

# Changing Families, Changing Food

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

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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 oppressive narratives may mean that both parents and children are attributed 'deficient' identities in ways that may (ironically) 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 our human dependency on intersubjective recognition.

Key words: wellbeing, empowerment, health and social care, enabling narratives, recognition, inter-subjectivity

## Introduction

A dominant idea within social theory is that contemporary life is characterised by increasing requirements for reflexivity in the face of a perceived decline in structurally based determinism (Beck, 1992; Giddens, 1994, 1998). As Beck et. al. (1994: 74) put it, 'the more societies are modernized, the more subjects acquire the ability to reflect on the social conditions of their existence and to change them accordingly.' The idea is that once individuals are freed from traditional structures, their capacity for reflexivity is unleashed in ways that challenge the traditional rules and norms that organise people rigidly along the axes of gender, class and status. The ideal citizen therefore is self-reflexive, autonomous and in control (Furedi, 2004; Rose, 1999; Taylor, 1989, 1994, Stacey, 2000). The concept of the 'autotelic self, who can rise to challenges by transforming them into opportunities, has also been placed at the core of 'positive welfare' (Giddens, 1994: 192-4). Health and wellbeing are now firmly located within this paradigm of the 'do-it-yourself biography (Beck, 1992) and within a policy framework of informed consumerism (Hughes, 2004; Powell and Hewitt, 2002; Newman and Vidler, 2006). In the White paper, *Choosing Health: Making healthy choices easier* (DoH, 2004) which unequivocally identifies the ideal service user as an informed consumer (Hughes, 2004; Powell and Hewitt, 2002), the role of the National Health Service (NHS) and other organisations is identified as one of enabling individuals to promote their own health and wellbeing. Terms such as 'health' and 'wellbeing' are imprecise and contested, but it is generally agreed that wellbeing is a broader concept than health and even one that can in certain cases be achieved independently of it (Schickler, 2006; Sointu, 2006). The policy emphasis on wellbeing is intended to encourage people to view their health more

holistically in relation to multiple aspects in their lives (Goldstein, 2003). For instance, wellbeing is associated with advantages such as autonomy, authenticity, being connected to and loved by others, and by having high levels of self-esteem. (Schickler, 2005). New Labour policy also makes clear links between wellbeing and employment (DWP, 2005). To a certain extent, therefore, health implies a sense of personal fulfilment rather than just the absence of disease (Sointu, 2006).

Being both content and healthy are framed within contemporary UK Government policy as achievable for the responsible individual who self-reflexively seeks her own *authentic* path towards self-actualisation (Sointu, 2006). The notion of authenticity, developed by Taylor (1991), is important in this context in that it suggests that everyone's quest should and will be different. It is based on the idea that each person must follow their unique path in life, which they must individually forge. 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. Similarly, 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.' Beyond this, policy is also fundamentally contradictory in the sense that discourses around individuality, wellbeing, authenticity and empowerment come into conflict with the mechanisms of governance and the influence of 'expert' knowledge. Health and wellbeing *per se* are not sufficient. The virtuous citizen is expected to reflexively achieve these by 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.' Individual reflexivity must therefore be contained within the boundaries defined by 'expert' opinion that is emeshed within the exercise of governance. As Rose (1999: 76) has pointed out, governance is required to 'define the norm and tutor individuals as to the ways of living that will accomplish normality'. For this reason, it perhaps not entirely coincidental that in policy the term wellbeing tends to be equated with work, meaning paid employment. Those who are unable or unwilling to constantly renew their fitness for the labour market are seen as the excluded cadres of the so-called 'dependency culture' (Levitas, 1998). In October 2005 a new strategy for the health and wellbeing of *working age people* (my emphasis) was launched, which stated in its introduction,

Work matters – it can help to improve your health, reduce health inequalities and offer improved opportunities. Due to changing demographics, having more people in work is increasingly important for communities and our

economy. The health and well-being of people of working age is therefore of fundamental importance to our future and we are committed to bringing about real and sustained improvement in this area. (DWP, 2005).

This last point is an important one to consider in relation to this paper which is partially based on an ESRC project *Parents, Professionals and Babies with Special Care Needs: Identifying Enabling Care*, (<http://www.shef.ac.uk/inclusive-education/disabledbabies/>). This project was carried out at the University of Newcastle and at the University of Sheffield and aimed to identify enabling care from the perspective of parents with disabled babies; to examine professional-client relationships; to investigate how meanings of 'impairment' and 'disability' were negotiated and constructed; and to look at how these meanings impact on care and perceptions of the disabled baby. This paper is also based on work that I have undertaken as part of a current Leverhulme project, *Making Healthy Families*, which is part of a larger research programme, *Changing Families, Changing Food*, that is being conducted at the University of Sheffield between 2006 and 2008. This project specifically investigates the links between food and family practises by focusing on a wide-range of community-based food initiatives that aim to overcome food poverty through improving people's (again normally women's) cooking skills. To date, 13 in-depth interviews have been conducted with public health managers and practitioners and a number of observations in cooking interventions have been made. While the collection of empirical data from this study is still at an early stage, I have written an extensive literature review for this project which has enable me to reflect on the rights of recognition, empowerment, agency and its limits. The insights I have gained have been applied to further develop analysis of the now completed research project *Parents, Professionals and Babies with Special Care Needs: Identifying Enabling Care*.

The research participants in the parents and disabled babies project were the parents, mainly mothers, of disabled babies and young children. In most cases, the mothers had been obliged to give up paid employment as work outside the home is extremely difficult to combine with parenting and caring for a disabled child, particularly as this nearly always entails engaging with a range of health and social service agencies and multiple practitioners. 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, as a practising member of a minority religious group, belonged to a stigmatised religious group. In stating this I wish to underline the fact that most research participants were highly circumscribed in their ability to seek agency, wellbeing and their own sense of authenticity through participating in paid employment. In addition, and crucially, parents were also contending with oppressive and dominant narratives that construct the birth of a disabled child as a tragic event that must almost necessarily lead to a type of impoverished life, characterised by a conspicuous absence of empowerment, for both parent and child.

Previous research (Fisher and Goodley, in press 2007; Fisher, in press 2007) in relation to the study ESRC *Parents, Professionals and Babies with Special Care Needs: Identifying Enabling Care*, which focuses on experientially acquired knowledge in the private sphere, has shown how parents are re-writing the dominant scripts of tragedy associated with disability. Far from seeing their child as 'disabled', for many parents the quality of their interdependent relationships with their children brought them to new understandings in which they valued human diversity and questioned pre-given ideas of 'normality' based on the notion of the so-called independent citizen engaged in paid employment. In fact, most parents were remarkably successful in self-reflexively constructing meaningful narratives stemming from enriching relationships with their children that promoted a sense of wellbeing. On this basis they could be perceived as the self-responsible agents of late modernity for whom reflexivity is a route to authentic selfhood.

Applying ideas associated with the politics and rights of recognition, I build on previous research (Fisher and Goodley, in press 2007; Fisher in press, 2007) by arguing that while the parents' of disabled babies are acting reflexively to enhance their own and their children's sense of authenticity and wellbeing, their quest to do so is being thwarted in a variety of ways when they come into contact, as they frequently do, with the health and social care services. As argued above, 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. Therefore parents' sense of agency and empowerment that stems from their reflexive questioning of hegemonic values of 'achievement' or 'normality' is being undermined by service cultures which, underpinned by the mechanisms of governance, identify both parent and child as normatively 'deficient.' Within the current policy framework, there is a danger that an overemphasis on the 'active voice' can lead us to overlook emotional injuries. This paper suggests that both parents and children are being subjected to oppressive frameworks of meaning that attribute to them 'damaged' identities whilst failing to recognise their particularity and authenticity.

## **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. 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 (Schatzman and Strauss, 1973 and Charmaz (1995, 2004).

*Both Parents, Professionals and Babies with Special Care Needs: Identifying Enabling Care and Making Healthy Families* are studies that owe much to feminist oral traditions in that they seek to reveal the perspectives of a marginalised groups of people who might have otherwise remained 'hidden' (Anderson and Jack, 1991; Oakley, 1993). At the same time, these studies also follow on from critical or postmodern narrative researchers (for example, Bertaux, 1981; Thompson, 1988; Goodley *et al*, 2004) and have as their starting point a subject that is not unified but constituted by a number of selves who may be in conflict with one another. As Hoggett (2001: 42) argues, there are 'powerful integrative forces at work within subjectivity', so we are both one and we are simultaneously many. This is consistent with Foucauldian theory that tends to conceptualise power as neither positive or negative but located at the micro level and related to the ways in which individuals either conform, consent or resist the external pressures (Foucault, 1980). The governed subject may therefore have a highly ambivalent relationship with public health organisations and is likely to both resent state incursions into the domestic sphere whilst simultaneously believing that it is incumbent on the State to take responsibility for citizens' health (McNay, 1992). This is not to claim that identity is an illusion. People create coherent narratives in relation to their lives in order to find meaning that will sustain them. The research discussed here is based on the idea that there is a hermeneutic relationship between the stories people tell and their experiences. The experience elicits the story and the story articulates and therefore modifies experience and a dialectical relationship exists between the narratives people draw on and the construction of "realities". Interviewees were therefore seen as not merely reactive but also architects of their own practices, understandings and identities. People are inevitably shaped by dominant narratives, however, they do not generally internalise them uncritically but often engage in sophisticated levels of reflexivity, defined here as the ability to question pre-given understandings and the often 'invisible' ideologies underpinning them. However, I would wish to qualify this by stating that reflexivity is not a freestanding quality that is acquired in a manner disconnected from environmental and structural factors. 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 re-writing dominant tragedy narratives in relation to disability through reflexivity although their agency to do so is curtailed as their subjectivity is also constituted through the stories that others tell about them. In other words, human agents are free only to a certain extent to seek their authentic selves in the interests of their wellbeing. To clarify this position further, I draw work relating to the politics of recognition as represented by Honneth (2001, 2003; Sointu, 2006; 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.' (Yar, 2001: 59) with all three types of recognition leading to human beings enjoying dignity and integrity. 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 in the wake of a marked 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 author positive biographies of their lives with their disabled babies may be impeded by forms of 'misrecognition' which positions them as inferior and vulnerable to patterns of disrespect which must be regarded as 'a serious violation of justice.' (Fraser, 2001: 24).

### **Reflexivity: from chaos to transcendence**

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, 1985; Fisher & Goodley, in press 2006). 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), a challenge that is, however, 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 as devastating. Words such as loss, grief, anger and numbness were frequently 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. I can't explain it...What happens then is it turns into anger and frustration, and then grief, it is grief. You look at him and you had this twin .... 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.

The grief is often compounded further by medical interventions that sometimes contribute to a child's suffering. Below a woman explains the devastation on realising that her son had auditory and visual impairments,

And all this stuff – oh God – the things that were done to him and he never saw it coming. He'd got a vision impairment, he's profoundly bloody deaf, he's got poor head control because of his situation, so he couldn't turn to see things that were going to happen to him. People grabbed him and did things to him, much worse than your average baby, he never saw any of it coming, heard any of it coming. The grief of it hit me like a wave. I collapsed actually for three days, couldn't cope.

Despite an initial feeling of crisis, prompted by both emotional and practical turmoil, many, indeed most, parents developed new understandings around disability and identity that counter dominant discourses based on deficiency and ontological separateness (see Fisher, in press 2007, Goodley and Fisher, in press 2007). This research tends to suggest that the birth of a disabled child encourages reflexivity that over comes oppressive narratives around disability. The extract below is taken from an interview of 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.

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, 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 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 are typical of many made by the interviewees. They evidence a form of reflexivity that questions the ideological premises on which actions and practices are based. Notwithstanding the pressures to internalise pre-given understandings, many of the parents' narratives in this study challenge accepted definitions of disability, parenting and care, opting instead for a new 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 initially devastating, it had, for some parents, led to a deep form of reflexivity that is profound, involving what, Gur-Ze'ev *et al.* (2001: 96) describe 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.' Reflection of this kind necessarily challenges hegemonic thinking and it leads to insights that resist normalising practices and their ideological foundations. According to Gur-Ze'ev *et al.*, (2001) the subject engaged in this type of reflection is 'the responsible or ethical subject' who, in his or her relationship with others, is called upon to transcend dominant narratives' by discovering some 'degree of authorship' (MacIntyre, 1985).

I suggest here that many of the parents of disabled children participating in the ESRC study are engaging in a form of responsible reflexivity that is linked to their embodied identities constituted within the family in which they are finding the space for 'cultural emancipation', defined by Mouzelis (2001: 445) as freedom from 'manipulative socialization' or what Bourdieu (1991) calls symbolic violence. In this respect, these parents appear to be asserting their right to construct positive biographies with their children in a way that is linked to their experiences of parenting and caring for a disabled child, in particular

the positive relationships they enjoy with their child. Their comments often evoke Diprose's (2002) notion of 'corporeal generosity', a type of generosity that is 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 – an openness that is not only a requirement for establishment of relationships – but one that conceives identity as constructed through openness to others. Crucially, intercorporeal generosity supports notions of alterity and ambiguity and the possibilities that these open. It is not based on a 'psychological rigidity' (p.91) that assumes everyone is the same and should engage in contractual exchanges based on an ideal mutual exchange between equals. 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 crucial aspect here is that the subject becomes the 'responsible' subject who is open to alterity, diversity and intersubjectivity in a way that renegotiates the tragedy model of disability. Consequently, parents are engaged in reviewing, writing and rewriting narratives of disability. In doing this, they are also re-claiming a space in which responsibility extends beyond the quest for personal wellbeing.

This type of subjectivity tends to be associated with values of mutualism and interdependence and is 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.

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 of individualised wellbeing and dominant models of idealised citizenship. Instead it would stress diversity in a way that acknowledges the value of diversity and gives voice to marginalised groups. It 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. An ethic of caring would necessitate a democratisation of the relationships between service users and providers and

an acknowledgement of the value of experiential knowledge acquired in the private sphere (Williams, 2002, Fisher, in press 2007).

### **Limits to reflexivity**

If there is tragedy for these parents it is that the subject is not entirely free to re-script her story independently as each story of the self is constituted in and through others with each story embedded within an entangled web of relations. 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. While parents and their disabled children gain positive attitudes to themselves through affective relationships within the home, this is often not reflected by their experiences in the public sphere, where the development of their self-esteem and their ability to create positive narratives of their lives with their children are being undermined by a lack of recognition on a number of dimensions. These are linked to both the inherent hierarchical nature of traditional doctor-patient relationships and to the medical model of disability that tends to position people with disabilities as 'deficient'. At the same time, parents may feel personally denigrated by if their way of life does not correspond with dominant narratives around 'achievement' as identified by Honneth (2003). Misrecognition may be attached to social marginalisation through socio-economic circumstances, religion and or disability (of the parent) and parents who simply lead unconventional lives are likely to be subjected to normalising judgements and the exercise of 'disciplinary power' (Foucault, 1979) relating to ideas of 'good enough mothering.' As Peckover (2002) has previously noted, normalising discourses are particularly salient for certain groups such as Black mothers, mothers with disabilities and lone mothers. I suggest here that the risk management agenda within health and social services is also contributing to processes of misrecognition by an over-zealous policing of people's lives (Furudi, 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, an approach that stresses risk avoidance above all else leads to new risks - the risks of misrecognition.

In writing this, I wish to emphasise that I do not intend to paint an overly gloomy picture of health and social services. There are many examples of good practice in which professionals clearly have 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 these insights are arrived at *despite* the dominance of narratives that act to define acceptable 'normality' within ever more circumscribed boundaries. Managerialist approaches to care, are based on binary understandings of normality and abnormality, (Fisher, in press 2007) converge with the medical model of disability in ways that attribute people subordinate identities. This type of misrecognition is not limited to issues of disability. As explained above, many parents who lead marginalised lives as a result of poverty, disability or religion - and who therefore do not conform to the blueprint of ideal citizenship - are suffering from additional forms of misrecognition. The risk agenda in particular presents a new risk - namely that of misrecognition. All these factors mean that in a variety of ways both parents and children may be constructed as 'deficient' citizens. Below, I provide examples.

While many medical practitioners exercise sensitivity, the process of diagnosis is often still framed entirely in the tragedy model of disability that can easily be perceived as effectively 'writing off' the child. The extract below is taken from an interview with Sadie, who had been a 'high-powered' sales manager enjoying a high level of recognition before the birth of her son, Tom, who was born with a rare syndrome. She 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 floppy legs and his muscle tone's poor' and 'he's not responding as he should'. He was sort of like a 'right off' by the end of the appointment. And I was absolutely devastated when I came out of it and I hadn't even got the strength to say 'why was he having a CT scan'. I didn't really know what one was and I didn't know why we were doing it and because he just so sapped my energy with this. 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.

Emma, quoted below, was a lone mother living on benefits in a disadvantaged area of Sheffield. The extract below 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.

As mentioned above, the risk agenda within health and social care services can act in ways that may appear insulting to members of subordinate groups in society. Sylvia, an outstandingly capable and intelligent woman, happens to be a lone parent living on benefits and a wheel-chair user. 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. Sylvia had previously explained to me that some of the medical staff had 'tipped off' the health visitor because they had concerns about the baby's welfare. The health visitor told Sylvia that Dr xxxx was concerned about her ability to look after the baby and whether she would have the 'appropriate things'. Sylvia explained her feisty response as follows,

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 Doulton 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. I was very angry and I was very calm. I'm quite good at being calmly angry at times.

While Sylvia was rightly annoyed, there are even more striking examples of the links between misrecognition and the risk agenda. Sharon is a lone parent with several young children and a member of a minority religion. Drawing on her religious beliefs, Sharon makes no distinction between children who have no special care needs from those who do not. In 2005, Sharon made a standard application to the Social Services for respite on the basis that her daughter, Aisha, has special care needs. Her request for respite was, unbeknown to her, assessed in terms of risk. The social worker in charge of the case decided that Aisha (aged 2 years at the time) was 'at risk' of being forced into an arranged marriage. Sharon was appalled by the allegation and embarked on a lengthy appeal process. The investigation concluded that there had been appalling mis-management and poor practice in the way the case was handled. It also concluded that negative stereotypical assumptions made about Sharon's religion fell within the remit of the Macpherson definition of racist (or religious) discrimination.

Honneth (2001, 2003) and Yar (2001) analyse the politics of recognition as inextricably entwined with the politics of redistribution<sup>1</sup>. From this perspective economic and cultural struggles are contained within the same theoretical ambit. While it is beyond the scope of this paper to provide a detailed

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<sup>1</sup> This contrasts with Fraser's two dimensional concept of justice that perceives struggles for recognition and struggles for the redistribution of resources as related but not reducible to each other.

discussion of this theoretical position, it is clear that the parents involved in this research often encounter enormous difficulties in accessing the resources they are entitled to and that the allocation of resources is underpinned by 'achievement' values (see Honneth) that fail 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 was, however, not vocationally relevant so she was regarded as ineligible. The fact that sign language was potentially the most effective way of communicating with her son was apparently of little consequence. 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. The constant battle to access services was a recurrent theme among parents who often associated the struggle with a sense of recognition. As one mother who had recently had a request for a special care seat rejected for her child who had special postural, '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'.

Recognition appears to be one of the key factors in providing enabling care. While much of the data used in this paper has been taken from the parents and disabled babies project, early data gathered for the *Making Healthy Families* project suggests that these insights are equally transferable to other areas of health and social care. In an interview in 2006 with Ann, a public health manager in Sheffield, I was told that, for many of the participants taking part in cookery classes, the primary benefit of attending was unrelated to cooking. The main gain of the interventions were, in Ann's opinion, to provide people with an emotionally supportive environment in which they feel valued. So many aspects of their lives, such as poverty, lack of education and in some cases domestic violence, had contributed to low levels of self-esteem. The first step, in empowering people, Ann thought, was to build up their sense of being a 'worthwhile and valued person.' Before this was achieved, efforts towards empowerment and self-efficacy were of little use. In relation to community-based food interventions, Ann explained,

For a woman, living with domestic violence, [she's] coming to that [the cookery class] because you're nurturing and you're caring and giving something to that woman that she will take away for an hour, an hour and a half. But it doesn't mean that she is emotionally and physically or mentally able to replicate that back in her own setting. She's needed something [recognition] from that session, that is different to probably what your agenda is.

The example provided by Ann shows how professionals are identifying needs other than those directly 'targeted' by the intervention. Several professionals



interviewed for the *Making Healthy Families* project argued that the willingness to go beyond formal targets was the hallmark of good practice. Recently, 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, or 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.

In relation to both research projects discussed here, I am developing a view that good 'ecologies of practice' may times stem from an understanding that where service users are subject to oppressive narratives that attribute them 'deficient' identities, this will have an impact on their ability to write a positive life script which is so crucial in supporting individual empowerment. The health and social care services are still dominated by modernist ideal of achieving a cure or a 'fix', defined as normality. 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 biographies with their children reflexively in a way that is linked with the rights of recognition. Consistent with contemporary social policy that requires subjects to individually forge authentic and positive biographies, they are renegotiating dominant narratives of disability. 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 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 among binary understandings, for instance normal, abnormal, independent, dependent. These converge with bio-medical interpretations of disability that are based on modernist preoccupations with cure and the restoration of normality. The experience of misrecognition often does not stop there. Parents living in disadvantaged circumstances or those leading less conventional lives risk being denied their own particularity and authenticity. This is linked in part to the dominance of the risk agenda within health and social services which

tends to implicitly associate difference or social marginalisation as a dangerous form of deviance. Placing people into subordinated categories can only hamper their development towards reflexive agency.

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. The openness to alterity – that is to difference and singularity - is integral to the rights of recognition. This fundamental 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 have engaged in reflexivity that enables them to develop relationships 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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