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**Experiential knowledge challenges ‘normality’ and individualised
citizenship: towards ‘another way of being’
(Pamela Fisher, in press 2007)**

Abstract

This paper draws on the narratives of parents of disabled babies in order to conceptualise enabling care. The analysis emerges from the Sheffield site of an ESRC research project *Parents, Professionals and Disabled Babies: Identifying Enabling Care*, which is being undertaken by the Universities of Sheffield and Newcastle-upon-Tyne. In New Labour Britain individualised citizenship and self-sufficiency are upheld as the embodiment of ‘the good life’. A culture of individualised citizenship obliges citizens to strive towards maximum independence, interpreted narrowly as self-sufficiency, and acts to devalue the lives of some disabled children and their parents. In the area of disability, this reinforces the individual model of disability and fails to properly value experiential knowledge acquired in the private sphere. This paper suggests that parents are engaging in reflection that counters hegemonic understandings by embracing alternative narratives that recognise diversity whilst questioning narrowly conceived interpretations of normality. This leads to the reconstruction of parental identities through discourses shaped by mutuality and interdependence.

(i) Introduction: from normalisation to 'Government of the Soul'

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. Robertson (2001, p. 122)

Historically, the term 'deviant' has been applied to a wide range of marginalised identities, including disabled people, who could then be deprived of their rights and privileges as human beings. The concept of normalisation, developed in resistance to the dehumanising treatment of disabled people, was based on a human rights approach that advocated that the normal conditions of everyday living should be made available to everyone (Walmsely, 2001). Wolfensberger (1972) took the concept of normalisation, that had initially been applied according to a Scandinavian human rights approach, and renamed it 'social role valorisation' whilst placing a greater emphasis on reversing the consequences of social devaluation and stigma. Recognising the social constructedness of 'deviancy', Wolfensberger's primary objective was the integration of 'deviant' or, as he saw them, marginalised individuals into society. When compared with their historical antecedents, such as incarceration, the normalisation and social role valorisation principles constituted a progressive step forward in the education and inclusion of marginalised populations, especially people with disabilities. However, there has also been the unintended consequence of reinforcing narrow interpretations of what constitutes 'normal' (Boxall, 2004, p. 28). This last point is central to this paper which focuses on the perspectives of parents with disabled babies and/or disabled young children.

My starting point in this paper is that in the case of families with disabled babies and young children the language of inclusion has been mobilised as a discourse of self-government as expressed in the managerialist approach to care that is reliant upon narrowly conceived performance criteria. Whereas the early managerialism of the Thatcher and Major years in the UK was primarily concerned with achieving efficiency savings (Pollitt, 1993), modern managerialism since 1997 has been expanded to include a particular 'ethic of personhood' based on individual autonomy (Giddens, 1998), which has been adopted as the blueprint for a new ideology of citizenship and self-government (du Gay, 2000; Munro, 2003; Newman, 2000; Rose, 1996). Managerialist strategies throughout the public sector, while still concerned with issues of 'efficiency, effectiveness and economy', are also applied ideologically to deliver the New Labour vision of responsible citizenship. The intention is that excluded groups, such as the elderly, people with disabilities, parents with children with disabilities, the young and people from minority ethnic backgrounds should be brought into the realm of 'mainstream' society constructed around notions of independence and paid work. Active citizenship is encouraged through self-investment in 'human capital', partly supported by the 'opportunity state' working collaboratively with individuals and families through various forms of partnership (see Poole, 2000, p. 109). Thus, social inclusion is sought through the 'colonization of identity', whereby marginalised groups are transformed into compliant collaborators who have internalised the New Labour vision. (Ling, 2000, p. 89).

While empowerment is writ large in policy documents (see Department of Health, 2001; Department for Education and Skills, 2003) in a manner that

acknowledges the creativity of individual employees, self-government is exercised over both service users and providers in subtle ways (see Masschelein and Maartins, 2002; McDonald, 2004). Professionals employed within the health and social services are encouraged to transform themselves through self-government into entrepreneurial agents without questioning the underlying value system that limits understandings of autonomy as something to be evaluated, audited and mapped according to pre-determined criteria. Individuality is achieved through the performance and mastery of pre-determined learning objectives and professional competence is reduced to the process of acquiring skills necessary for efficiency rather than developing insights that promote critical self-reflection or lead to a greater understanding of people's diverse lifeworlds (Askhim, 2003). Within this discourse paid work is not only interpreted as a right but also as the first duty of a good citizen, except for people with disabilities for whom it has become both a 'duty and a right' (Williams, 1999, p. 672). Notions of autonomy and independence are clearly linked to activities within the public sphere, thereby reinforcing the discursive categorisation of disabled people as either self-sufficient workers or 'dependent others' (Sevenhuijsen, 2000, p. 14). While the interests of carers and those who are cared for have often been regarded as antagonistic (see, for example Watson *et al*, 2004), the view taken here is that narrow interpretations of normality can have a direct and negative impact on the status of people with disabilities, who may 'fail' to conform to the prevailing standards of 'normality', whilst devaluing the role of family members who, in the context of mutually rewarding relationships with their disabled children, acquire valuable expertise that tends to remain overlooked.

(ii) Analytical Framework

The health and social care professions are increasingly being encouraged to work towards a partnership model which values clients' perspectives (Avdi *et al*, 2000, p. 329). This development is now reflected in a number of government documents that link education and health to the wider aim of social inclusion (for instance, *Every Child Matters*, DfES, 2003; *Choosing Health: Making healthy choices easier* DoH, 2004). While recent initiatives towards more balanced relationships between professionals and clients are welcome, they are far from securely embedded in policy which continues to promote self-government among individuals and organisations in ways that support the values underpinning the existing social system (Lyotard, 1984; Ling, 2000, Parton, 2005). Within this discourse 'normality' is constructed as contingent upon the attainment of independence, narrowly interpreted as self-sufficiency (that is as the ability to do things without help or assistance especially, I would add, to *earn one's living*) (William, 1999, 2002)¹. The concern to 'empower' individuals is driven by a particular view of the subject, defined narrowly as the reflexive and 'autotelic' (Giddens, 1998) agent of late modernity. According to this discourse, the socially excluded are seen as unable or unwilling to appropriately manage their lives (Rose, 1996)

I argue here that services are tending to overlook expertise that disabled children and their parents acquire in the home environment as this does not

¹ This interpretation should be distinguished from the independence as defined by the independent living movement that conceptualises independence in terms of agency (Morris, 1996). Seen from this perspective, disabled people are no longer the objects of care but the recipients of support that their autonomy and self-determination.

fall within the kind of managerialist framework, characterised by Lyotard (1984) as 'performativity', that supposedly leads to 'the good life', that is, one of so-called self-sufficiency. Through highlighting the perspectives of parents, this paper contributes to previous research arguing that lay people possess expertise by virtue of their experientially acquired knowledge (Busby et al., 1997; Monaghan, 1999). I suggest here that knowledge learned within the private sphere can contribute to more inclusive forms of care that do not construct difference as a problem or an abnormality to be resolved through technical and assimilationist programmes. This is not intended as a criticism of the many committed professionals working within social and medical services: many parents speak highly of the services provided. However, this study suggests that professionals are impeded in their quest to provide more responsive care by a culture that devalues knowledge that is not 'legitimised' (Lyotard, 1984). Many interventions for families with disabled children appear to constitute part of a parent management strategy which constructs knowledge as something that flows from professional to parent and from the public sphere into the private. As Tronto (1993, p. 135) argues, a political order based only on 'independence and autonomy [...] misses a great deal of experience, and must somehow hide this point elsewhere. For example, such an order must rigidly separate public and private life.'

Against such a discursive backdrop, disabled children and parents of disabled children are held individually responsible for adapting as closely as possible to 'normality'. It should be pointed out here that the gender neutral term 'parent' tends to deflect from the reality that it is generally *mothers* who are the primary carers of children and this is more the case when the children are

disabled (see Read, 2000; Traustadottir, 1991, 1995). Moreover, disabled children are more likely than other children to be brought up in a household with a lone mother (Beresford, 1995 cited in Read, 2000, p. 53).

The focus on knowledge developed experientially within the private sphere is continued in the latter part of this paper in which I point out how parents' understandings are contributing to the development of theoretical and philosophical positions that counter the view that 'the good life' is only to be achieved through aspiring to 'normality' as defined by dominant notions of independence - that is by entrepreneurial individuals in the public sphere. In challenging dominant images of normality this paper contributes to earlier work which has argued that parents of disabled children often do not subscribe to the personal tragedy model of disability (Glendinning, 1983; Goodley and Tregaskis, 2004; Roll-Pettersson, 2001 and Carpenter, 2000). Whilst acknowledging the considerable contribution made by materialist writers, for instance, Barnes (1998), Finkelstein (1991) and Oliver (1990), who have provided analyses of the social, economic and material conditions that create 'disability', this paper questions materialist tendencies to neglect impairment. It therefore follows on from poststructuralist research that has challenged biologically determined interpretations of learning disabilities by drawing on the idea of 'distributed competence' to argue that 'learning disabilities' should not be regarded as a fixed and unchanging category but as a largely socially constructed label (Goodley and Rapley, 2002, p. 133). The paper also owes much to feminist writers who have challenged notions of independence based on a restricted definition of self-sufficiency and criticised instrumentalist approaches to care and their concomitant tendency to

devalorise activities and knowledge associated with the private sphere (Corker and French 1999; Cushing and Lewis, 2002; Kittay, 2002; Lloyd, 2001; Morris, 1996, Rössler, 2002; Thomas, 2001; Sevenhuijsen, 1998). While I would wish to stress that the goals of autonomy and self-determination are crucial for disabled people, who have historically been denied the right to exert autonomous choices, this paper equally points to an understanding that personal autonomy is essentially something that is found within relationships of interdependence.

(iii) Methodology

This study is based on fieldwork conducted in 2004 and 2005 by researchers from the University of Sheffield for an ESRC research project *Parents, Professionals and Babies with Special Care Needs: Identifying Enabling Care*, (<http://www.shef.ac.uk/inclusive-education/disabledbabies/>). The fieldwork conducted in Sheffield centred on 25 families with disabled babies and/or children. In-depth interviews were conducted with the families who were divided into 2 groups. The first group of participants, whose children were aged between 3 and 5 years old, 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 provided a longitudinal perspective through participating in a number of interviews conducted over an 18-month period. An ethnographic component involved (i) the observation of parents, children and professionals in a variety of clinical, social services and home settings and (ii) immersion within the wider support networks of parents.

The research 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.

The link between stories and the construction of self identity is now well theorised (Giddens, 1991; Plummer, 1983; Ricoeur, 1992; Rosenthal, 1993; Taylor, 1989) and this has been the experience in recent research in which (Fisher and Goodley, in press, 2007) have explored the private experiences of subjectivity as distinct from the public presentation of self. In prioritising parents' stories, we sought to provide our research participants with the space to express and develop narratives that resist dominant discourses that frame disability in terms of individual deficits. In this respect, our project also follows on from a body of work inspired by Foucault (for instance Radley, 1994; Samson, 1995) that identifies medical knowledge as an institutional form of social control for the management of deviance.

(iv) Parents question narrow interpretations of 'normality'

In the UK New Labour's approach to family life was laid down in the consultation paper, *Supporting Families* (Home Office, 1998), a document which emphasised the Government's interest in the family as a forum in which the values of good citizenship are learned (Maclean, 2002). As Gillies (2005, p. 77) puts it, the instrumental approach adopted in *Supporting Families* '...depicts parenting not as an intimate relationship, but as an occupation

requiring particular knowledge and skills [...] The term “parenting support”, in particular, describes the method by which parents are encouraged to reflect on and regulate their performance, through reference to “expert” advice and training.’ Fairclough (2000) argues, that parenting practices are increasingly isolated from the interpersonal context of the private sphere and presented as methods to be learned that are underpinned by the notion of the reflexive late modern agent and individualised citizenship (Gewirtz, 2001; Gillies, 2005).

In the boxed text below I describe my experience of attending, as a researcher, an evening class in the north of England that was held for parents of children labelled as autistic. My account suggests that the class, based on the medical model in its rehabilitation variant, constructed children as developmentally delayed and assumed a binary opposition between the categories of normal and disabled. The aim of the therapy was to assist parents to work with their children in order to correct ‘deviant’ behaviour.

The deficit model and performativity in the context of a parenting class

I observed an evening class of about 30 parents who have children with the label of autism. It was presented as an opportunity for empowerment, to help parents support the positive development of their children. The class was structured primarily around identifying the ‘difficulties’ that arise as a result of autism. These were presented in a highly structured manner as the ‘triad of impairments’, that is (i) impaired communication; (ii) impaired social relating; and, (iii) restricted and repetitive behaviour and interests. Each area was sub-divided into a number of ‘difficulties’: impairment of communication was, for instance, presented as including difficulties such as ‘uses little facial expression’, ‘uses little gesture’, ‘understands and uses words literally’, ‘repeats or echoes words’ etc. Binaries of normality and abnormality were explicitly reinforced with the autistic child presented as deficient in all areas identified. After a lengthy list of deficits had been described by the professional leading the session, one of the participants asked in frustration whether these ‘problems’ could be addressed or whether it was a merely a case of identifying them. The professional leading the group assured her that improvements could and were achieved; it was important for parents to have a detailed overview [of problems] so that they would be able to work with their children enabling them to desist from their

abnormal behaviour, which would, in turn, enable them to live *normal and independent lives*. [my emphasis].

At times, the narrowness of the interpretation of normality bordered on the comic. It was pointed out that children should be taught to accept losing with grace. If they lost in a board game, they should learn to say 'Well done! Congratulations on winning. We must have another game some time.' This advice was greeted with a degree of humour from some of the parents who presumably felt such a reaction would be unusual even among 'normal' children. At no point, was the concept of 'normality' problematised and there was little reason for positive comment except for one item of good news relating to pathology, namely that 'autistic children have fantastic memories'.

The following day I spoke to one of the participants at the class who was the mother of a five-year-old autistic boy. She told me, 'Why don't they point out that so many of the difficulties come from other people's attitudes? You come away from something like that feeling like your child's a real loser. I think the view presented was very one-sided.'

Another parent, Olivia, whose 3 year old son has been diagnosed with global development delay and autism told me after the class, 'I hate the word *normal*. It gets used so much - even therapists use it. And you think, "well why is he not normal because what is normal? There's no definition". They've all got guides about what they should be doing at what ages and that is the bible as far as they're concerned. If they're not doing that then there's something wrong.... you end up getting very depressed.'

The approach in the parenting class described above was premised on binary analyses or 'either or' frameworks of meaning, located around understandings of normal or abnormal, health or impairment, competence or incompetence and independent or dependent. Within this framework, the 'autistic child' was constructed as deficient and the expected role of the parent was to support their child to come as close as possible to normality in order to access the rights and responsibilities of full citizenship. Based on what Lyotard (1984, p. 4) has termed 'a thorough exteriorization of knowledge with respect to the knower' knowledge in this context was a commodity to be passed from expert to parent. Little, if any, space was provided for knowledge that was not consistent with the pre-given framework. Reflection was encouraged by the parents but it was a form of reflection that Gur-Ze'ev *et al.*, (2001) acts *only* to confirm and advance

the realm of the currently 'self-evident' without raising questions that might undermine the rules themselves (Gur-Ze'ev *et al.*, 2001). This kind of reflection threatens to deny parents opportunities for thinking about their children in ways that are not framed in terms of the deficit model of disability.

Fortunately, parents participating in this study have shown the ability to engage in sophisticated reflexivity and to develop counter-narratives that resist the view that disability can only be understood in terms of deficiency (see Avdi *et al.*, 2000; Oliver, 1990; Murray, 2003; Waltz, 2005). The experience of having a disabled child had, for some parents, led to a deep form of reflection that cannot be compared with the type of instrumentalist reflection fostered within the 'autism class'. Instead they are engaging in reflection that challenges hegemonic thinking and are gaining insights that resist normalising practices and their ideological foundations. Consistent with the findings of Swain and French (2000), some parents came to the understanding that difference can be regarded positively.

(v) Creating new narratives

Serious illness, acquired disabilities, and decisions around abortion have been previously identified as events that interrupt life narratives (Ezzy, 2000; Frank, 1985; Fisher & Goodley, in press 2007). Metaphors that carry a sense of disorientation, such as losing one's map (see Frank, 1995, p. 5) or 'narrative wrecks' (Dworkin, 1993, p. 311), are often applied to evoke the experience of such events. What is disrupted is a coherent sense of life sequence or, as the philosopher Carr (1986, p. 96) puts it, 'the whole which comprises future, present and past.' Creating narrative coherence in the uncertainty endemic to

postmodern times is a struggle for everyone but, as Carr (1986) points out, it is a struggle that is intensified by events, such as illness, which seriously disrupt the anticipated lifestory. According to Carr (1986, p. 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. This type of experience is something which resonates with parents whose life stories are also unexpectedly 'interrupted' by the birth of a disabled baby. The creation of new meaningful narratives within such circumstances is often a struggle but it is one which retrospectively, appears worthwhile.

Ben: 'another way of being'

Lesley is a woman with two children with special care needs. The oldest, Ben, is just under three. Ben has been diagnosed as severely autistic and is unable to communicate with spoken language. However, Lesley explained in detail how Ben has sophisticated communication and social skills that were tending to be overlooked. As Lesley put it, 'I think a lot of the things that he does probably look meaningless to people, but it seems to me that just about everything Ben does has some meaning for him. If we can understand it, it will help us communicate.'

Lesley provided numerous examples of Ben's communicative inventiveness. If a favourite book of his borrowed from the nursery had to be returned, Ben would place it under a chair to show that he wanted to keep the book a little longer. He would flap his arms to convey his pleasure at seeing someone and, according to Lesley, was highly astute in assessing people's feelings towards

him. A fleeting glance into someone's eyes meant a huge amount (see Billington, 2006). Ben had developed a complex signing code with his parents that did not rely on conventional communication techniques. Lesley explained how Ben had on one occasion 'lost it' and bit her hand in response to intense frustration. Full of remorse, Ben had tried to comfort her by taking his favourite book to her. 'That was his way of saying "sorry"', she explained. Since then whenever Ben feels he can't cope with a situation, he takes hold of Lesley's hand and gestures as though to bite *without* actually biting. This was Ben's way saying that he temporarily felt unable to cope. Whenever it happens, Lesley now responds by removing him from a situation that he perceives as stressful. Through encouraging him to communicate on his own terms, Lesley was sure that his 'normal' social skills were also improving in the sense that he was taking a more flexible approach to life because,

He sort of understands that we're doing our best ... and while it's not going to be perfect, we're doing our best to help him. If we show that we care about understanding what he's feeling, he can accept more in terms of things not being 'right'.

Lesley felt that interventions that operated according to a deficit model of autism and insisted on 'normal' communication and behaviour could act in ways that were unhelpful. Within the family, they had learned to take Ben on his own terms and to accept his communicative code as the starting point. While they had been advised that they should try to prevent repetitive behaviour developing, Lesley's view was that repetitive behaviour sometimes helped Ben 'to feel safe'. Once he felt safe, she explained, he communicated more, became more receptive to learning, was more likely to tolerate deviations from his routine, and was therefore able to progress and acquire new skills.

Lesley explained that the family had frequently come up against an uncomprehending world in which people felt that they were ‘pandering’ to Ben’s whims. Nevertheless, she remained convinced that life had become much easier for the whole family, especially for Ben, since they had realised that having autism was ‘not a disaster but a completely different way of being.’ Lesley was sure that Ben learned much more when he was valued on his own terms and when people worked with him according to his own abilities rather than his perceived deficits. Similar to many parents participating in this study, Lesley’s confidence regarding her own expertise was growing. She explained,

It’s very hard for people to accept that we might actually be acquiring expertise in this area. That is not intended to threaten anybody but a lot of people experience it as professionally threatening. I think they don’t want to know about the things that we’ve found out.

Lesley’s perspectives on her son’s autism resonate with a body of research that calls for expanded understandings of autism suggesting that the inner life of those diagnosed as autistic should be seen more in terms of neuro-diversity and less in terms of disability (Baker, 2006; Billington, 2006; Baron-Cohen *et al*, 1993; Happe, 1999). It seems that the parents of children diagnosed as ‘on the spectrum’ could offer valuable insights in this respect and that their views might usefully be employed to adapt and to develop services that are currently *delivered* on the basis that legitimised expertise is constructed by professionals within the public sphere.

(vi) Embodied morality and interdependence

In *Moral Understandings*, Walker (1998) argues that morality is not a dimension of reality beyond or separate from shared life or a distinct and detachable set of understandings within it. Moral practices are inextricable

from social roles and positions. On this basis, the quest for pure moral knowledge is unrealistic. Morality is always embodied and situated and created through our relationships with others. The research conducted for this study tends to suggest that the parents of disabled babies and children may constitute the type of moral community that Walker (1998) had in mind. Through their personal experiences of parenting and caring for their children, many parents develop insights into the values of mutuality and interdependence that transcend dominant notions of 'normality' and autonomy that are based on ontological separateness. From this latter perspective, each individual is expected to acquire the skills and knowledge to develop relationships in ways that are *reciprocally* beneficial. Reciprocity relies on a contractual form of agreement in which each party is expected to contribute to the relationship in measurably and definably equal ways. As Masschelein and Simons (2002, p. 597) explain, this is a model that demands that relationships be seen as,

...[...] calculable and calculating relations, as relations in which a transparent and *reciprocal* communication is central. Social relations understood in this way rest ideally on a contract or agreement and on negotiation between equal, autonomous and entrepreneurial subjects'. (my emphasis)

Diprose (2002), drawing on the phenomenological work of Merleau-Ponty, constructs an alternative view of identity as embodied and intersubjective. Arguing against the limitations of 'contractual relationships' based on an economy of exchange between *individuals*, she writes about 'corporeal generosity'. This involves an openness to others – an openness that is not only a requirement for the establishment of communal relations – but one that conceives identity as constructed through openness towards others. Crucially, intercorporeal generosity supports notions of alterity and ambiguity and is not

based on the assumption that everyone is the same. As Dipose (2002, p. 91) puts it, 'Such "psychological rigidity" is a kind of parsimony that closes off the other's possibilities in direct relation to the reduction of ambiguity involved.'

Dipose's analysis evokes Lesley's position which she expresses as follows,

But actually, why should you want to get rid of it [autism] anyway because I think some of the experiences that we've had with Ben are just amazing and very humanising really. I mean some of the things he's able to tell us, I really think that some adults would be struggling to find the words for that and the fact that we've worked very hard together to always find a way of understanding each other, it's sort of very enriching. Nobody in the services has told us anything about this at all, we've had to find out this for ourselves.

Lesley's sentiments also resonate with Kittay's (1999) account (cited in Hanisberg and Ruddick, 1999) of parents' experiences of caring for disabled children,

...with their impairments, with the special care they require, their lives direct us to the point and purpose of philosophy – the pursuit of wisdom. Their lives help us in our quest to discern what the meaning of life is; what makes life worth living or what makes a good life; what makes relationships ethical; what personhood is; [...] I have always, [...], seen philosophy as refracted through my experience with Sesha.

Some would assert that such parents are 'in denial', that they have failed to grasp the true tragedy of their child's impairments (see Roll-Peterson, 2001). An alternative reading would be that they have developed a more complex worldview in which binary opposites based on narrowly defined performance criteria of normality are no longer meaningful. Their narratives evoke understandings and insights of life's entanglements, complexities and contingencies which, in turn, appear to promote thinking that is consistent with feminist notions of interdependence (see Cushing and Lewis, 2002; Sevenhuijsen, 1998, 2000; Tronto, 1993; Williams, 1999, 2002). In the extract below taken from an interview with a father, Terry (who has son who has to be permanently ventilated), there is no sense that parental devotion, whilst

clearly evident, is accompanied by a refusal to take reality 'on board'. As Terry put it, whilst showing a photograph of Ian on his mobile phone,

He's great... so those are the vent tubes. He's got very limited physical ability ... but he's so alive and so vital and so he's still Ian [...] Whilst we embrace and love and cherish the Ian that we have, there was a point when we knew we'd lost the Ian that we thought we had.

This type of reaction was typical for many parents participating in this study who emphasised the mutuality and richness of their relationship with their children whilst simultaneously not shying away from the more challenging aspects of parenting a disabled child. In most interviews, one discourse does not replace another, instead they intricately interweave, 'either/ ors' are replaced by 'ands'. This complexity of understanding is often connected to a sense that subjectivity is constructed around 'being together' rather than around individualised citizenship (Foucault, 1982, p.232). The idealised self-sufficient subject is replaced by one embedded in a sense of other-relatedness. To use Frank's term (1985, p. 35), the 'dyadic' subject is created who recognises that '...even though the other is a body outside of mine [...] *this other has to do with me, as I with it.* [italics in the original]. It also evokes the idea (Longmore cited in McRuer and Wilkerson, 2003) that disabled people's position of marginality provides them with unique insights that point the way towards a society based on values of diversity and interdependence.²

The extract below, was taken from an interview with Tom,

We're all going to be..., you know, it's a cradle to grave, you know, seven ages of man, we start new and cheeky and dependent and we're all going to end up that way. And it's stupid not to create an empathic society that responds to people in need... because it involves us all.

² 'They [disabled people] declare that they prize not [...] independence but interdependence, not functional separateness but human community. This values-formation takes disability as its starting point. ' (Longmore cited in McRuer and Wilkerson, 2003, p. 7).

Sylvia, a lone parent and wheel-chair user with a young daughter with the label of cerebral palsy stated,

I think about these things. I mean Jane [PA] wouldn't have a job if I wasn't disabled, you wouldn't have a job if Sarah [daughter] wasn't disabled, you know, we are all dependent on each other. What's interesting for me is that this changes the value judgement that goes with the idea of dependency. If you bring an idea of everybody being dependent on each other, suddenly the value judgement starts to go out of the window because you're beginning to say "well actually I can't function unless these other pieces, or people, are in place."

Sadie had been a successful sales manager before the birth of her son, Thomas, who has a rare and complex syndrome. Here she explains how the 'battles' involved in caring for him have changed her,

Oh I've definitely grown. Anybody that's a parent of a kid with special needs – well not anybody but most people, find things in them that they never knew were there. [...] The majority of people find a whole extension in their personalities, there's a whole different level of patience and tolerance, a whole endurance level that they didn't even know they had [...] So you do grow as a person. I'm a much more tolerant, empathetic person than I ever was before.

Sadie told me that she would no longer be satisfied with a career in sales as she now regarded this as 'too superficial, too selfish'. She had recently become involved in conscience raising work in relation to Charge [the rare syndrome that her son has been diagnosed with]. Now committed to using her experience of parenting a disabled child to create a more empathetic climate for others in the same position, she stated, 'My values have changed. I'm no longer interested in competition and material success. I want to change the services so that they are better at improving the connections between people, the way people respond to each other – it shouldn't just be about "fixing" people.'

According to Gur-Ze'ev' *et al.*, (2001) the subject engaged in this type of reflection breaks through the common sense of the normalisation process to become 'the responsible or ethical subject' who, in his or her relationships, is called upon to transcend dominant narratives' by discovering some 'degree of authorship' or counter-authorship by questioning established maxims. The parents in this study were clearly engaged in reviewing, writing and rewriting dominant narratives that link 'normality' to the self-sufficiency of the reflexive agent of late modernity. In its place comes the insight that we are all implicated in obligations and dependencies.

(vii) Conclusion

In response to what she sees as encroaching governance, Fraser (1997, p. 81) has suggested that marginalised groups would be better served through the constitution of 'subaltern counterpublics' in which they are able to develop 'counter discourses' and construct oppositional interpretations of their identities and interests. The narratives of the parents participating in this study suggest that they are finding 'space' within their private worlds to question pre-given understandings in ways that creatively circumnavigate prescriptions regarding 'normality' based on individualised self-sufficiency and ontological separateness. Many parents did not consider that difference should be constructed as a problem or an abnormality to be resolved through technical interventions but instead regarded their child's disability as a constituent component of human diversity and therefore as a quality to be valued. These views are important in the development of more responsive and caring services and also for the construction of more positive understandings of disability. Equally, the parents in this study did not generally subscribe to the

idea that the entrepreneurial, autonomous self provides the only blueprint for achieving 'the good life'. Instead they were embracing alternative 'ways of being' and are challenging the narrow parameters of individualised citizenship that emphasises entrepreneurial success in the public sphere. Many saw lives based on mutuality and interdependence not as a form of second-class citizenship but as a way of being in which relationships and meanings develop in alternative patterns that challenge the boundaries that define normality according to narrow measures of self-sufficiency.

(7,499 words inclusive of bibliography and abstract)

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