Modes of care and mothering: How does citizenship and care intersect in the lives of mothers of disabled children?

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Introduction
British feminists have long argued that welfare policies in the UK rely on gendered assumptions about care responsibilities, which maximise the role of women as carers while minimising the role of the state (Graham 1983; Lewis 1992; Ungerson 1987; 1990). The introduction of community care in the UK in the early 90s is one such example of a shift away from institutional care towards care within the community, which quickly became care within the home, by women (Baldwin and Twigg 1991; Orme 2001). Welfare policies have been able to rely on women to be informal carers through a range of social norms, cultural expectations and material practices which have positioned women as the presumed primary carer (Finch & Groves 1983; Finch and Mason 1993). Changes in household structures, women's involvement in the labour market and changes in gender norms have seen some move away from women taking on the caring role to the exclusion of other aspects of life and identity (Lupton & Barclay 1997; ONS 2007; Sullivan 2000; Ungerson 2000). However, feminists argue that social conditions, gender norms and welfare policies continue to create traditional demarcations of gender roles within the home (Charles 2000; McKie et el. 2002; O'Brien 2007).

Skeggs (1997) is one of the key writers who explore how gendered social and material processes continue to place women in the role of family carer. She explores how the contexts within which individuals are involved in caring activities frame and influence what is seen as care, who is seen as a carer, how care is performed and how it is received. Significantly, in an argument similar to that earlier proposed by Finch and Mason (1993), Skeggs argues that in social conditions of inequality and lack of material resources and options, women can internalise the caring role via incorporating it into their sense of self. Being the carer, offers an identity others validate as legitimate and valuable, when other identities are not available. Therefore, processes of both self-regulation and agency within gendered and class boundaries, influence the patterns of care women continue to enact and how they and others read it as part of their identity as women, mothers and workers. Therefore exploring the social, cultural and political contexts within which care occurs is important to understanding its significance (Kittay 1999). This also recognises that these processes and relationships between caring, identity and social position will be played out differently in different national contexts; crucially in contexts of different modes of welfare provision. Therefore it should be acknowledged that the specific connections between caring identities and roles and welfare provision made here are specific to the UK.

The focus of this paper is mothers looking after disabled children. This is done for several reasons. First, Traustadóttir (1991; 1995) argues that when a child is disabled equalities of care responsibility can quickly disappear as the more intensive care is still directed towards women. Second, in the past there has been hostility towards feminist work on care within disability studies. Disability writers have long argued, going back to the community care debates, that feminists are much more interested in

the 'plight' of the informal carer, than they are of what happens to the disabled person (Begum 1992; Keith and Morris 1995; Morris 1993a). This was seen very clearly when some feminists advocated a return to institutionalised care as a way to resolve the problems created by community care; institutional care which disability activists argue is a key factor in the marginalisation and exclusion of disabled people from society (Rummery 2002). This paper will bring together a discussion of women as presumed primary carer for a disabled child, with an appreciation of the implications for the disabled child in this way of 'fixing' the 'problem' of who looks after them.

The final reason for the focus on disabled children is that it is a useful vehicle within which one can discuss contemporary shifts within the organisation of care. New methods of providing and distributing care within the welfare system in the UK are reopening the debates about who should care for those in need of care and how it should be paid for. These shifts are very visible in the care of disabled children and have significant implications for how they are cared for, and by whom. For the purposes of this paper I am going to discuss just two shifts in welfare provision that directly affect the care of disabled children. The first is the greater emphasis being placed on early intervention programmes for disabled children, which advocate identification of disability or 'developmental delay' as early as possible, followed by therapies in the home, by 'informal carers', with the aim of minimising the severity of the disability. The second is what has been referred to as the increasing 'conditionality' of welfare provision; that is the increasing requirement for recipients of welfare to prove their eligibility to receive welfare assistance for the caring responsibilities they have (Dwyer 2004). This paper will explore early intervention and conditionality from the perspective of mothers who are witness to their significance in their daily lives and the care of their children. Through examining the perspectives of women providing such care in these contexts, the paper will discuss what these changes imply about how care and disability is framed within contemporary welfare practices. In doing so it will seek to draw connections between what care is said to constitute and who provides it, with broader questions about citizenship and social recognition of dependency for both mothers and disabled children.

The paper draws from an Economic and Social Research Council[1] funded study of families with disabled children, before moving on to that discussion I will provide a brief description of the study.

The study
The study examines the perspectives and experiences of parents with very young children, using methods drawn from ethnography in order to explore the cultural, social and material practices and relationships that make up and inform the parents' lives with their children. The research, which took place over three years, was based in two English regions; at the centre of the fieldwork were 33 families who were involved in the study for over eighteen months. A series of three in-depth narrative interviews (tape recorded with consent) were undertaken. In addition, observations of a number of formal and informal care encounters also took place. Alongside the work

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with the families mixed focus groups with professionals working in health, education, social care, and the voluntary sector also occurred.

The basis for a family's inclusion was that they defined their child as having specific care and support needs and that the child was within the age range used in the study. The study was framed in terms of parents, rather than, mothers, because we did not wish to presume, and indeed replicate, the gendered division of labour. Therefore recruitment sought both mothers and fathers; unsurprisingly the majority of people who contacted us to participate were mothers. Throughout the study mothers were in almost all cases the main carer of the child (the shifting gender dynamics around parenting and care are explored elsewhere (McLaughlin 2006; McLaughlin et al. 2008)).

Mothers as therapists
Across the boundaries of healthcare, social services and education, early intervention has become a defining framework for how young disabled children are looked after. Portage workers, physiotherapists and others visit homes to provide therapies, train informal carers in the techniques and monitor progress. Early intervention places great significance on informal carers participating in therapies and treatments. Often therapies are designed around every day life; bath time, feeding, and chatting with the child become opportunities to work with the child to improve their mobility, physical dexterity and language acquisition. The assumption is that mothers will incorporate these therapeutic activities into their caring role.

However, do mothers want to turn themselves into therapists and their home into a medical venue? From our study there were often times when mothers were concerned about taking on therapy roles, whether as part of helping their child's development, or simply to keep them alive, as part of their portfolio of care. For example, Frank was first released from hospital after being born premature still dependent on oxygen and tube feeding; technological supports Debbie, his mother, willingly took on in order that he could come home. Later, once Frank had improved and was no longer on regular oxygen, he suffered a serious infection that placed him back in the hospital and back on oxygen. Once the immediate crisis passed the hospital consultant moved to get the child back in the home as soon as possible. A plan was developed that would see his mother again in charge of monitoring his oxygen, this time Debbie, along with her husband, said no:

> … we'd dealt with oxygen, but not at those levels, and there's only so much you can cope with. We knew what was normal, for us 'normal' was the low levels of oxygen, whereas Frank was on high levels of oxygen. It gets to the point where you have got too many things to think about, I couldn't do it, we didn't want to do it… we'd had a period of nearly a year where he'd had none of that, he wasn't on oxygen. And then when it came to the point where we might have to do some of those things again, you don't want it. You're tired, it's then not normal… it's then a medical problem and somebody else will have to deal with it. (Debbie, IV1)

Debbie was concerned that their involvement in the medical management necessary to keep Frank alive, left little space or time to be his parents: 'if we'd come home and he

was monitored continuously, you get to the point where we would be watching the monitor and not Frank' (IV1). Such interventions were someone else's responsibility and did not belong in the home, where they turned an intimate family space into a medical arena. The intensity of medical intervention, in particular the presence of technologies that kept Frank alive, became, from Debbie's point of view, a barrier to parental care and response (Place 2000). Debbie's decision is counter intuitive to the assumption that mothers will always want their child home as soon as possible and will willingly take on the role of nurse or therapist in order to do so. In many cases this is what mothers would choose to do, but the actions of Debbie also highlight the implications of home based therapies. Such therapies necessitate a change in identity for both mothers and the intimate space of the family, which is not without cost. Home visits occur in a space that has a set of multiple intimate and complex meanings around family lives and identities (Levine 2005), yet it is within this space 'that professionals impart their expectations of children's development' (Leiter 2004: 840).

In addition, mothers did not always agree with the therapies being pressed on them and their child. In particular they queried those treatments unwilling to break free of medical models of development:

> The portage worker is an example of somebody who did nothing constructive to help. One time she brought me a chart to fill in and tick off tasks each day: achieved, not achieved, partially achieved, which is just too controlling and you can't do that. I felt she was policing how much I was doing each day, because she seemed to be disappointed with the level of progress that Joe was making. And, after that my feeling from her, was always this hidden agenda of, well you're not doing enough that's why you're not making progress, that's always what I got from her. (Kay, IV2)

Kay eventually asked the portage worker to stop coming; her decision came from a view that setting and achieving goals for Joe, made against markers of medically defined physical and mental development, was being privileged over broader criteria of what creates a child's quality of life. In addition the portage worker did not seem to allow Joe any choice or agency over whether he wished to participate in such treatments.

The societal and medical assumption is that the 'good mother' incorporates medical care into her caring portfolio; the implication of this is that at times mothers felt that they had little choice but to participate. Lisa, whose 3 year old daughter Zoe has cerebral palsy, spoke of striving to follow the treatments and exercises prescribed by the physiotherapists in order for her to improve. She put a huge amount of pressure on herself in order to prove to others that her child was developing. At the same time she questioned her ability to aid her child:

> She has her physiotherapy, which I do with her. I don't do half as much as I'm supposed to because she just won't tolerate it at all… It's like I've been taking her up to Pelican school because I really want her in there and in order to do that I've got to prove to the education authority that she will benefit from their methods… I know if she went to school there, and I wasn't there she'd just do fine. But because I'm there she just wants to be sitting on my knee and just wants cuddles and wants us to give her a drink and she just screams… I

quite often feel I'm not the right person to look after her, [pause] because I feel like she's not coming up to her potential with me because she's still so much a baby. (Lisa, First Interview)

Lisa follows the prescriptive requirements of physiotherapy for the promise of Zoe being allowed into the school that is her first choice; she is following this ritual to perform the role of the good and compliant mother (a role she feels others doubt she can achieve because she is young and single).

What lies behind the push for early intervention? It is perfectly feasible that a key aim is to improve the quality of life for young children with disabilities as they develop and to enable them to become participants in society. However, in the concerns some mothers have with it and with the processes embedded within, there are potential issues. While some interventions are geared towards keeping the child alive; others are concerned with improving the child, helping them get closer to normality. It is within the drive for normality that concerns of this mode of medicalised care can be raised. From a disability studies perspective it is possible to argue that the prioritisation of seeking normality is influenced by the importance of being normal to being recognised by others, state actors and social actors, as a legitimate citizen. The push to get better increases the requirement for children and their parents to work to overcome their disability, or they will be judged as different, other and less than those defined as normal. Psychological and medical therapies directed to get the child's development closer to normality help secure the importance of being normal to be able to participate in society. It emphasises that the child should adapt to the social requirements of a society ill equipped to deal with disability, rather than looking at adapting society to the differences created by impairment. Mothers are being encouraged to ensure their children can get closer to normality and therefore become as adults the legitimate citizens who are not a 'burden' on society. It is understandable that mothers participate in the regulative adaptation of their child, whether this is behavioural adaptation to be more 'acceptable,' or physical therapies aimed at helping the child speak or walk. Mothers recognise the social consequences of not being able to do these things and therefore they participate in activities which will shape their children into acceptable citizens.

While in contemporary society disability is being incorporated into the social body in ways that promise citizenship rights, at the same time, other social processes, such as early intervention, appear to heighten the importance of being 'normal' to also being seen as a citizen (Asch 1999; McLaughlin 2003; Rapp and Ginsburg 2001). The danger is that therapeutic practices associated with seeking improved development have the potential to disallow recognition of other forms of development and quality of life. When mothers reject some of the practices of early intervention what they are potentially doing is challenging this model of citizenship on behalf of and with their children and beginning to posit a different way of understanding what the purpose of care is and what its aims should be.

Conditional Care
As has been seen in other research with mothers with disabled children (Traustadóttir 1991; Traustadóttir 1995) mothers play multiple caring roles. The assumption, drawn from gendered norms and discourses, is that mothers play such multiple caring roles

because they are mothers. However, mothers do not necessarily see the ever expanding list of activities added to care as being something they automatically should do and indeed be able to do. In her first interview, Jane (IV1) commented: 'you're more of a carer than a parent: carer, psychologist, teacher, you name it you've got every role to play.' Looking closely at the language and narratives generated by mothers we can track aspects of the care they are excepted to provide for their disabled children, which they define as outside of what they perceive as the 'normal' care mothers should provide.

For example, mothers noted that their caring role would continue into their child's adult life; however, this was not always presented as a natural extension of the mothering role:

> I know he's only seven but I'm quite aware that he might not leave home when he's 16 or 18 and, go off to university and things like that. He could be a lot more based at home. If not all his adult life, for a much longer time than you would expect. I think of myself as a carer. I think it's just, it's another one of these like balls that you're trying to juggle, as well as being a parent, you're not a parent of a child who can even dress himself and things like that, Jack still needs a lot of help getting socks and shoes and can't do buttons, things like that. (Jane, IV3)

Part of the attempts to keep such caring distinct from being a mother is read through the previous expectations they have for what mothering involves, crucially that it has a normal trajectory towards the child developing into an independent adult (Gray 2001; Rehm and Bradley 2005; Taylor 2000). This trajectory is not as clear cut for those with disabled children, and the added responsibilities they associate with this are not something all mothers defined as their caring role as mothers. If the additional caring activities are not a continuation of being a mother, then from their perspective it is not obvious or essential that it should be their responsibility to carry on these additional responsibilities.

It is important to be specific in identifying what are the 'additional responsibilities' mothers define as not their responsibility. We need to be clear about what aspects of care mothers say are outside of the reasonable boundaries of their caring role. The areas mothers most often highlighted as problematic are those they felt were a direct product of the inadequacy and complexity of the welfare services meant to support families with disabled children:

> I used to spend Monday afternoon every week fighting for services for Joe, or arranging appointments, or administrative stuff. And then instead of just being his mum, I'm his case manager, I'm his physio, I'm his speech therapist, I'm his advocate. (Kay, IV1)

Kay (IV1) went on to say, 'the amount of time I must spend in an administrative role, not being his mum, not being a carer, but writing letters of complaint too, I wrote to the local MP about 10 o'clock last night about getting adaptations to the house, because we're not entitled to any help with that, so we're still carrying him up and down the stairs. It's all of that kind of stuff; it's very wearing and very stressful.' Alongside the increased care a disabled child may require, mothers also find

themselves having to take on the role of fighter or negotiator with welfare services in order to get support and resources.

The burden of care, from the mothers' perspective, is the time taken up chasing for services, such as Disability Living Allowance (DLA), direct payments, respite care, and educational resources, which they have an expectation is an entitlement they should automatically receive. It is this expectation which shapes their view that having to battle for support is outside of their care responsibilities. However, what they find is that in order to receive such services they are required to fill in long and complex assessments, so that others can judge whether they do have a right to receive them. Form filling is hardly new to social services. However, within current welfare practices in the UK there is a significant level of micro collection of data meant to represent life, which intervenes in the allocation of citizenship rights. Within the DLA entitlement is mediated via medically shaped bureaucratic processes. The current methods of evaluating whether families qualify for DLA require accurate and medically validated measurement of how severe the disability is and how much care it requires. It necessitates the production of minute levels of detail about the 'burden' of caring for a disabled child in order to qualify for support. Across 52 pages parents go into extensive detail about their child, solely focused on the medical condition and what limitations the child faces. It is no surprise that mothers (and many professionals) find the DLA form a complex task, but also one that they find literally exhausting in the intimate scrutiny it demands of their child's difficulties:

> His DLA's up for renewal again, so I usually start about six months beforehand, and start writing a diary, and I'll get in touch with Disability North and get one of their advisors, she'll go through filling the forms out for us, because if you put one word that's wrong it'll have consequences. (Angela, IV3)

Mothers struggle with the time taken up getting care support for their child; this is not a product of the disability. Instead it is increasingly prominent in mothers' lives due to the requirements of conditionality within welfare. That is the need to participate in the collection of detailed information in order to get support, which previously would have been an entitlement to receive:

> Sarah: … red tape bureaucracy, form-filling, sometimes does take precedence over *life*, or just living. (Sarah and Nick, IV3, our emphasis)

Conditionality also echoes some of the problems associated with early intervention, in particular the emphases given to medical criteria of limitation. Children are recognised via the same categories that early intervention seeks to resolve, which identify their failure to live up to certain social ideals of acceptable living and capability. In the process medical categories dominate in authorising 'entitled bodies' (Kelly 2005: 197); framing the child in particular ways, which both signal them as flawed citizens, and also restrict their rights to be supported and cared for. The DLA provides no space to do anything other than catalogue inadequacy, fixing the child in the category of the disabled other to normal society. Welfare mechanisms for attributing rights demand a level of categorisation that strip the individual of broader aspects of who they are and what contexts inform their social position. Fault comes

with the categories of contemporary identification, either as a welfare dependent (Fraser and Gordon 1994; Fraser and Gordon 1997) or as a disabled child unable to be the normal child. There is a level of medical (and social) scrutiny mothers *and* their children face from state institutions that hinder their full citizenship. As conditionality (Dwyer, 2004) increases as an element of welfare provision, the implication is that having to pursue services and rights of citizenship will continue to grow as an element of the caring portfolio of mothers of disabled children.

Transformative potential of care
So far the discussion has been focused on how care practices can emerge from or contribute to limitations in access to citizenship rights and recognition. However, forms of care mothers are involved with and how they articulate that as part of their subjectivity hold out the possibility of challenging prescriptive versions of citizenship.

If we look at the kind of care identity women articulate we can also see care's expansive possibilities and political potentialities. Mothers talked of a changed life, where accomplishment, as well as exhaustion, was now part of not just what they did, but also who they were. As part of changed subjectivities mothers talked of seeking out new ways of developing the skills they had acquired. So, for example, Jemma talked of going to college to train as a class room assistant to work with children with learning disabilities after spending time volunteering in her daughter's class room. As mothers' skills and experiences developed they were often likely to develop other extended roles.

Caring for a disabled child generates a level of change that goes broader than how carers think about their own identity. In addition, it is closely connected to changing views regarding social responsibility and disability. Mothers find new meaning and senses of self in their caring role, in particular fighting injustice against their children and others becomes an important part of what they define as the caring role and is embedded in their identity:

> Well, I have changed, I have become more assertive and not letting things lie, and really pushing… and I think getting out there and finding out the information for yourself, and finding out your rights and your wrongs, and talking to other parents who've been through similar things before you, that's definitely helped. (Angela, IV1)

In defining their caring role, mothers include their battles with statutory services regarding conditionality. As Corinne (IV1) asserted: 'but like a normal person, her rights need to be respected as well, as the rights of a normal person are respected.' Mothers spoke proudly of their strategies for getting what they can for their child. Such changes are not confined to women from educated, middle class backgrounds; in a way the most acute transformations and desires to challenge what others 'offer' for the child come from mothers (such as Angela) from relatively under privileged backgrounds, who refuse to be grateful for what is provided for them and their child. Such mothers challenge both the gendered and classed discourses that assume they are unable to articulate the care needs of their child.

Therefore the caring identity of mothers of disabled children is not always perceived as a private role, it can sit in the public realm of the care plan meeting and the statementing process required for resources to be allocated to the child when in school. Transformative care activities engage with re-evaluation of identity, the future, family templates and biographies, and political and ethical values. In becoming carers, mothers, along with their children, move through transitions which ultimately broaden care to encompass political dimensions which, through collective friendships and bonds, mean that they actively seek to incorporate political values and activities into the caring role they embed in their lives and their identities. Care activities sit within a political discourse able to challenge rights discrepancies and to identify the child and family as full members of society.

Mothers are thus politically active on behalf of their children, seeking recognition for their child's right as future citizens. Their version of citizenship draws their private caring practices into the public sphere, alongside a continued belief in entitlement to receive care from that public sphere. As such they are mediators on behalf of their children; however this also involves the children as active participants themselves. A key theme for mothers who rejected some forms of support for their children and advocated others, was seeking modes of care that enabled the child's agency to be incorporated in what was done, by whom and how.

Citizenship, recognition and dependency
In the previous sections the paper has sought to explore particular aspects of the care mothers of disabled children are expected to provide and receive under contemporary welfare provision and regulation. Mothers are encouraged to participate in medical therapies that seek to make children as normal as possible as a condition of them being seen as a useful citizen. While assessments of welfare eligibility, emphasise the significance of medical criteria as a way of classifying disability in order for parents to receive any state support in caring for their child. When mothers resist the conditions placed on them and their child's recognition by state welfare, they seek to include in their care practices a challenge to contemporary forms of narrowing the scope and boundaries of formal care. This is the link between the feminist interest in the gendering of care responsibilities and the disability movement concern with the modes of care made available to disabled people. By capturing the difficulties mothers face in the refusal by others to care for them as well as their children, what is being captured is the social exclusion of people (mothers and children) who experience disability from citizenship rights. Mothers can be important political actors who challenge, through their care activities, the privitisation and marginalisation of care. In the values of care offered by mothers, and some fathers, alternatives to the conditionality of what is offered to them, can be seen. What these different frames point to are alternative frameworks for recognising disability and care within welfare citizenship.

The dominant mode of recognition in contemporary western society continues to be that of the individual autonomous adult; this is the figure which both early intervention and conditionality judge the child's potential against. The difficulty for disabled people has been the connection made in liberal models of citizenship between individual autonomy and having the rights of citizenship (Silvers and Francis 2005; Silvers et al. 1998). When disabled children are expected to fail to live up to the

vision of the fully autonomous individual as they develop they continue to be seen as 'outside the range of human acceptability' (Landsman 2003: 1980). The only choice then provided is to overcome such failings, through early intervention, as the route through which to obtain citizenship recognition. Mothers who incorporate early intervention therapies into their caring role do so, both out of a wish to improve the quality of life of their child, and also out of an attempt to give them access to the category of the modern citizen.

The only way then for disabled children to acquire citizenship rights as they develop towards adulthood is to prove their ability to overcome disability and not require care and support. What lies unsaid in this is a discomfort with dependency:

> We admire the powerful wheelchair racer, the accomplished deaf drummer, the renowned paraplegic artist, the popular blind singer. They have disabilities, to be sure, but they have overcome them in ways that society values – by having an unusual talent, by being competitive and successful, and above all by being apparently independent. (Levine 2005: 378)

Dependency is neglected in considerations of citizenship, when citizenship is framed as the right of the autonomous individual. In part this is because being dependent is seen as a signal of an inability to be a full citizen (a view held by Rawls (1985) for example), leading to others becoming the voice of those identified as such: whether children (disabled or not), the 'mentally ill' or the 'intellectually impaired'. Such judgments have led to the marginalisation of disabled people and others, as they have been seen as incapable of participating in society. Assumed to lack the abilities of the autonomous individual, they are also denied the rights of the individual. It is in this context that charities, state institutions and relatives (including mothers) have been able to make decisions on their behalf, which have contributed to their marginalisation and discrimination.

The disability movement have struggled, and in some areas been successful, in dismissing such assumptions and implications, calling instead for recognition of the potential for disabled people to participate in society and decisions about their own lives. Much of this work, understandably due to the counter it provides, maintains the centrality of independence and autonomy (Morris 1993b). Alternatively, by acknowledging, as mothers do within a politicised discourse, relations of dependency and mutual obligation that are central to the human condition, it may be beneficial to bring dependency and citizenship together rather than separating them. Without this the resolution of dependency remains within the family, in particular the woman care provider. An injustice is maintained when care is seen as a value of the private domain, keeping hidden the connections of dependency, which allow the allegedly autonomous individual to function in the public sphere (Nelson 2002). Caring is a social practice (Sevenhuijsen 1998), which emerges from the 'reciprocal dependencies' (Fine and Glendinning 2005: 616) inherent in the human condition and denied by false models of individuality and autonomy. Recognising dependence also recognises interdependency.

Recognising interdependency brings important dimensions to questions of justice. Honneth (2004) asserts that recognition is a matter of justice because social validation enables positive realisation of the self. If we adapt his position to argue that the self

develops via caring relations of interdependence, then there is an obligation within the social to recognise and more significantly incorporate interdependency into our ties of citizenship and responsibility. It points to the broader social responsibility to participate in care practices with all kinds of people, outside of the presumed role and identity of 'mothers'. Alongside formal concepts of justice, 'fair treatment for people with disabilities' (Goering 2002: 375), recognition of interdependency means that independence is not a precursor to be a citizen. There are ways in which disabled people can be independent and autonomous individuals, but like the rest of us and to varying degrees, there are a ways in which they may not. What is needed is an appreciation that being fully independent is not a requirement to participate and take decisions about one's own life. Like a redistributive model of justice, it calls for the state to do more than not hamper the opportunities of the individual to be who they would want to be; it requires the just state provides support and material resources. It also broadens the responsibilities of good citizens to include participation in ties of caring interdependence (Lister 1997; MacKay 1998; McKie et al. 2002). Out of the social conditions that influence the raising of a disabled child, mothers, via their blurring of public and private boundaries in their care of their child, offer one partial vision of seeking modes of care which do more than treat a condition and require social recognition of difference.

Without a debate about the responsibilities of the state and society to care, rather than just mothers, the privatisation of care goes on unquestioned and the marginalisation of such families continued. Where care provision is presented as individualistic, as focused only on the 'condition' rather than the child, as concerned only with overcoming the tragedy of disability, as a form of charity and private responsibility, rather than public right and entitlement, families remain locked in marginalised positions that construct them as 'troubling' to society and enforce the caring role on the mother.

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