impairment is important for these families, because they often rely on services, which has the potential to challenge the ideal of the independent and self-reliant family (Voysey Paun 2006). When mothers describe how they as parents work hard and take responsibility for their child, they can rely on services without undermining their dignity and worth.

How can the negative impact of stereotype and prejudice on families be understood using the social model?

The impact on families of prejudice seems not to be destructive of psycho-emotional well-being in the way that Thomas describes for individuals, at least for the mothers interviewed in this study. At the same time, encounters with prejudice are not trivial or unimportant. The understanding that there are negative views about impairment certainly matters to families, and they may work hard to protect family members from the likely harms of such negativity, as for example described by Belinda. Even though families did not seem to experience the socially engendered undermining of psycho-emotional well-being, the prejudice that they encountered nevertheless
bespeaks disadvantage. Prejudice has an impact on family life. It matters to families in that families may be fundamentally misunderstood by others as burdened by tragedy, or misperceived as having a child who is inferior, leaving parents feeling misunderstood, hurt and angry, as evidenced in Jean, Maureen and Diane’s accounts. Even though they do not internalize the stereotypes to which they are exposed, parents strongly object to their child or themselves being stereotyped as inferior or lacking.

How then, within the social model, can the experience of prejudice by families be accounted for? It is suggested here that the harm to families lies in their being seen by others as pitiable, as abnormal or as lacking, even though family members do not accept or internalize these negative views. Thomas’ model identifies disablism as harming through the negative impact of prejudice on psycho-emotional well-being for adult women with impairment. One possible solution could be to expand Thomas’ model of ‘barriers to being’ to include any negative psychological impact, even where the sense of self is not undermined or diminished (e.g. Reeve 2004). This step, however, would not address the concern that Thomas’ model may overvalue the negative impact on psycho-emotional well-being for individuals in that it focuses on the outcome of prejudice. It may also need to now include the harm that arises from being misperceived. It may be that even where, in Thomas’ terms for individuals with impairments, psycho-emotional well-being is not harmed, stereotypes and prejudice about impairment and disability can still be understood as being harmful to disabled persons to the extent that stereotypes and prejudice prevent people with impairment from starting social interactions on an equal footing with others. The disadvantage for family members of children with impairment of being misperceived because of stereotype and prejudice may similarly be understood as a wrong, even though their psycho-emotional well-being is not harmed. The wrong lies in the misperception placing family members with a child with impairment on an unequal footing, compared with other families. It is thus suggested that the harm that families experience can be understood as a harm of misrecognition, rather than a harm that is dependent on the extent of psycho-emotional harm that is consequent on misrecognition.

The theoretical account proposed here for the harm posed to families by prejudice avoids identifying the harm of prejudice as solely about its negative impact on psycho-emotional well-being. It is proposed that families with a child with impairment are harmed when they experience prejudice, whether or not they also experience psycho-emotional harm. It may be that the process of having to deal with prejudice about impairment is a consequence of disablism, regardless of the degree to which psycho-emotional well-being is undermined. This theoretical account may be an example of what Fraser (2001) and others (Goffman 1963) have called ‘misrecognition’. Fraser proposed that ‘it is unjust that some individuals and groups are denied the status of full partners in social interaction simply as a consequence of institutionalized patterns of cultural value’ (2001, 26). As Fraser noted, one of the advantages of this accounting for the social harm or wrong of misrecognition is that identifying the wrong does not rest on the extent of psychological harm for the misrecognized. The social model of disability may be bolstered by clarifying that the harm of disablism along the psycho-emotional dimension lies in the harm of misrecognition, as well as in the undermining of psycho-emotional well-being.

Although not using a social model perspective, Green’s (2007) findings share a similar concern to acknowledge the harm that prejudice can do to carers. Green seeks to compare the harms to emotional well-being of material disadvantage and prejudice, and concludes that the greater harm of material disadvantage warrants greater focus for intervention. The findings reported here usefully add to Green’s findings, in that the
social model perspective framing the current study proposes that both material
disadvantage and prejudice are targets for social change. Identifying the harm that each
dimension of disablism causes is critical to then being able to overcome disablism.

Prejudice about having a child with impairment can also harm families when it works
to exacerbate material barriers in family life. Prejudicial ideas about impairment in
families, such as the idea that a family with a child with impairment should expect to be
treated differently because they have a child who is different, may serve to increase
material disadvantage, in the same way that social modellists have argued that the idea of
impairment as tragedy has been so undermining for individuals with impairment
(Abberley 1987; Oliver 1996).

Limitations

It is important to acknowledge the limitations of this study. We considered the accounts of
daily life of a small group of families and do not claim that the findings apply to all
families with children with impairment. The families in this study were clients of the then
NSW Department of Ageing Disability and Home Care, who were willing to participate
in this research project, and whose children had impairments that were evident and visible
at a first meeting. It may be that when a child’s impairment is not outwardly obvious,
family members may experience different kinds of prejudice. It may also be that families
who did not wish to participate in research experience having a child with impairment or
disability differently. The families in this study were purposively selected and with
varying life situations. The conclusions drawn about their experiences of prejudice may
not represent the experiences of all families. So, for example, it may be that some parents
do internalize disablist ideas (Neely-Barnes et al. 2010), however, this was not evident in
the sample of mothers in this study. The account of the harmful impact of prejudice
offered here need not invalidate other possible family experiences. It may be that families
who experience the undermining of psycho-emotional well-being were unwilling to
participate in research. This study accessed family life from the perspective of the primary
carer, the mother, as the person most responsible for organizing daily family life. Other
family members’ perspectives were obtained via the mother. Their perspectives,
independently gained, may yield a different view of family life. This study draws upon
Thomas’ particular iteration of the social model of disability, which was developed based
on the experiences of adult women with disability. Other social models of disability may
offer different perspectives.

Implications

The social model distinction between impairment and disability highlights the extent to
which harm for families is created by the social and often inadequate or inappropriate
response to impairment rather than being inherent in the experience of having a child with
impairment. Applying Thomas’ social model to family experience of prejudice throws
light on the mechanism by which prejudice can be understood as a harm to families of
children with impairment, even though prejudice is not internalized. Some of the
experiences of parents reported in this study, such as claiming a normal routine of family
life, are similar to the experiences of parents reported in different places and times (e.g.
Darling 1979; Voysey Paun 2006). The reasons for such apparent similarities over time
warrant further inquiry. The social model may benefit from identifying the disadvantage
of being misperceived due to negative ideas or stereotypes about impairment and
disability in social interaction, even where such interactions do not result in harm to identity.

How families view their own situation has implications for services. Services will be unable to respond effectively to family need if their own prejudicial ideas prevent service providers from hearing what families have to say. Services need to be made aware of and to support the ‘natural’ protective work of families, removing any distorted understanding of families and family life. A service approach that presumes that families with a child with impairment are different from other families is likely to be at odds with the families’ perspectives as documented here. The idea that these families are different from other families, because they experience particular stresses or sorrows, has this shortcoming. If families with a child with impairment see themselves as like other families, then a framework which assumes difference is unlikely to be acceptable.

Many questions await further exploration. These include the following: by what mechanisms do families with a child with impairment resist internalizing the prejudice that they encounter? Are there circumstances, as suggested by Neely-Barnes and colleagues (2010), in which families with a child with impairment do internalize prejudice? How prevalent are prejudicial ideas about children with impairment and their families? Is the impact of prejudice experienced by children with impairment similar to or different from that experienced by their family members, and if so in what way? To what extent are children with impairment protected from the impact of prejudice by their families? We offer this study and its findings as one step in a programme of research exploring these questions within a broader policy framework of understanding and planning social responses to children with impairments and their families.

References


