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## **Wellbeing and empowerment: the importance of recognition**

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## **Abstract**

Health and wellbeing are now located within a policy framework that emphasises the empowerment of the individual 'consumer'. Within this paradigm, empowerment is writ large and wellbeing is seen as a 'civic duty'. The role of the health and social care services has been identified as one of enabling service users to promote their own wellbeing. In this paper, it is argued that dominant narratives relating to 'achievement' and 'normality' may result in forms of 'misrecognition' that act to undermine the positive sense of self that is crucial for self-empowerment. It is suggested that while the parents of disabled babies often act reflexively to create empowering life narratives within the private sphere, this is not always facilitated by their encounters with health and social care organisations where neo-liberal ideas and biomedical narratives, based on a modernist view of identity as individual and existing prior to society, mean that parents and children are attributed 'deficient' identities in ways that undermine empowerment. With reference to 'the politics of recognition', it is argued that services that seek to empower must value diversity and alterity whilst respecting human dependency on intersubjective recognition.

Key words: wellbeing, empowerment, health, social care, recognition

## **Introduction**

This paper considers both hegemonic and counter-hegemonic understandings of disability and discusses the internal contradictions within New Labour policy which have limited notions of wellbeing, empowerment and authenticity to those consistent with a neo-liberal concept of healthy citizenship. Under New Labour policy has been underpinned by a notion of empowerment that is supposedly based on the notion of the reflexive agent of late modernity. The idea is that once individuals have been freed from traditional structures, they have the capacity to act reflexively and create their own authentic identities free from the trammels of traditional oppressive rules and norms that organise people rigidly along the axes of gender, class and status. The ideal citizen, therefore, forges her authentic personal destiny through reflexively transforming challenges into opportunities (Beck 1992, Giddens 1994, 1998). Drawing on interview and observational data collected for an ESRC study

*Parents, Professionals and Babies with Special Care Needs: Identifying Enabling Care*, the paper suggests that while parents of disabled babies are constructing authentic and counter-hegemonic understandings of disability, and of their lives more generally, their ability to do so is undermined when they come into contact with health and social care services where the discourses of governance and of governmentality restrict definitions of authentic wellbeing and empowerment to those consistent with the neoliberalism of the dominant symbolic order. The parents are therefore engaged in seeking authenticity whilst simultaneously resisting dominant narratives that frame authenticity within the parameters set by neo-liberal interpretations of good citizenship. At the same time neo-liberal understandings are validated and bolstered by the bio-medical model of disability that is based on individual deficiency. As Donna Haraway (1993) has noted, the modernist notion of the body as an individualised machine has yet to yield to postmodern readings of the body as embedded within wider systems of recognition and misrecognition. While Haraway (1993) sees 'the body' as a mobile field constituted through multiple and overlapping systems, biomedicine generally treats individuals as stable and discrete units of analysis. Consequently, a particular blueprint for good citizenship is promoted, based on ontological separatism, and associated with the view that success is achieved by rugged individuals in the public sphere. Little or no space is available for interpretations of wellbeing and empowerment that are not equated with narrow forms of individual self-sufficiency (Rose 1999). Nevertheless, previous research (Fisher and Goodley 1997, Fisher 1997) has suggested that many parents of disabled children challenge the idea that the birth of a

disabled child will almost necessarily lead to a type of impoverished life, characterised by a conspicuous absence of empowerment, for both parent and child. In developing these counter-positions, parents might be regarded as the very embodiment of the ideal of reflexive citizen or the 'autotelic' self who transforms challenges into opportunities (Giddens 1994: 192-4). However, it is argued here that parents' attempts towards the construction of their own wellbeing are being undermined by their contact with the health and social care services where they are confronted with oppressive frameworks of meaning that attribute 'damaged' identities to them and their children whilst failing to recognise their particularity and authenticity.

Applying arguments drawn from the politics of recognition, in particular those of Honneth (2001, 2003), this paper argues that identities are formed intersubjectively and that misrecognition occurs when parents and children are measured according to normative frameworks of reference, based on ontological separatism, that promote a connection between difference and individual deficiency. While parents' interpersonal experiences within family contexts may act to contribute to the construction of authentic and meaningful narratives of wellbeing, these are not validated by professional patterns of recognition that are restricted within the parameters defined by 'expert' agendas and interventions. At a broader level, the paper also raises questions as to the nature of wellbeing, highlighting in particular the importance of according recognition to the diverse ways people seek to construct authentic routes towards wellbeing and empowerment.

## **Policies of empowerment?**

Central to this paper is the idea that policy is characterised by the contradictory aims of encouraging citizens to take responsibility for their own wellbeing whilst also requiring that they should find it within the boundaries laid down by 'expert' opinion. The White paper, *Choosing Health: Making healthy choices easier* (DoH 2004) unequivocally identifies the ideal service user as an informed consumer (Hughes 2004, Powell and Hewitt 2002) and the role of the National Health Service (NHS) and other organisations as one of enabling individuals to promote their own health and wellbeing. Seen from this perspective, the current policy direction towards catering for individual needs may appear to constitute a positive step towards supporting individuals in their quest to discover and to gain recognition for their personal authenticity. There are at least two major problems with this discourse. First, based on an understanding that self-reflexivity is equivalent to agency, it tends to exaggerate voluntarism and to underplay constraints. As Archer (1990) has argued, people may be reflexively aware of institutions and structures that constrain their choices whilst nevertheless remaining powerless to change these. Secondly, Hoggett (2001: 45) calls for 'An appreciation of the passive voice' which allows for a more nuanced and gendered account of the stressful and disempowering environments that many welfare subjects experience.' In this paper it is suggested that the disempowering environments identified by Hoggett (2001) arise when wellbeing, authenticity and empowerment are framed by the mechanisms of governance and the influence of 'expert' knowledge. The virtuous citizen is expected to reflexively achieve her sense of wellbeing and empowerment through incorporating expert advice into her

deliberations. As it is put in *Choosing Health*, 'People want to be able to make their own decisions about choices that impact on their health and to have credible and trustworthy information to help them do so. They expect the Government to provide support by helping to create the right environment.' In seeking their authentic route towards empowerment citizens are expected to avail themselves of 'expert' assistance that is ideologically embedded within the prevailing neo-liberal order. Authentic empowerment must, paradoxically, be constructed in ways that are consistent with hegemonic citizenship. Such an interpretation runs contrary to the idea that everyone's authenticity and quest for wellbeing is unique, and should not be curtailed by the dominant order (see Taylor, 1991).

The mechanisms of governance - and of governmentality - that underpin New Labour policy in relation to 'normal' and healthy citizenship are framed within a contractual model of relationships based on a view of identity as being essentially individualised (Fisher 2007). This view is reflected, for instance, in family policies that promote a highly instrumental approach to parenting. Whilst the importance of family life is stressed as a forum in which the values of good citizenship are learned (see, for example, *Supporting Families*: Home Office 1998), good parenting is seen as quasi-contractual in nature, based as it is on the idea that the identities of family members must be regarded as essentially independent and atomistic. As Gillies (2005: 77) puts it, *Supporting Families* '...depicts parenting not as an intimate relationship, but as an occupation requiring particular knowledge and skills'. The result is that parenting practices are increasingly isolated from the quality of interpersonal

relationships and the 'skills' of good parenting are constructed as detachable entities in ways that define family relationships in contractual terms between independent human actors. Parents are expected to improve and regulate their parenting skills with reference to 'expert' training. Similarly the type of values that parents are expected to instil in their children are those of ontological separateness, particularly with regard to the value of economic self-sufficiency through paid employment. In 1997 the then Social Security Secretary Harriet Harman stated: ...'Work is the only route to sustained financial independence. But it is also much more...It is a way of life...Parents don't just work to support their families financially, they also work to set an example to their children...' (Harman 1997 cited in Lister 2000: 39-40). Since that time the policy connection between wellbeing, empowerment and economic self-sufficiency has been clearly entrenched (see DWP 2005). The notion that life within the private sphere may also provide the basis for self-esteem and wellbeing and be seen as a hallmark of participation is conspicuously absent.

This last point is an important one to consider in relation to many of the research participants referred to in this paper, who were parents - mainly mothers - of disabled babies and children. Employment was not an option for most of these parents, who were full-time carers. It is not uncommon for parents to attend up to ten appointments in a single week. While keeping up with appointments alone is more than enough to preclude a parent from paid work, many of the mothers could be regarded as socially excluded on a number of other dimensions – many were lone parents, some had disabilities



and one belonged to a stigmatised minority. In stating this I wish to underline the fact that most research participants were highly circumscribed in their ability to seek empowerment and wellbeing through participating in paid employment. Equally, many of their children were unlikely to be in a position to take up full-time paid employment in future adult life. Therefore parents and children alike were vulnerable to the oppressive discourses of welfare, identified by Hoggett (2001) that construct wellbeing and empowerment around economic self-sufficiency.

## **Methodology**

For the parents and disabled babies project in-depth interviews were conducted in Sheffield with 25 families with babies and young children with special care needs. The families were divided into 2 groups. The first group of participants provided retrospective accounts of their experiences, including those of medical and social care services, since the birth of their child. The second group involved families who had children up to 2 ½ years of age at the start of the project. These participants offered a longitudinal perspective through participating in a number of interviews conducted over a period of up to 18 months. The approach in the interviews with the parents was conversational and prompts arose from what the interviewees told me. There was also a strong ethnographic component to the methodology, involving (i) the observation of mothers, children and professionals in a variety of clinical, social services and social service and home settings and (ii) immersion within the wider support networks of parents. It should be noted that the families were from differing socio-economic groups, and those from marginalised

populations such as unemployed lone parents, particularly if they were disabled or from minority ethnic groups, appeared to be subjected to more intensive forms of misrecognition in the form of state surveillance. Finally, focus groups were conducted to include the perspectives of a range of medical and social care professionals working with the families. The material was analysed using grounded theory techniques (Schwartzman and Strauss 1973, Charmers 1995, 2004).

*Parents, Professionals and Babies with Special Care Needs: Identifying Enabling Care and Making Healthy Families* was a project that owed much to feminist oral traditions in that it sought to reveal the perspectives of marginalised groups of people who might have otherwise remained 'hidden' (Anderson and Jack 1991, Oakley 1993). At the same time, it was also based on critical or postmodern narrative researchers (for example, Bertaux 1981, Thompson, 1988, Goodley *et al.* 2004) which have as their starting point a subject that is not unified but constituted by a number of selves which may be in conflict with one another. This is not to claim that identity is a myth. As Hoggett (2001: 42) argues, there are 'powerful integrative forces at work within subjectivity', so we are both one and we are simultaneously many. People create coherent narratives in relation to their lives in order to find meaning that will sustain them.

Whilst people are inevitably shaped by dominant narratives, they do not generally internalise them uncritically but often engage in sophisticated levels of reflexivity that can lead to the ability to question pre-given understandings and the often 'invisible' ideologies underpinning them. However, these

processes are not freestanding or acquired in a manner disconnected from environmental and structural factors or from experiences of either recognition or misrecognition. Crucially, identity is formed intersubjectively. As Butler (2003 cited in Magnus 2006: 50-53) argues, the subject is not free to tell their own story since '...every 'I' begins in and through others.' Human subjectivity is therefore intersubjective with the subject coming into being in and through her concrete relationships with others, whilst also bringing other subjects into being through her own acts. Human beings do not have a 'choice' as to whether or not they respond to others - they necessarily become responsible to others through being addressed. Agency therefore entails responsibility towards others and we are obliged to give value to others as they depend on us for an authorial form.

### **Analytical framework**

I have stated above that families are challenging dominant narratives in relation to disability but I am arguing in this paper that their agency to do so is curtailed by a symbolic order constituted through bio-medical understandings of individual pathology and neo-liberal scripts of self-sufficiency. To clarify this position further, I draw on the politics of recognition as represented by Honneth (2001, 2003), Sointu (2006) and Yar (2001). Intersubjective recognition, these writers assert, provides the bedrock for the development of the inwardly reflective competent actor required in modern Western individualism (Sointu 2006). Through recognition, the agent attains a positive 'practical-relation to self' (Yar 2001: 299), which is necessary for the self-empowerment of the 'autotelic' self (Giddens 1994) who can take advantage of the opportunities and manage the risks associated with life in late modernity.

Therefore, not only is recognition important in enabling the subject to develop a positive narrative of self, it is also a prerequisite for agency.

In Mead's social psychology the self internalises recognition from others as a source of shared social understandings (the 'me') which then gives the 'I' its own externally validated status (Honneth 1996: 66-91). More recently, Honneth (2001, 2003) has argued that our distinctively human dependence on intersubjective recognition is institutionalised in society in three spheres of life: these are 'love' (the central idea of intimate relationships), the 'legal order' (equality in relation to the law) and 'achievement' (gained when the subject is allowed to enjoy self-esteem from their abilities that are respected and valued by others). In all three domains, 'the establishment of one's understanding is inextricably dependent on recognition or affirmation on the part of others', and all three types of recognition lead to human beings enjoying dignity and integrity (Yar 2001: 59). Honneth (2001: 50) describes 'integrity' in this context as the ability 'to rest secure in the knowledge that the whole range of their practical self-orientation finds support within society.' Patterns of recognition around 'love' and 'achievement' are of particular interest in this paper. 'Love', Honneth argues (2003, 2006), is gained primarily through family and friendships relationships and is therefore associated with the private sphere. 'Achievement', by contrast, rests upon success in the public sphere and has, to quote Honneth (2003: 141) '...a value standard whose normative reference point is the economic activity of the independent, middle-class, male bourgeois'. The enactment of this type of achievement, related as it is to notions of hegemonic masculinity, is dependent on access to power and on

the mechanisms of complex structures embedded in socio-economic relations. Groups who have more restricted access to this type of power occupy subordinate positions that act to impede the development of self-esteem. Seen from this perspective, the parents (mainly mothers) of disabled children *and* the children themselves constitute subordinate groups on the basis that they are rarely engaged in paid employment and their activities are necessarily based primarily in the private sphere. Under New Labour this has become all the more salient with the remoralisation of citizenship based on labour market participation (Rake 2001, Lister 2000). When the parents of disabled babies venture into the public sphere with their children, they are often positioned by others as supplicants who are seeking to access resources and services. This means that both parents and children frequently fall victim to a one-sided valuation of achievements which is also linked to the distribution of resources in society. I argue here that the quest of parents to construct positive understandings of the value of their lives with their disabled babies is being impeded by forms of 'misrecognition' which position them as inferior and vulnerable to patterns of disrespect.

### **From chaos to resistance**

The birth of a disabled child, the onset of a serious illness and acquired disabilities are events that throw life narratives into disarray (Ezzy 2000, Frank 1995, Fisher and Goodley 2007, Fisher 2007). People affected by unanticipated crises often describe their feelings by using metaphors that evoke a sense of disorientation. Commonly, they may speak of losing their path in life or their map (see Frank 1995: 5) or they may describe themselves

as wrecks (Dworkin 1993: 311) that have run aground, washed up 'on the rocks' of their ruined lives. The worst aspect of this is apparently the sense of losing an anticipated life-course in which past, present and future run together in a coherent whole that makes sense (Carr 1986). Arguably this is a condition that affects everyone to lesser or greater degrees within the uncertainties that characterise life in late modernity (Beck 1992). This instability, however, constitutes a challenge that is intensified by events which disrupt the life-course – for instance the onset of a disability or illness. According to Carr (1986: 96), a 'responsibility' is placed on those who undergo interrupted life narrative to create a new story which gives the narrator 'something to live up to' by reinterpreting the past in a way that enables the construction of a new future.

The birth of a disabled child was identified by some parents – although by no means all - as devastating. Words such as loss, grief, anger and numbness were used to describe feelings experienced around the time of diagnosis. One woman of Pakistani origin, whom I shall call Sofia (**all the names of the research participants and their children have been anonymised**), put it in the following way when she described her emotions on learning that her son had cerebral palsy,

It's very difficult, you can't take it in. You feel as if somebody has come over, hit you with something and is constantly just battering your head, it's just this feeling of empty numbness. [...] What happens then is it turns into anger and frustration, and then grief, it is grief. [...]. I remember taking him upstairs and sitting by the window and just holding him and he was laughing and gurgling and just doing what he was doing, this chubby gorgeous, beautiful little baby, big brown eyes. I just held him and I just cried for him, I cried for the loss of his life in terms of what he could have been, I cried for the loss of my normal baby.

Despite an initial feeling of crisis, prompted by both emotional and practical turmoil, many parents developed new understandings around disability and identity that counter dominant discourses based on deficiency and ontological separateness (see Fisher 2007, Fisher and Goodley 2007). The extract below is taken from an interview with a woman, let's call her Linda, with children diagnosed with autism and learning difficulties,

I wouldn't change 'em. I've been told and I've read in books that if I were to continue with my family, there would be the possible chance of another child being autistic, but that wouldn't bother me. I wouldn't be bothered at all about having another child with autism, because they are lovely kids.

### **Motherhood: from discourses of 'normality' to an appreciation of diversity**

There are some who may argue that Linda was simply constructing a narrative that was consistent with dominant ideas of motherhood. Presenting a self as a responsible mother involves self-governance around what can and cannot be voiced (Miller 2005). Experiences that are not consistent with the construct of ideal motherhood may be suppressed and can lead women to question their own abilities as women. However, the parents interviewed for this study showed little evidence of representing an over-idealised condition that fails to take account of their child's special needs. Below, Linda's statement tends to suggest that the positive relationship she enjoys with her children is not based on an over-idealised interpretation of motherhood,

You do have days like that, where you can't quite get your head around why your children are the way they are, but in a positive way there are children who are very much like the next children down the road, whereas mine aren't, mine are unique and in a way I'm sort of glad they are the way they are, because they've taught me something as well and everybody around me. I think you've got to have a child in your family with some form of disability to really be able to understand it.

Linda continued to explain how the experience of having a disabled child had transformed her perspective,

I think they've taught me to look at people in different ways now, like if I'm in town, and I see a man and he walks past and he's talking to himself, if you don't really know what's going on, you are going to think, oh he's drunk, or, oh he shouldn't be out on his own him, he's a loony. And that's small minded people who don't understand, but now I look at people differently and I think he may have got a learning difficulty, it doesn't necessarily mean that he needs to have someone with him all the time, why shouldn't he be independent.

Many parents very obviously derived great pleasure and fulfilment from their relationships with their children in ways that acknowledge and value diversity.

When I asked another parent, Karen, whose son had been diagnosed as having severe learning difficulties and autism, whether she would wish him to be any different, she replied,

I don't know.... erm... it's hard to say really. I mean it would be nice for Antonio to be able to do what every other child can do but yet I wouldn't want to take his identity away from him because that's his identity, that's who he is. I mean, I think that if I took it away from him I don't think he'd actually be Antonio, he wouldn't be the child I've brought up, he'd probably be a different child.

Karen later added when explaining the diagnosis,

When they told me that Antonio had autism and one of the doctors said that I had to grieve for him, I'm like 'why have I got to grieve for Antonio, he's still Antonio, he's always been that way, he's no different just because he's got a label' do you know what I mean? It didn't... it's not as if he's died or anything, that's what they say 'I should have grieved for him' as if he's died and I've got something completely different, do you know what I mean? And I'm like 'yeah, but I've always known Antonio this way, he's never changed, he's no different to what he was.'

Linda's and Karen's comments, typical of many made by the interviewees, evidence a form of wellbeing that defies those perpetuated by the dominant symbolic order. Notwithstanding the pressures to internalise pre-given understandings, the parents' narratives are characterised by openness to complexity and interdependence that leads to a wider interpretation of



citizenship. While the experience of having a disabled child was sometimes described as a shock, it had often led to what Gur-Ze'ev *et al.* (2001: 96) has described as a '... moment of rupture [when] new possibilities arise from the very fact that the self-evident, the facts, do not have the last word and the violence of the normalisation process is broken, postponed or questioned.' Under certain circumstances, there is the possibility that such 'a moment of rupture' may lead to a process whereby new understandings are constructed that counter normalising practices and their ideological foundations. The parents participating in this study appeared to be discovering what MacIntyre (1985) terms a 'degree of authorship' within the private sphere where they were able to find some space away from the 'symbolic violence' of the public sphere (Bourdieu 1991). While the mutually rewarding relationships with their children provide the necessary basis for this, this process of constructing new understandings that are authentic and empowering is constantly being undermined by an absence of recognition in the public sphere, where individualised and contractual relationships, underpinned by neo-liberal and biomedical narratives, are promoted as the ideal.

In contrast, the relationships that the parents enjoyed with their children tended to evoke Diprose's (2002) notion of 'corporeal generosity', which she defines as embodied, intersubjective and formed with reference to social and familial situations. Unlike dominant notions of generosity that tend to be based on an economy of exchange between individuals, corporeal generosity involves an openness to others. Crucially, intercorporeal generosity supports notions of alterity and ambiguity and the possibilities that these open. As Diprose (2002: 01) puts it, 'There is a reciprocity of giving, but not reciprocity

in the content of what is given, and generosity is only possible if neither sameness nor unity is assumed as either the basis of the goal of an encounter with others'. The subject becomes the 'responsible' subject who is open to alterity, diversity and intersubjectivity. From this perspective, moral behaviour defies all forms of codification or standardisation associated with the rational ends of contractual relationships. As the moral philosopher, Levinas (see Bauman 1991: 214) has argued, the Other necessarily eludes our full understanding, but the ethical relationship begins with the willingness to be open to everybody's unique subjectivity. There is a moral duty to recognise the Other that exists *solely* by virtue of the Other's existence. Gratuitous generosity of this kind is not, and cannot, be linked to 'rational' goal-orientated ends. However, for Diprose (2002) the openness to others is not merely a requirement for the development of mutually rewarding relationships, but a position that conceives identity, and wellbeing, as constructed through openness towards others.

### **Recognition and an ethic of caring**

Morality based on corporeal generosity is associated with the values of mutualism and interdependence and is, therefore, less concerned with the idealised forms of self-sufficiency that so often underpin the delivery of health and social care interventions. According to Williams (2001), these values could form the basis for what she terms 'an ethic of care', an ethic which would usefully provide an alternative model to the discourses embedded in current social policy that situate paid work as the first responsibility of citizenship. Such an ethic of caring would validate all caring activities undertaken in both the public and private sphere and would enable both men

and women to participate in caring activities and combine these with paid employment. Williams (2001: 474) argues that the current emphasis on paid employment is based upon a traditional notion of a male worker, that is 'a relatively mythical self-sufficient being whose care needs and responsibilities are rendered invisible because they are carried out somewhere else, by someone else.' Personal autonomy is, according to Williams (2001, 2002), always embedded in relationships of interdependence in which diversity is valued and the voices of marginalised groups heard. An ethic of caring is therefore linked to struggles for 'recognition' (Fraser and Honneth 2003) and, as Williams (2002: 505) points out, this necessarily raises issues around *how* social and health care services are delivered. A shift from individualised citizenship informed by neo-liberalism to one constructed around an ethic of caring would necessitate a democratisation of the relationships between service users and providers. It would require an acknowledgement of the value of experiential knowledge acquired in the private sphere (Williams 2002).

An ethic of caring could, Williams (2001, 2002) suggests, form the basis for a new type of citizenship that recognises everybody as interdependent and having the potential and responsibility to be caring and cared for. Crucially, an ethic of caring would provide the basis for an alternative to counter the notion that empowerment and authenticity are necessarily associated with ontological separateness, and that equate dependency with failure. This has been the position developed by the mutual aid aspects within certain 'self-care' movements that attempt to provide an alternative to the management, commodification and curricularization of professional care. In *The Careless Society*, McKnight (1995) has argued that formerly 'competent' communities

have been colonised and disempowered by a burgeoning welfare 'industry' that seeks its own expansion by constructing needs as unfortunate individual absences or deficiencies. Complex social problems are therefore redefined as individual pathologies that require individualised remedial tools and techniques to correct. The agents with labelling powers are the caring professionals who disempower their 'clients' by constructing them as a class of deficient individuals in need. Through these processes, families and communities falter and collapse. McKnight's main argument is that 'care' should be reclaimed as a quality and power that is inherent within people, families and communities rather than as a service provided by professionals. This is consistent with Williams' (2002, 2002) notion of an 'ethic of care' which values interdependence and diversity whilst empowering people to develop their own authentic ways towards wellbeing.

### **Misrecognition and the limits of empowerment**

Many of the parents involved in this study were in the process of constructing life scripts embedded in an ethic of care by rejecting ontological separateness and pathological interpretations of dependency. Families were building networks of interdependence that often extended into their local communities, and these were not based on the assumption that each individual should contribute according to a contractually based 'rights and responsibilities' agenda. Quite often relationships based on an appreciation of difference – on corporeal generosity - were deemed to be more mutually rewarding. However, these nascent attempts towards counter-hegemonic forms of empowerment were constantly being undermined by parents' and children's encounters with

health and social care providers where the dominant ideology positions disabled children as deficient whilst failing to recognise the value of relationships between children and parents. Fanon (1967 cited in Hoggett 2001: 49) uses the expression 'psychical invasion', developed in relation to racism, to indicate the violence that can be committed when a dominant cultural group or class invades a subject's discursive mindscape and shapes what they are able to feel or think. I suggest here that the parents and children participating in this study were subjected to frameworks of meaning-making which restrict ideas of empowered citizenship to those consistent with neo-liberal and bio-medical notions of self-sufficiency.

Sadie, a mother, who had previously enjoyed professional high status in a prestigious sales position, provided an example of this by explaining how she had experienced the diagnosis of her son as entirely framed within a deficiency model that had effectively 'written him off'. Sadie described the consultant's first assessment of Tom in the following terms,

It was all, 'he's got this facial palsy and we don't know what that's about' and 'he's got floppy legs and his muscle tone's poor' and 'he's not responding as he should'. He was sort of like a 'write off' by the end of the appointment. [...]. We both came out of there really deflated and feeling like we'd got this real loser baby that had everything wrong with him and it was terrible.

Experiences of denigration were by no means limited to negative interpretations around children's lack of viability for 'normal' citizenship. Parents were also subjected to additional forms of misrecognition if their way of life did not correspond with dominant narratives around neo-liberal 'achievement' as identified by Honneth (2003). Often multiple forms of misrecognition converged to position them as 'deviant' and 'dependent.' As

mentioned above, some of the parents who participated in this study lead marginalised lives as a result of poverty, disability, their religious beliefs and/or because they were lone parents. Peckover (2002) has previously noted, normalising discourses are particularly salient for certain groups such as Black mothers, mothers with disabilities and lone mothers.

Emma, quoted below, was a lone mother living on benefits in a disadvantaged area of Sheffield. The extract quoted shows how the tragedy model of disability can combine with social disadvantage in ways that denigrate both children and parents,

**Emma:** I can just remember not liking him [the consultant]. Erm.... I think it were.... at one point when he was talking to us about Clare [daughter] and it seemed he were talking down to us. Erm.... and you know....

**PF** Why was that?

**Emma:** He gave us the diagnosis and sort of left us to sort of deal with that news. Then a couple of days later he came to speak to us and what he said was is that they know that she is brain damaged but they didn't know to what extent at the time when they told us, but he did think that she'd be really bad.

Emma and her baby had been subjected to misrecognition related to the biomedical model of disability and to Emma's socio-economic marginalisation. Both types of misrecognition are embedded within neo-liberal and medical narratives based on a view of identity as essentially individualised. Reliant on narrow understandings of self-sufficiency, these narratives tend to shore up binaries such as 'normal' and 'deviant' and 'independent' and 'dependent'.

There is a further important issue to consider that contributes to a culture in which professional practice is encouraged to focus on the identification of 'deviancy'. In recent years, particularly in the wake of the tragic death of

Victoria Climbié in 2000, the health and social services have themselves been subject to an unprecedented level of surveillance in how professionals manage 'risk'. In addition, the devolved mechanisms of governance, that were supposedly intended to empower public sector agencies, have arguably resulted in increased government control but with less central accountability (Clarke and Newman 1997). As a result practitioners are obliged above all to make 'defensible' decisions. I suggest here that the risk agenda is reinforcing the processes of misrecognition by an over-zealous policing of people's lives (Furedi 1997), which is also linked to an increasing tendency to perceive individuals' 'needs' for resources and services in terms of personal failings (Kemshall 2002). This is not intended as a criticism of individual workers or practitioners who, as Gummer (1998) and Carson (1996) have pointed out, are increasingly likely to be individually blamed if things go wrong. However, as Kemshall (2002) has stated, the current preoccupation with risk often means that needs are pushed aside and professional activity becomes almost uniquely focused on the identification of individual failings.

Some of the parents' experiences in this study suggest that the assessment of risk is measured according to the extent of a person's deviation from the ideal form of citizenship as defined by hegemonic understandings that codify people as individually competent or incompetent. In other words, standards of defensibility are decided according to service users' apparent level of conformity to neo-liberal standards of citizenship, as defined by centrally prescribed performance criteria. This results in multiple forms of misrecognition. Below, I provide some examples of this.

Sylvia is an outstandingly capable and intelligent woman who enjoys a rich and mutually rewarding relationship with her children, family and others in her neighbourhood. However, as a lone parent and wheel-chair user unable to pursue economic self-sufficiency, Sylvia does not conform to the standards of self-sufficient citizenship deemed appropriate for parenthood. As a result, she has been subjected to an intensified form of surveillance. After the birth of her daughter, Sarah, who was diagnosed with cerebral palsy, Sylvia felt that she was singled out in ways that invalidated her sense of self. In the extract below, she is relating an incident that occurred in hospital after Sarah's birth. Sylvia was discussing her imminent discharge from hospital with a health visitor who wanted to 'inspect' Sylvia's home to assess it for its suitability for a child.

And so I said 'well, you know, I don't feel at all happy about this inspection.' I said 'you don't do it for anybody else and it seems to me that you're only doing it because I'm disabled – we need to talk about this'. I said to her 'could you give me the list of standards' and she said 'what do you mean?'. I said 'well obviously this isn't something that is subjective, it needs to be objective, so there must be a list of standards that are alright. If you give me a list of standards then I'll know whether it's Royal Dolton plates or Marks and Spencer's plates, whatever it is I'll get them Whatever your best is for Ruth, my best will be much better I can assure you'. She just looked at me like I was this awful woman.

Sharon provides another example of how the risk agenda and the mechanisms of surveillance associated with it result in damaging forms of misrecognition. Sharon is a lone parent with several children living in an economically disadvantaged area of Sheffield. She is also a member of a minority religious group. In 2005 Sharon made a standard application to the Social Services for respite on the basis that her daughter, Aisha, had special care needs. Her perfectly reasonable request for respite was automatically



assessed in terms of risk without her prior knowledge. The social worker in charge of the case decided that Aisha (aged 2 years at the time) was 'at risk', among other things, of being forced into an arranged marriage at some future point. Sharon, appalled by the allegation, embarked on a lengthy appeal process which cost her nerves and resulted in many sleepless nights. While the appeal process resulted in Sharon's complete vindication, she felt that her ordeal was directly linked to her marginalisation and that a married middle class couple would not have been subjected to the same degree of scrutiny. Disturbingly, it seems that a parent who asks for support (and is therefore perceived as lacking in the necessary self-sufficiency) is likely to be perceived as posing a risk to their own children.

The impact of misrecognition is not restricted to negative evaluations that disempower those labelled deficient or even to risk assessment exercises that equate 'dependency' with risk. Recognition and misrecognition are also closely bound up with the distribution of resources in society. Consistent with materialist arguments and the experiences of other movements for economic and social rights, the struggle for resources was a potent source of counter-hegemonic discourse for the parents of disabled children. Parents involved had often encountered enormous difficulties in accessing the resources they were entitled to. The allocation of resources, underpinned by 'achievement' values (see Honneth 2001, 2003) often failed to give recognition to the value of their lives with their children.

When Sadie's son, Thomas, was diagnosed as 'deaf', Sadie was anxious to learn sign language so that she could communicate with him. She discovered, however, that there was no support for families of 'deaf' children to get free sign language learning. Sadie had been forced to give up her lucrative work and the family was in the process of selling their house. If Sadie had been an unemployed lone parent seeking to join the workforce by undertaking vocational training, the necessary support would have been immediately forthcoming. Her wish to learn sign language, as it was not vocationally relevant, was regarded as ineligible. As far as Sadie was concerned, the fact that monetary resources were not available to her in order for her to learn sign language was evidence that her relationship with Thomas was not valued. Experiences similar to Sadie's were a recurrent theme in many of the interviews with parents who often associated the struggle for resources with issues of misrecognition. One parent, who had recently had a request for a special care seat for her child with postural difficulties rejected, explained, 'Sometimes I feel as though I'm scrounging'. When I asked her if she would appeal, she replied, 'No, because I feel as though they'd make me feel like a scrounger. And I'm not scrounging, I'm fighting for my baby'.

I wish to emphasise here I do not intend to detract from the excellent practice within health and social care that is often evident. The research revealed many examples of practice in which professionals showed an understanding that enabling care is dependent on relationships of recognition in which difference is not constructed as a problem. One such example is provided by

Sofia, an Asian woman with a young son, Ahmed, who had been diagnosed with cerebral palsy. In relation to her son's consultant, Sofia commented,

He actually listens to me and he actually makes a note of everything I say. He takes in what I'm saying, positive or negative. [...] He takes me seriously. He sees Ahmed as an individual, not as a bundle of problems. Had he not been that responsive, I might have been quite negative towards him. As a parent, you see, you need to grab on to something that gives you a bit of hope. [...] He was my pathway, my manual to this new world, this different planet.

I have the impression, however, that empowering care such as this is achieved *despite* the dominance of narratives that act to define acceptable 'normality' within ever more circumscribed boundaries. Gleeson and Knights (2006) have written about 'ecologies of practice', that is micro-cultures in which professionals are neither 'victims', whose practice is determined entirely by the dictates of the audit culture, nor purely strategic operators who seek to challenge managerialist structures. Disputing the traditional sociological dualism between agency and structure, Gleeson and Knights (2006) argue that professional practice is mediated by both agency and structure and sustained through the working out of tensions at different levels of experience. These are connected to both external criteria of performance and those 'ecologies of practice' (Stronach *et. al.* 2002) that are negotiated 'on the ground' between practitioners, service-users and managers. I am developing a view that good 'ecologies of practice' may at times stem from an understanding that where service users are subject to oppressive narratives that attribute 'deficient' identities, this will have an impact on their ability to write a positive life script (which is so crucial for empowerment). As Robertson (2001: 122) comments, 'In practical terms, education or welfare systems that operate on the premise of normality and the reduction of difference, will always leave some people out. It is part of their logic'.

## **Conclusion**

The parents interviewed are asserting their right to construct their lived relationships with their families and children, friends, and service providers in a way that is linked with the rights of recognition. This is being achieved through inter-subjectively acquired understandings of recognition that value alterity – that is each person’s particularity and authenticity. In doing this, they are also challenging discourses around health and wellbeing that locate these as individual responsibilities (Crawford 2006). However, reflexivity that questions pre-given understandings and may lead to the construction of authentic forms of wellbeing and empowerment does not occur within a vacuum. Whilst families are re-negotiating the tragedy model of disability through an appreciation and enjoyment of their relationships with their children, they are, at the same time, encountering the ‘symbolic violence’ of seeing their children’s unique authenticity and selfhood being effectively erased by the dominance of managerialist based forms of care that are organised according to neo-liberal interpretations of empowerment and wellbeing that are premised on binary understandings of normal, abnormal, and independent, dependent. These binaries, constituted through modernist narratives that view identity as individualised, converge with bio-medical interpretations of disability that also equate success with cure and the restoration of normality, defined as self-sufficiency. The resulting forms of misrecognition are further intensified by surveillance procedures that pathologise parents living in disadvantaged circumstances or leading less conventional lives. Difference or social marginalisation comes to be seen as a dangerous form of deviance and

only forms of empowerment and wellbeing that adhere to 'expert' agendas and interventions are viewed as legitimate.

Based on a specific understanding of selfhood, the modern health user is required to be the responsible agent who exercises self-mastery (Rose 1999) and self-mastery is seen as crucial for personal wellbeing, which is now '...regarded as a state of virtue' (Furedi 2004 cited in Sointu 2005: 261). The notion of the ideal empowered consumer of late modernity increases the pressure to be recognised but appears to place the burden entirely onto the individual. With regard to the parents of disabled children, they may be perceived as either passive victims or, at worst, as posing potential threats to their children. An openness to alterity – that is to difference and singularity - is integral to the rights of recognition. This insight appears to provide the basis for parents' heightened awareness of how an individual's authenticity can be discovered within intersubjectively constructed identities. According to Honneth (2001, 2003) our distinctively human dependence on intersubjective recognition must be realised in both the private *and* public domains of life. In the private sphere, parents are constructing counter-hegemonic understanding that enables them to develop relationships with their children in which they both gain and provide recognition based on affection and love. The common experience of the refusal of recognition in the public sphere needs to be addressed by health and social services that are so often shaped by discourses that identify 'achievement' in narrowly normative terms. As Honneth (1996) writes, the refusal of recognition is a form of coercive identification that is embedded in unequal relations of power. It seems ironic

that the ideal notion of the empowered consumer of late modernity increases the pressure to be recognised while at the same time creating a culture which undermines this.

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