



Motherhood, Parenting & Women With Disabilities: A Literature Review

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Many of the mothers with disabilities that have been interviewed both in Australia and overseas have reported that society doubts that they can perform the job of mothering adequately (Elvish et al 2006; Aunos & Feldman 2002; Blackford et al 2000, Thomas 1997; Blackford 1993, 1999, O'Toole 2002; McKeever, 2003). Historically society has always disapproved of disabled women bearing children marginalizing them by using negative attitudes and by using a barrage of skepticism and prejudicial assumptions relating to an inadequacy when providing care and well-being for their children (Krowse et al 2002; Feldman et al 2002, Prilleltensky 2004). Therefore it is not surprising that parenting by women with disabilities is often seen as a negative experience instead of a positive event and despite the growing number of women in our society who have a disability this attitude still seems to exist. However as there are no agreed standards as to what constitutes "good parenting" how can one know that a "good parent" is? (Kroese et al 2002). Does each person rely only on their own childhood experiences? If this is the case then perhaps the reason why there are numerous negative studies regarding the correlation between dysfunction in children and parental disability (McConnell et al 2003, Feldman et al 2002, Prilleltensky 2004) is because most researchers are white middle-class, well-educated people with white middle class ideals. The myth surrounding women with disabilities has taken on an almost fairy tale like drama except instead of the girl being a princess, she is more likely to be depicted as being the mean, ugly hunchbacked witch (who incidentally is childless). These myths are kept alive by such notions as "all disabled families with children are cursed with a terrible misfortune from which they

never recover (OToole & Doe; 2002) and that “children born to disabled mothers are oppressed, presumably from the many hours of caring” (Blackford, K 1999)

The amount of information regarding mothers with disabilities is woefully few, with many papers being prepared overseas; Canada, USA and UK with very little literature pertaining to Australia. To prepare this paper a number of research papers were read and issues were identified by the number of times there were mentioned. These have been have been extracted and put into some semblance of order of importance as perceived by both the research and the women with disabilities that had been interviewed. The majority of research papers reviewed were qualitative in nature and held personal interviews with women who had a myriad of disabilities. Women who responded to these had disabilities that encompassed physical, mental illness, learning difficulties (also phrased as intellectually disability), chronic illness and MS. The main areas identified as problem areas were as follows; Support, both personal and professional; Information, availability or lack of; Transport; Accessibility, Housing and Economics. The following is a summary of findings:

SUPPORT

No parenting is undertaken in isolation and the higher the number of helpful support contacts that mothers with disabilities have, the higher the psychological well-being and the more positive the parental attitude became (Ehlers-Flint 2002; Kroese et al, 2002). For the purpose of this paper support has been categorized into two areas 1) service providers; encompassing personal care, medical authorities, wider community etc and 2) family, incorporating immediate and extended. It is also recognised that not all women need the same amount of support as others do. For example; a woman with a physical disability might need different support surrounding mobility issues than a woman with learning disabilities would

Many of the women interviewed reported that they felt that they were under the scrutiny of health professionals (Ehlers-Flint 2002; McKeever et al). There was a genuine fear that the child might be taken away if the “authorities” deemed the mother unsuitable (Thomas 1997) which caused many women to feel that they had to perform before family, friends and professionals to “almost over achieve” in their parenting methods (Thomas 1997). This fear also prevented many women from asking for too much help from either their community nurses or personal carers, feeling that too many questions may be perceived as not coping (Thomas 1997;

Llewellyn & McConnell, 2003; Prilleltensky 2004, Thomas 1997). When support was given by personal carers some women reported that the baby was ignored and all help was given to the mother "often overlooked or refused to support their mothering roles" (McKeever et al 2003). Several mothers were unable to receive adequate assistance with those housekeeping activities typically associated with mothering such as the cleaning of children's rooms, grocery shopping and laundry (McKeever et al 2003; 185). However, this finding wasn't consistent as Thomas states "many health professionals tended to take over the care of the baby instead of giving useful information (Thomas 1997). In some cases personal care services don't always appear to recognise that mothers with disabilities have obligations to care for others (Prilleltensky 2004, Reid et al 2003). By helping the baby and not giving enough support to the mother, the women interviewed felt that they were seen as being powerless (Thomas 1997). It must be noted that whilst health professionals had been identified as needing to be more helpful, many women also reported that not all medical authorities treated women with disabilities in this way and many were extremely supportive and caring (Thomas 1997).

All women reported that support could be given in two ways which they classified as helpful and unhelpful (Prilleltensky 2004, Reid et al 2003). Unhelpful support was when contact was spasmodic or irregular; when an over-burdened family could not give the time for example. In fact negative support can damage confidence and self-esteem, whereas positive support helps build empowerment and positive reinforcement (Ehlers-Flint 2002; Feldman, 2002) and all women stated that if they felt more positive about their skills when they were supported on a regular basis. Helpful support was also identified during times of crisis (Prilleltensky 2004, Reid et al 2003) and for relieving some of the stress of looking after children; child care (Kroese 2002). However, on the whole support needs were unmet within the community and for some women they felt isolated in employment, friendships, neighbors etc where they felt that they didn't know anyone well enough to confide in (Feldman, 2002). Whilst not much is known about the quality and level of assistance provided by neighbors, friends, community organisations or social service professional (Ehlers-Flint 2002) researchers felt that this was an area that needed further investigation (Ehlers-Flint 2002; Llewellyn & McConnell, 2002, Feldman, 2002, Kroese et al, 2002). Researchers did note that the relationship between the professional and the mother served as a model for the infant/parent relationships and is a laboratory for

developing abilities that contribute to that relationship (Ehlers-Flint 2002; Kirshbaum, 2000).

Support for mothers with disabilities was seen as being of extreme importance in order to provide a buffer zone to help mothers cope with raising children and family members and/or partners were ranked as being amongst the highest rate of support group (Ehlers-Flint 2002; Llewellyn & McConnell, 2003). This seems to be true especially for people with learning difficulties whose support outside the family was often lacking (Kroese 2002; Llewellyn & McConnell, 2002). In many instances family was the only support that mothers had, however some families, it was reported, had acted negatively when the woman became a mother which only added to doubt her competence. Women with intellectual disabilities have a high rate of abuse and violence from family members, which can obviously have a negative impact on their parenting skills if reliance on family is the only form of support (Ehlers-Flint 2002). In the main there appeared to be a genuine lack of resources for women with learning disabilities (Ehlers-Flint 2002). Mothers living with family often relied on their relatives for support and were less inclined to receive outside services which put the mother in danger of becoming socially isolated (Ehlers-Flint 2002). For it is a problem that most young adults with learning disabilities do not have friends (Ehlers-Flint 2002; Llewellyn & McConnell, 2002, Feldman, 2002, Kroese et al, 2002). Research also found that there was genuine fear from mothers with learning difficulties is, that if they don't appear to be good mothers then the child will be removed by the appropriate authorities. Likewise, suspected "others" within the community might be judging them and their ability to be good mothers thus they [the parent] tend "not to have anything to do with them" (Ehlers-Flint 2002).

It is therefore not surprising to note that mothers with learning difficulties are thought to be the most socially isolated parents in the community (Llewellyn & McConnell, 2002) and whilst there is a great deal of attention on parenting skills and abilities not much attention has been given on support from family, friends and the service system (Llewellyn & McConnell, 2002). It would appear that there is a definite need for service providers to be more actively involved in linking mothers into the wider community (Ehlers-Flint 2002; Llewellyn & McConnell, 2002). Ehlers-Flint in her paper "Parenting Perceptions and Social Supports of Mothers with Cognitive Disabilities" found there was a need for therapeutic support or intervention in the parenting attitudes of mothers with intellectual limitations (Ehlers-Flint 2002). This was a

successful method of supporting mothers because they felt that their therapist heard their concerns, were empathic and non-judgmental but straightforward and shared in a quality relationship (Ehlers-Flint 2002). Which seemed to be a general conclusion by many women that they were not asked what they wanted but instead was told what they wanted. (Prilleltensky 2004, Thomas). A condition that appeared to happen frequently, that in the face of "pervasive stigmatization" suffered by mothers with intellectual limitations, support that is respectful and adjusts to mothers' particular abilities and challenges can be effective (Ehlers-Flint 2002; Kirshbaum 2000). For mothers with mental illness, support when having a depressive episode, during hospitalization and after hospital care was identified as being extremely important (Thomas & Kalucy; 2003) but not readily available. As no information, in Australia, about this area was found at the time, it would be of interest to explore the type of support available for mothers with mental illness.

INFORMATION

Whilst there is a plethora of information readily available about women, their pregnancy and their babies there is very little information concerning women with disabilities who wish to become mothers. After many hours of research two books have been allocated; *Motherhood and Disability* by Ora Prilleltensky and ***** (both of which are books published out of Australia. NSW Network of Women with Disabilities are in the process of publishing a kit called "Pregnancy and Parenting with a Disability: A Resource Kit".

Internet searches isolated "*Parents with disabilities Online*"; *Through the Looking Glass*" *Disability Pregnancy and Parenthood International*"; "*Disabled Parents Network*", "*Moms and Dads with Cerebral Palsy*"; *Mothers with Attitude*"; "*MS Moms*" and "*Pregnancy for Women with Spinal Cord Injury (SCI)*". There is a newsletter for children of parents with learning difficulties called "*Healthy Start*" *NewsUpdate* which published out of the University of Sydney, for the federal government as an *Early Childhood – Invest to Grow* initiative.

The lack of available information was identified as a major issue with the majority of women that were researched reaching far back from the time when the women were girls. There is very little, if any, "facts of life" information given to girls or women with disabilities and hence mothers with disabilities may be less aware of what is happening to their bodies during the time of pregnancy than abled-bodied women do

(O'Toole 2002). If there is any information it is usually of the negative kind, that bombards women with statistics about the high rate of sexual abuse and the general negative aspects of disability. Information, it seems appeared to be very ad hoc, was sometime found by chance and from other people, now always from those who mothers thought would have the answers like the medical profession (Thomas 1997). The definite lack of literature not only impacted on the woman with the disability but also on the treating medical profession as well (Llewellyn & McConnell, 2002; McKeever et al; 2003). Any information found was aimed at white, middle-class, English speaking mostly educated urban mothers (McKeever et al; 2003) leaving those mothers who are already marginalized, more in the dark than ever. All women wanted information that targeted both mothers with [intellectual] disabilities and service providers, teachers and other relevant parties who, it was felt, needed to be readily available to help support women who wish to become mothers. (Aunos & Feldman: 2002). For information is power and with more knowledge mothers with disabilities can interact more appropriately and effectively with their children and parental responsiveness and affection can increase with instruction, modeling and feedback (Ehlers-Flint 2002: Feldman et al 1986; Feldman et al 1989). However, it is most important to note that training programmes need to be tailored to the learning style and instruction strategy of women's capabilities and comprehension (Ehlers-Flint 2002).

ECONOMICS and HOUSING

The majority of women in these studies lived in deprived conditions and this was of great concern (Kroese et al, 2002) to all mothers. Economic difficulties were reported as being burdensome (Ehlers-Flint 2002; Reid et al 2003, McKeever,) and impacted on women in different ways. Stresses of poverty and lack of support can compound difficulties. With a high rate of poverty, single parenthood and attitudinal barriers that characterize the lives of many mother with disability there is a high risk to the family well-being (Ehlers-Flint 2002: Prilleltensky 2004). For example; all the mothers studied in Feldman's research showed that those living independently all lived below the poverty line, were highly stressed and socially isolated (Feldman, 2002). And the impact of physiological and health changes in mothers with chronic illness were frequently exacerbated by reduced income associated with disability and motherhood (Reid et al: 2003).

For those mothers with physical disabilities the high cost of house modification was crippling for those living in their own home. A problem the world over appeared to be that limited government housing was available that catered for mothers with disabilities and this situation was forcing many women to live in rented accommodation (Ehlers-Flint 2002; Reid et al 2003, McKeever et al). For those mothers living in rented accommodation this also meant that any assistive devices needed could not necessarily be done (Reid et al 2003, McKeever et al). This may be due to the landlord being unwilling to pay for modifications or for women to invest a large sum of money into a property that was not her own. This was seen as an acute problem for when their disability changed then their housing needs changed which meant that many women needed to readjust if they couldn't economically afford to renovate or upgrade (Reid et al 2003). Problems with moving to different locations as disabilities changed was also a concern for when the children were older for many mothers lived in a home that was inappropriate and would not move because of the disruption to children's' lives (McKeever et al). Moving out of an area into an accessible home also presented problems with schools, transport and work as well (Reid et al 2003).

In all it appeared that there is a basic lack of funded supports that meet the requirement of mothers with disabilities (Ehlers-Flint 2002; Prilleltensky 2004) despite the fact there is a growing number of parents with disabilities and it is well documented that poverty, insensitive attitudes and inadequate services are impediments to any successful parental ability ((Llewellyn & McConnell, 2003; Prilleltensky 2004).

ACCESSIBILITY

Women with mobility disabilities reported many accessibility difficulties when caring for their children. Inaccessible actual space and public places for example; playgrounds, sports arenas day care centre (Reid et al 2003, McKeever et al:2003). Socialising the baby and the mother was harder because not all family and friends had physical access to their homes. This meant that lack of access took away any spontaneity of visiting when prior, lengthy arrangements had to take place in order to see someone (Reid et al 2003).

TRANSPORT

For mother who did not drive or had no access to a private vehicle, transport could be problematic and was often seen as unreliable especially for mothers who worked and needed to take and pick up their children from school (Reid et al 2003, McKeever et al; 2003). Overseas, many forms of commercial transport was also reported as being inflexible and unsuited to their responsibilities as mothers for many didn't either the facilities for carrying babies or the insurance for carrying your children in their vehicles (Reid et al 2003, McKeever; 2003).

OTHER ISSUES

Other issues that were raised included those initial worry that the taking of medication might harm their baby whilst still in the uterus and that stopping taking their medication would have an adverse affect on their disability. They also reported that many medical personnel gave them wrong or misleading information, almost as if they [doctors, nurses] were unsure what was safe and what wasn't. (Thomas; 1997). As the child grew older mothers that used wheelchairs worried about the impact that this image would have on them reporting that the "feared their child would be self-conscious of their mother in a wheelchair which might lead that child to be ostracised from their peers (McKeever et al 2003). Women also reported of the strain that doing all the things needed to do to look after children; spend quality time; do the housework; sometimes work from home. They also worried that they often "borrowed" from their sleep time and worried that this may impact on their disability in the long term (McKeever et al).

POSTITIVE ASPECTS OF MOTHERHOOD

Disabled parents appreciate the incredible gift that their children are to them; know that this interfamilial transmission of disability culture is a gift; are lucky to be parents and hence are fiercely protective (O'Toole et al) with pride, joy, company and playfulness etc ((Ehlers-Flint 2002; Kroese et al, 2002) being reported as delights to mothers. Of the many positives that mother with disabilities can bring, the ability to celebrate the difference of children, unlike perhaps non-disabled parents who see disability as a load or burden (O'Toole et al). Likewise mothers with disabilities are continually finding ways around problems, to adapt equipment and other technology to achieve their goals (Reid et al 2003), an attribute that shows determination and

strength of character has to been seen as a positive attribute to teach children (Ehlers-Flint 2002; Reid et al 2003).

CONCLUSION

It would appear that for parenting to be successful, mothers need to have support networks linking them into the community so that they and their children do not become isolated (Llewellyn & McConnell, 2003). For there are particular concerns about mothers living alone who have fewer long-term relationships which offer no emotional support. Likewise a study is needed to explore the nature and factors influencing changes in support networks over time.

There is a need to review the services provided to better promote family ties which in the long-term provides a better means of support instead of relying on transient service providers (Llewellyn & McConnell, 2003). Service providers need to be better trained and there needs to be a more sensitive approach together with a standardization of information that both mother and service provider can adhere to.

To approach families using in-depth studies that have positive parenting experiences and promoting positive child outcomes (Prilleltensky 2004) with the idea of identifying strengths of mothers with disabilities by portraying positive experiences would provide support in a two-fold manner. By asking mothers what "they" need and for providing support where it is need helps build positive support which is highly beneficial, for the paths our lives take are influenced by how we think and feel about ourselves; how we think others see us (Llewellyn & McConnell, 2002).. This type of work would help minimize difficulties or potential problematic family situations. By identifying and reducing social constraints the public perception of mothering with disability could shift to a more favorable direction (Prilleltensky 2004).

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