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**Date deposited:** 8<sup>th</sup> February 2013

**Version of file:** Author final

**Peer Review Status:** Peer reviewed

## Citation for item:

McLaughlin J. [Understanding disabled families: Replacing tales of burden with ties of interdependency](#). In: Watson, N., Roulstone, A., Thomas, C, ed. *Routledge Handbook of Disability Studies*. Abingdon, Oxon, UK: Routledge, 2012, pp.402-413. ISBN: 9780415574006.

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McLaughlin, J. (2012) Understanding disabled families: Replacing tales of burden with ties of interdependency, In: Nick Watson, Carol Thomas and Alan Roulstone (eds.) Routledge Companion to Disability Studies. London: Routledge. 402-413

## **Introduction**

Family life in the context of disability has been the focus of a significant amount of research across a range of disciplines. Healthcare studies, medicine, social policy and psychology all have a long term interest in disability and family life; collectively they have produced a particular image of such lives which documents the burden of care such families face and celebrates the ability of those non-disabled family members able to cope with such demands. This narrow approach has been criticised by the disability movement as yet another version of disability as tragedy. To counter this new research within disability studies, sociology and anthropology, is seeking to represent alternative and positive understandings. The aim of this chapter is to discuss this new work.

Before mapping out the new perspectives emerging from contemporary work on family and disability it will be useful to lay out a few clarifying points. First, what is family? Family is one of those common place terms, which because of its regular, every day use it is easy to miss the complex social processes that lie behind framing it in certain ways. Without going too far into the sociology of family, or the anthropology of kinship, it is important to stress that while our most immediate image of family is that of the nuclear family of mum, dad, children, sharing both biology and a household, we know that this is a social construct, however dominant (Carsten, 2004; Edwards et al., 1999; Finch, 2007; Franklin & McKinnon, 2001; Morgan, 1996). There is much debate about whether we live - in the West - in an era where there is greater recognition of varied forms of family life, which mean that many no longer live in the nuclear family model presented above (ONS, 2010). Therefore it is important that research exploring 'family' does not begin with too many presumptions of what it is that is being studied, and provides a space for people to define what family means to them. This is particularly important in the context of disability, where the caring networks around disability rarely are contained by household, or by family as equating to biological relations. Instead neighbours and friends can be equally, if not more, important in mutual caring activities. Second, a significant focus in the research on families and disability has been on families where the child or children are disabled (my own research has had much of this focus). This is an important area to look at, but it is also important to not exclude other ways in which disability and family come into contact, in particular the experiences and perspectives of disabled parents, and the specific issues created by the forms of disability which come with ageing. In this chapter I will use the phrase 'disabled families' to equate to family formations, however constituted, where at least one member is disabled. In such contexts it is the family as a whole who live and experience disability, although the specifics of those experiences amongst the members will vary, as well as the response to being a disabled family. The phrasing symbolises the ways in which others, formal services, community and neighbourhood respond to the family differently in light of disability. The chapter will highlight some of these dynamics. Much of the discussion will concentrate on issues related to childhood disability, but I will also bring in issues relating to disabled parents and disability across the life course.

Third, a core theme of this chapter is to challenge dominant narratives around family and disability which emphasise the burden it produces and the qualities of families who are able to cope. Below I will discuss why this framing is problematic. Nevertheless, while advocating different ways in which family and disability can be understood, I do not want to suggest that disabled families do not face difficulties. We should not be aiming to replace one problematic nightmare scenario, with an equally problematic fairytale. Statistical data, with all the caveats around reliability, point to the economic difficulties families face through: a) the extra costs of looking after someone who is disabled (Beresford, 1994; Preston, 2006); b) the removal of family members from the labour force to provide care (Carmichael et al. 2008); c) the consequences of those in a family who would usually be in the labour market being unable to work due to the problems disabled people face gaining and remaining in employment (Magadi, 2010); and d) the lack of sufficient benefits for those unable to work due to disability (Barnes & Mercer 2005). Families also talk of the difficulties and battles over getting appropriate support from formal services, while also concerned about the level of scrutiny their lives fall under from those services, an issue felt particularly strongly by disabled parents (Swain & Cameron, 2003). In addition, work with people who are disabled, whether children or adults, has identified forms of abuse and neglect which they have suffered at the hands of family members and the inadequacy of social services in response. Finally, existing social hierarchies, for example located in terms of class or capital (Gillies, 2005; Sharma, 2002) and ethnicity (Chamba et al., 1999; Shah, 1995), have inevitable consequences for access to resources and support for families.

As mentioned above my own research is particularly focused on childhood disability, throughout the discussion of this chapter I will draw from a completed research project I was a member of which explored the perspectives of parents with disabled infants and babies. The details of the project and its methodology are published elsewhere (McLaughlin et al., 2008). I want to acknowledge here the work of the other members of the research project, in particular Dan Goodley, Emma Clavering, Pamela Fisher and Claire Tregaskis. The chapter is split into three sections. The first outlines the problems with the burden fixation and the alternatives that are emerging. The second section explores the significance of medical therapies and treatments in the lives of disabled families. The final section explores the meanings associated with care and the value of recognising the interdependencies which lie at the heart of all family life.

### **Disability as a burden and families who cope**

Read (2000) and Runswick-Cole (2007) highlight ways in which disabled families are often assumed to be problem families, both in how the state responds in the provision of support and how others around them withdraw from contact. When not faced with hostility or suspicion, instead what many report is the language of pity. This focus on pity is not just found in social responses, but is also visible in the expansive research literature found amongst health care studies, medicine and social policy. A search for articles on disability and family will come up with an array of work focused and framed around burden (just a few examples include Brinchmann, 1999; Canam, 1993; Dyer, 1996; Hannam, 1988; Kim et al., 2010; Partington, 2002; Snell & Rosen, 1997).

To some degree there has been a move away from the burden fixation in contemporary healthcare and social policy literature. We now have tales of families who overcome difficulties, who learn to cope, followed by psychological profiles of which families adapt or accommodate to disability and the strategies they develop in order to do so. The media and charity spot light is often on such families too, particularly if it is a non-disabled sibling or child who cares for their disabled sibling or parent. The problem with such media stories and family models are manifold. First, for those families judged not to cope blame is easily placed. If some can manage, why can't others? Second, such explanations easily fall into stereotypes and assumption. For example, the wonders of the British Asian extended family and the way in which they simply absorb caring responsibilities (Katbamna et al. 2004). Or, in contrast, assumptions that disabled parents or a single parent household will be unable to cope. Such assumptions are problematic because they do not reflect the social realities of any of these groups' lives. It is not necessarily the case that within an Asian context that there is an extended family ready and waiting to take on such responsibilities (Ali et al. 2001). Neither should it be assumed that a disabled parent or single parent household cannot cope, or that they do not live within an extended care network, who are ready and willing to help share caring activities (Traustadottir & Sigurjonsdottir, 2008). Third, the focus is on the non-disabled person and their trials and tribulations, this focus places the disabled person as other to the family. Fourth, the analysis remains trapped in an understanding of disability as pathology, something external, which befalls, a previously perfect or innocent family who must accommodate. Finally, the focus remains with the individual and their innate abilities to cope, or how they can learn to cope, via the right adoption of techniques and strategies.

What becomes invisible in such accounts are the social contexts that produce burden and the significance of multiple forms of capital and resources, in supporting some to 'cope' better than others (McKeever & Miller, 2004). What families talk of as burdensome in their lives is not the disability they or a family member has, it is the battles with social services and health care providers to receive adequate and appropriate care provision. The current difficulty is that the long term trend in welfare provision across Europe is a move away from universal entitlement, towards conditionality (Dwyer, 2000; Dwyer, 2004); that is the requirement to prove need – either financial or support – before services are allocated. This is seen in a range of support services related to disability in the UK, for example disability living allowance and statements of need in education. Every indication suggests that conditionality in welfare will only increase for the foreseeable future; the implication is that having to pursue services will continue to grow as an element of the caring activities of disabled families. If this is where burden is found then it is important to maintain a concern with this on the research agenda and to challenge this direction of travel in welfare provision.

As discussed above the burden literature produces a sense that the disabled child is an intrusion in to what otherwise would be a productive and happy family life. Such an approach is exemplified in literature on siblings of disabled children or children of disabled parents. Here, again the dominant voice and concern has been one revolving around the non-disabled children whose lives are disrupted by having a sibling or parent who is disabled. In both scenarios the common themes include: such children have to grow up too quickly as they must care for themselves; their lives are centred around caring for others,

whether parent or sibling; they grow up resentful of the way in which having a disabled parent or sibling means that they are not provided with enough attention and instead lead lives of isolation where things such as holidays or having friends over is made impossible by the presence of disability within their childhood (Bischoff & Tingstrom, 1991; Cuskelly & Gunn, 2006; Giallo & Gavidia-Payne, 2006). It would be wrong, as before, to suggest that such problems do not occur or that it is untrue that non-disabled children who grow up around disability, may feel a sense of loss when they compare their childhood to that of others (Heaton et al., 2005; Hodapp & Urbano, 2005). But this is not the only element of the story and the only people to be concerned about. Research with children themselves, disabled and non-disabled, fills out a different picture of what growing up in a context of disability within one's family also provides. For non-disabled siblings or children of disabled parents, their experiences can also be positive as they grow up with different priorities, interests and worldviews on disability and the value of being in caring relationships with people who are 'different' (Canary, 2008; Stalker & Connors, 2004).

By considering the perspectives of disabled siblings, we realise that the earlier work leaves the impression that only non-disabled children can be siblings. Instead disabled children are siblings too, siblings who can provide something positive to the lives of others in the families they are part of. Anthropological literature exploring sibling relationships between disabled and non-disabled siblings has done a better job of considering how the siblings become part of each other's lives, supporting each other, changing each other, and carrying those relationships (positive and negative) into adult life (Davis & Salkin, 2005). Crucially what this research also points to is the importance of doing research with the children themselves (Balen et al., 2006; Clavering & McLaughlin 2010; Marchant, 2004; Save the Children, 1999), in order to find out what they define as significant to them, what influences their world view, and what they see as the key areas that affect their lives negatively and positively. There is now a growing body of research doing this, often using innovative and participatory methodology to examine disabled children's views and experiences of the barriers to social participation (Susinos, 2007); the importance of play (Goodley & Runswick Cole, 2010), their quality of life (Dickinson et al., 2007; Young et al., 2007), their developing sexuality (Addlakha, 2007); their disability in the context to other aspects of who they are (Islam, 2008; Singh & Ghai, 2009); and transitions within healthcare, education and into adulthood (Galambos et al., 2007).

### **The search for cure or therapy**

There is substantial research literature which highlights how parents with a child who is developing or behaving differently, will seek medical explanations and treatment. This is particularly marked in areas such as Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) (Bull & Whelen, 2006; Singh, 2004), where both the diagnosis and some of the relevant treatment options (in particular the use of medications to subdue behaviour and mood) are highly contentious within disability groups. Other writers have explored why parents may seek 'normalising' surgery for their children, for example leg lengthening in the case of restricted growth, or facial cosmetic surgery in the case of Downs syndrome (Hansen & Hansen, 2006; McGrath, 2001; Thiruchelvam et al.,

2001; Woodgate & Degner, 2004). Parents often frame such strategies in the quest for some kind of normality. However, there is a wide debate in disability studies and medical sociology as to whether medical diagnosis and therapy, while obtained in an effort to help the child, also contributes to emphasising their difference and medicalising their identity (Blum, 2007; Conrad & Potter, 2000; Gillman et al., 2000; Hedgecoe, 2003; Rapp et al., 2001). Our own research indicated that parents seek from medicine abdication from blame, and a promise that through a cure the child could one day be normal (McLaughlin & Goodley, 2008). Medicine can also be understood as a response to parents' own discomfort with disability. At times we have seen parents contribute to positioning their disabled child as not a full member of the family through expressions of failure to bond, comparisons to other 'normal children', and through parental desires to 'normalise' their behaviour so they – the child and the parent – experience less social discomfort. However, it is important to explore why parents may struggle, at least initially, with raising a disabled child (Allen, 2004; Ferguson, 2001; Green, 2004).

This understanding requires an appreciation of contemporary contexts of parenting. All parents in the West are under a heightened gaze through increased levels of medical advice and guidance on how to raise perfect children: the more this is emphasised and wished for, the more parents of disabled children and the children themselves are constructed as failures (Landsman, 1999; Larson, 1998; Rigazio-DiGilio, 2000). Parents are failures both via the assumption that they must have done something wrong to produce this disabled child and also to have produced a child, which it is assumed, will not be able to grow to be the socially useful citizen expected by the state and others (McKeever & Miller, 2004). As such disabled families can find themselves falling in to the same 'problem' categories of other 'troublesome' families, such as single parent households, or 'workless/workshy' families. Disabled children do not fit contemporary narratives of family life, contributing to the difficulties parents may face finding a space within their own family narratives for their child (Dowling & Dolan, 2001; Jenks, 2005). Such contexts encourage a sense amongst families that a disabled child, is a different child, and that the solution, for everyone's interests is to minimise that difference, through whatever routes.

However, while such contexts can be important and are a motivation to involving medicine in a child's life, this is not the only dynamic at play in the involvement of parents with medicine. First, the quest for normality is not shared by all parents, or a quest that all stay rooted too. In our own research with parents, some talked of recognising the costs of too much time spent trying to find the medical explanation for their child's differences, or trying to get them closer to the developmental markers they had fallen behind on. Instead they began to explore new ways of thinking of their child, their family and their futures together, which incorporated difference and impairment. Crucially, parents talked of the importance of the child's own identity and character in reshaping family life. In a counter point to the notion of burden, here the disabled child brings something of value in to the family which changes it and signals their centrality and importance to the lives they are part of. Second, we need to be careful to avoid seeing all inclusion of medical therapies and treatments – including drugs in the context of behavioural problems – as necessarily problematic. In the cases of some long term and degenerative conditions these treatments can be absolutely necessary in keeping the child alive, in providing improved quality of life and enabling the child to grow up in to adulthood. This is most clearly seen in conditions such as Cystic Fibrosis and Duchene Muscular Dystrophy where improved medical intervention, alongside

better social care, are clearly significant in the improved quality of life and increased life span of people with these degenerative conditions. The reality for many disabilities is that medicine is part of life, the social and political implication of this for disabled families, is to ensure that this involvement does not become the key factor in shaping the person's life and identity, or that of those around them, and that medical actors do not become too powerful in dictating the choices and experiences of that person and family (Larson, 1998).

Understanding what social significance medicine has within disabled families is best understood, by studying how that occurs, rather than assuming particular implications of what follows from the presence of medicine in a family's life. In our own research after diagnosis, parents can become focused on acquiring and participating in therapies and treatments to aid their child. They may willingly take on such activities; however, it also may be something which they – particularly mothers – are assumed to want to get involved in. This assumption can lead to question marks being raised about parents who appear unwilling to play their role in such treatments and therapies. Mothers can feel little choice but to participate in such interventions. However, they can also question both the validity of the intervention and their participation in it. In particular, they can become aware of the risks such therapies carry that they may change the dynamics of the intimate space of family life. This can lead parents to become choosier about medical interventions and appointments they feel it necessary to attend; in so doing they seek to reclaim their child and provide space for a range of their development to occur more freely. Rejection of certain medical practices can be understood as elements in ongoing processes of redefining family life in the context of disability (Frank, 1995; Jenks, 2005; Taylor, 2000).

Some of the technologies which families have to learn to use to enable a disabled person to be at home, particularly technologies which aid breathing or eating, are both intensive and intrusive (Place, 2000). However, work influenced by social studies of technology is also highlighting how over time, families, both the disabled and non-disabled members, work together to minimise the disruption and dominance of medical interventions or therapies into their lives and spaces of intimacy. In such processes they can also seek to positively incorporate such interventions and technologies, which do not deny their presence or benefit, into their lives. This understanding is beneficial for the recognition it provides of the agency of disabled users of such technologies and interventions in responding to them and not being dictated by them. One example of this is the creative use of assistive communicative technologies by disabled young people, to experiment with new ways of representing themselves and producing forms of identity and subjectivity which break free of notions of them as 'technologically dependent'.

### **Care and interdependency**

Care is a problematic category in disability debates. Feminists have rightly been criticised for being solely bothered by the 'burden' of care within the gendered division of labour within families. While fundamentally important to feminism in the 1970s and 1980s (Finch & Groves, 1983; Land, 1978; Ungerson, 1987; Ungerson, 1990), and an important challenge to state approaches to depositing care responsibility on to the family (for the most part women, particularly within the care of children and older relatives), this work was

problematic for how it approached disability. In addition, via the significance of charitable organisations in 'caring' for disabled people, care is sometimes framed as an act of charity. Disability writers have pointed out that the language of charity is inappropriate; in particular how it acts to disallow the sense that the disabled person has a right to query the care they receive (Hughes, 1999; Lindemann, 2003). Charitable caring for Hughes 'mobilised the emotions invested in the tragic and the pitiful' (Hughes, 2002: 577), while Kittay suggests that care is understood not as a right but instead is provided 'out of a gratuitous kindness, a kindness they have no right to demand' (2002: 271).

While acknowledging these concerns, I would argue that in the contexts of understanding the lives of disabled families, care is both something to be interrogated and also reclaimed from its problematic associations (McLaughlin, 2006; Traustadottir, 1991; Traustadóttir, 1999). This can be done by understanding the relationship between care and subjectivity, politics and interdependency. Without denying the problems found in feminist work, there is much in contemporary feminist explorations of care within and outside family that is of value here. Still pivotal in such work are the arguments of Finch and Mason (1991; 1993). They propose that the processes through which women become the predominant carers involve 'negotiations' within families; negotiations which often leave women with the least socially acceptable excuses to leave care to others outside or inside the family. For many women, the role of carer gives them value and appreciation, providing them with a socially acceptable identity, which is not available elsewhere:

People's identities are being constructed, confirmed and reconstructed - identities as a reliable son, a generous mother, a caring sister or whatever it might be... If the image of a 'caring sister' is valued as part of someone's identity then it eventually becomes too expensive to withdraw from those commitments through which that identity is expressed and confirmed (Finch & Mason, 1993: 170).

Skeggs (1997) also explores the gendered subjectivity of the carer, and the social conditions that support and legitimate particular identities. Being a carer becomes something that is not just incorporated into things women do. It is also translated into aspects of the self, providing respectability and recognition. A process Campbell and Carroll (2007) argue is not as possible for men due to the influence of hegemonic masculinity (Connell, 1987). Therefore exploring the social, cultural and political contexts within which care occurs is important to understanding its significance (Kittay, 1999).

Such contexts that lead to women being seen as the natural carers and women adopting such identities appear particularly marked in the care of disabled children. When mothers are asked to provide key roles in the day to day treatments and therapies for their child, this is based on their presumed inherent ability to care. Over time this becomes part of the processes that consolidate the gendered division of care. The expertise mothers develop in treatment and supporting the child leads them to continue to be seen as the obvious carers for their child, which excludes others from participating in those activities. In our research we have seen fathers' identities as carers unrecognised by others, while mothers are readily identified and identify themselves as carers.

However, such assumptions and identity dynamics are not the same when the mother is disabled. Instead, whether the child is disabled or not, the first response by formal services

and often others around the woman is to assume that the disabled woman will lack core skills which others must provide, justifying significant scrutiny of her and her relationship with her child (Berman & Wilson, 2009; Booth & Booth, 1994; Booth & Booth, 1997; Booth & Booth, 1998; Booth et al., 2006). This is not to say, like all mothers, disabled women would not benefit from support and advice, the problem is the way assumptions tied to their disability impose readings of their mothering as inevitably lacking (Coren et al., 2010; Llewellyn, 1995; Llewellyn, 1997; Llewellyn & McConnell, 2002). In such contexts it is difficult for the disabled mother to define for themselves what the support they would benefit from is and to set the boundaries to when it is legitimate for others to question their parenting skills. Increasingly however, research is including an appreciation of the ways in which disabled parents 'can be assisted to live successful family lives in the community' (Traustadottir & Sigurjonsdottir, 2008: 331).

The assumptions made about non-disabled women as carers and disabled women as inadequate carers take us towards a consideration of the politics of care. There are a variety of ways through which to bring politics into the discussion of care. One is the significance of variety of social discourses embedded in gender, class, disability, age, and race and ethnicity in framings of who can and cannot care. Another I wish to discuss here is in considerations of what the content and boundaries to care are (McLaughlin, 2006). In our research, mothers found new meaning and senses of self in their caring role, in particular fighting injustice experienced by their children and others became an important part of what they defined as the caring role and was embedded in their identity. In defining their caring role, mothers included their battles with statutory services on behalf of their child. Therefore their caring identity was not perceived as a private role, it spread out into the public realm of challenges to resources and against inequality. This allows for a broader understanding of the relations, experiences, engagement, interdependences and politics involved in caring activities (Watson et al., 2004). It also creates a space to recognise the agency and identity of disabled people within caring roles, pushing towards a position that blurs the notion that there are those who care and those who are cared for (Fine & Glendinning, 2005; Lloyd, 2000; Lloyd, 2003).

Care can be rescued from associations with charity if we remember that all those participating in care are nested in sets of reciprocal relations and obligations (Kittay, 1999). These relations emerge from the significance of vulnerability to the human condition (Shildrick, 1997). Recognising the inevitability of vulnerability brings with it recognition of interdependency, in contrast to charitable notions of dependency and burden. The value of interdependency is also the way in which it asks questions of society and the state and pushes care out of the privacy of the family into the public sphere and debates about citizenship (Sevenhuijsen, 1998). It points to the broader social responsibility to participate in care practices with all kinds of people. It broadens the responsibilities of good citizens to include participation in ties of caring interdependence (Held, 1995).

From this perspective, evaluating the contexts around disabled families includes questioning to what degree professional, institutional and community settings provide spaces for development of affirmative and productive relationships with them. A turn to the complexities of interdependency provides us with more productive ways of conceptualising the lives of disabled families. Without a debate about the responsibilities of the state and

society to care, rather than just the family, 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 person, 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.

## Conclusion

This chapter has sought to present aspects of the lives of disabled families which become invisible when the focus is on burden. Instead of a disabled family member being thought of as someone or something a family has to manage, cope with, adapt to, here I have explored disabled family members as full and valued participants in family life. While the language of burden is problematic we do need to remember the routes through which disabled families are marginalised in society, in particular via the ways in which caring responsibilities are naturalised as private and gendered. Instead we need an understanding of disability and family which integrates disabled people into the families they are part of (rather than seeing them as an unwelcome intrusion) and integrates family into its social, political and cultural contexts. This can occur via recognising ties of interdependency which refute clear boundaries between the carer and the cared for, the private and the public and the disabled and the non-disabled.

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