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Oulton, Kate and Heyman, Bob

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### Original Citation

Oulton, Kate and Heyman, Bob (2009) Devoted protection: How parents of children with severe learning disabilities manage risks. *Health, Risk and Society*, 11 (4). pp. 303-319. ISSN 1369-8575

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Oulton K. and Heyman B. (2009) Devoted Protection: How children with severe learning disabilities manage risks. *Health, Risk & Society*, **11**, 313-319.

Devoted protection: How parents of children with severe learning disabilities manage risks.

Kate. L. Oulton, Centre for Nursing and Allied Health Professions Research, Great Ormond Street Hospital, London.

Bob Heyman, Centre for Health & Social Care Research, University of Huddersfield, Huddersfield.

Acknowledgements:

The research on which this paper is based was funded by the Research Advisory Board of Barts & the London NHS Trust as part of a PhD programme. The study was undertaken with the support of Islington Primary Care Trust, who received funding for this support from the NHS Executive. The views expressed are those of the authors, and not necessarily those of the any other party. The authors would like to thank the parents who took part in this study for giving up time to share their experiences and provide feedback about the findings.

Kate L Oulton  
Centre for Nursing and Allied Health Professions Research  
Level 7, Old Building  
Great Ormond Street Hospital  
Great Ormond Street  
London  
WC

0207 405 9200 ext 5504, [Oulton@gosh.nhs.uk](mailto:Oulton@gosh.nhs.uk)

## Abstract

This paper aims to explore the risk perceptions of parents caring for children who have severe learning disabilities and complex medical needs. The paper draws upon a qualitative study involving 20 parents, mostly mothers. The findings document the demanding care requirements which these parents had to meet. Parents viewed their role in terms of devoted vocation rather than meeting a burdensome obligation. This dedication interacted with heightened risk consciousness to fuel a sense of undelimited responsibility. Parents tended not to place sectoral or temporal boundaries around their responsibility for the care of their child. This approach was mediated by a prevailing but not universal mistrust of the caring capabilities of others. Although parents sometimes temporarily transferred caring duties to others, they usually retained a sense of anxious responsibility for such care, supervising or auditing the activities of other carers rather than delegating risk ownership. Trust was conferred on others only when they had demonstrated a good track record of care for the child, and were seen to have acquired detailed idiographic understanding of their individual complex needs. The findings can be understood in relation to a broader societal context of individualisation of responsibility.

## KEY WORDS

Children with severe learning disabilities

Risk management

Individualisation

Responsibilisation

Qualitative research

Grounded theory

Devoted protection: How parents of children with severe learning disabilities manage risks.

## INTRODUCTION

This paper analyses selected findings of a qualitative study designed to explore the experiences of parents, mostly mothers, caring for children with severe learning disabilities. From a medical perspective, the birth of such children tends to be viewed as a seriously adverse event. It will be argued that parents of children rejected this perspective, developing a sense of undelimited responsibility for the care of their child which was driven by mutually reinforcing dedication and risk consciousness. Parents tended not to place sectoral or temporal boundaries around their responsibility for their child, and attempted to retain risk ownership even when they shared care with others. This approach in turn generated further risks and adverse consequences.

Beck's (1992) well-known and controversial risk society thesis depicts a phase shift from modernity to late modernity involving tension between two transformations: firstly, a refocusing of concern from promoting technologically fuelled development to mitigating the complex risks arising from such development; and, secondly, individualisation, the redirection of responsibility for risk management from the collective to the personal level. More recently, Beck (2000) has emphasised the cultural rather than ecological roots of a heightened risk consciousness based on pervasive uncertainty about personal futures rather than global catastrophe (McGuigan, 2006, p. 215).

Risk consciousness and individualisation collide particularly intensely with respect to the safety and well-being of children, a central preoccupation of late modern societies.

Childhood in general is seen as more dangerous than it was in the past (Kelley, Hood, and Mayall 1998). An approach to risk dominated by fear of strangers has been dismissed as 'paranoid parenting' (Furedi, 2001). However, detailed qualitative analysis of how parents and children approach risks demonstrates that they adopt a more nuanced and varied approach to risk management. Autonomy and safety balances are negotiated in relation to consideration of specific circumstances, streetwise skills and the need to learn (Jenkins 2006).

Parents of children with serious disabilities are required to manage their child within a care ecology which has become highly individualised, providing a clear exemplar of Beck's thesis which has been little examined in the social science of risk literature. Parents were previously advised to send their child to live in mental handicap hospitals (Hall 1997), rarely seeing them again after they had been institutionalised (Oswin 1978). However, these children are now expected to live in the family home. In consequence, parents have become increasingly 'responsibilised' (Rose, 1999) for providing their personal and specialised care (Alaszewski and Manthorpe 1998; Beresford 1994; Kirk and Glendinning 1998; McKeever 1991). This individualisation of a very demanding caring role in turn raises new risk issues affecting parents and other children, not just the child with severe learning disabilities as will be illustrated below.

#### Epidemiological Evidence Concerning Risks to Children with Severe Learning Disabilities

The selection of risk concerns, both by the research community and parents, reflects wider social values (Douglas 1966). Research concerned with risks to children with disabilities has mostly focussed on abuse and unintentional injury. This collective choice perhaps reflect implicit prioritisation of child protection over the enrichment of child development

opportunities. Research discussed below suggests that parents attend selectively to similar issues.

An extensive review of four decades of research documenting the abuse of disabled children (Westcott & Cross 1996) highlighted numerous methodological shortcomings in these studies, such as vague and inconsistent definitions of abuse. Issues related to the dependency of this population group further complicate definitional problems. Poor practices, for instance, inappropriate use of medication and inadequate treatment of pain may be tacitly tolerated (Cross 1998; NSPCC 2003), and therefore not categorised as abusive. Large-scale studies of abuse focussing on children with severe learning disabilities have not been undertaken. The best evidence derives from studies of children with any disability carried out in the USA (Crosse, Kaye, and Ratnofsky 1993; Sullivan and Knutson 2000) and the UK (Spencer *et al.* 2005). These studies have found incidences of abuse two to four times higher among children with disabilities than among non-disabled children. However, correlational studies cannot demonstrate causality even if other variables, inevitably selected, are controlled for. For example, the observed relationship might have arisen because abuse is more likely to be detected if a family is receiving services for a child with a disability.

Relative probabilities must always be interpreted in relation to absolute levels, sometimes not cited in study reports. The latter will, in turn, depend upon the operational definition of the event category under consideration. Research evidence suggests that the base rate for child abuse is high. Sullivan and Knutson (2000) undertook a detailed analysis of school, foster care review board and police databases. They estimated the prevalence of maltreatment to be 9% for non-disabled children and 31% for disabled children. Emotional abuse and neglect mostly involved family carers, whilst non-family members perpetrated 60% of sexual abuse offences.



The studies outlined above did not focus on specific forms of disability. However, consideration of their circumstances suggests that children with severe learning disabilities may face greater risk of abuse than do those with other disabilities. These circumstances include receipt of intimate personal care from multiple caregivers, restricted communication ability and impaired capacity to resist or avoid abuse (Briggs 1995; Cross 1998; NSPCC 2003). Moreover, behaviours suggestive of abuse may be mistakenly judged to be part of the child's disability (Paul and Cawson 2002). Suggested strategies for reducing the vulnerability of disabled children to abuse, such as safety awareness training and improved sex education (Briggs 1995), are unlikely to benefit children with severe learning disabilities. Evidence of their vulnerability comes from the finding that, with socioeconomic status and health indicators such as birth weight controlled for, children with moderate/severe learning disabilities were significantly more likely than others to be registered with a child protection agency (Spencer *et al.* 2005). However, a UK-wide survey (Cooke and Standen 2002) found that only 14% of local authorities could state how many abused children on their child protection register were disabled. Morris (1999) has argued that disabled children receive less attention from child protection services than do non-disabled children despite being at higher risk of abuse, making them doubly vulnerable.

#### Risk of accidental injury

A second major research focus has been the risk of children with disabilities experiencing accidental injury. A large Australian study (Sherrard, Tonge, and Ozanne-Smith 2001) compared injury rates among 185 young people (5-29 yrs), with intellectual disabilities (the

internationally accepted term, equivalent to the term learning disabilities which is mostly used in the UK), with rates among people of a similar age who did not have intellectual disabilities. One third of the population sample were severe/profoundly disabled. The researchers found that young people with IDs were eight times more likely to die, and twice as likely to be injured, as a result of accidents than their non-disabled counterparts, with the highest rate (33%) for those whose ID was severe/profound. Increased risks of asphyxia, aspiration, drowning and falls in the learning disabled population largely accounted for their greater risk. Sherrard, Tonge, and Ozanne-Smith (2001) concluded that young people with IDs were six times more likely to be injured whilst receiving professional care, and almost twice as likely to be injured within the home as their non-disabled counterparts. The former finding might reflect, in part at least, the greater proportion of time that children with LDs spend with professional carers. Nevertheless it does suggest that professionally managed care environments can be places of relative danger rather than safety.

#### Paid Carer and Parental Perspectives on Caring for Children with Severe learning disabilities

The evidence presented above suggests that children with severe learning disabilities face higher risk of abuse and unintentional injury. This work provides the context for consideration of how paid and parental carers of such children identify, select and interpret risks. As always the 'virtual risk objects' (Van Loon, 2002, p54) which concern parents must be conceptually distinguished from the equally constructed risks selected for epidemiological research. Some partially relevant research has involved carers of adults with moderate learning disabilities, and has been concerned with the balance between safety and autonomy. Alaszewski and Alaszewski (2002 p57) noted that current literature

often expresses a stereotypical view which represents the learning disabled adult to as wanting the right to take risks, against the wishes of risk-averse parents. Heyman and Davies (2006) argue that professional and researcher depictions of family carers as over-protective implicitly presuppose that safety concerns cannot be rationally justified. They and adults with moderate learning disabilities adopt complex, varied approaches to risk management, involving balances between autonomy and safety. However, parents of children with learning disabilities belong to a risk-conscious culture, and have to take into account the greater vulnerability of children with LDs, as documented above.

Little is known about how parents view the safety/autonomy dilemma for a child with severe learning disabilities. Because such children may never develop any sense of danger (Burke and Cigno 2000; Sellars 2002) parental protectiveness in response to perceived dangers may be anticipated. Nevertheless, an acceptable range from autonomy to safety can be identified in some areas. Leaving the child with other carers reduces the child's dependence on parental support but requires them to cope with parental absence. Allowing even a small amount of mobility increases the child's personal autonomy but requires acceptance of increased risk. The present paper will explore parental approaches to assessing and managing risks for a child with severe learning disabilities in qualitative detail.

## METHODOLOGY

Data were collected in 2003-2004, primarily through individual interviews with the principal parental carer of a child with SLDs. Focus group interviews were also undertaken in order to enable participants to draw on others' experiences, and give feedback on provisional findings. A grounded theory methodology (Strauss and Corbin 1998) informed by

participatory, disability and feminist research paradigms (French, Reynolds, and Swain 2001), was adopted. Data collection and analysis were undertaken concurrently, allowing the direction of enquiry to be influenced by emergent themes.

A research advisory group (RAG), made up of parents, professionals, academics and a representative from a national disability charity, provided methodological and ethical advice. The project received local research ethics committee (LREC) approval from each area used for recruitment (see below). Anglicised pseudonyms have been used throughout the data analysis, and details which might allow individual respondents to be identified have been deleted.

## Methods

Because of the sensitive nature of the study, interviews were conducted if possible without the presence of the child with severe learning disabilities. A light interview structure, organised around an evolving topic list, was used. Interviews were audio-recorded for full transcription. Parenting was discussed in relation to the following issues: daily care; use of support services; familial support; schooling; parenting; participation in society; responsibility; and health. Interviews lasted 1.5-3.5 hrs. Respondents were invited to choose the interview location, with all but one conducted in their home. Parents were invited to comment on the research process, and were provided with the contact details of an appropriate support organisation.

## Sampling

Parents were recruited in London, an area which provided access to a socially and culturally diverse population who had experienced services provided by different local authorities. Parents were contacted through five special schools for children with severe learning disabilities and one such school for children with severe physical disabilities. In total, six schools catering for children aged 3-19 years, drawn from three boroughs, assisted with recruitment. The populations served by the schools varied considerably. Two schools served a predominantly White, affluent, middle class population, living in a green belt area. Two inner city schools served an ethnically mixed population with largely high deprivation levels but pockets of affluence. Two inner city schools served a largely ethnic minority population with widespread deprivation.

Teachers in each school sent parent information leaflets home to parents. Parents interested in participating were asked to contact the researcher directly for more information. Three-quarters (15) of the final sample of 20 parents were recruited through special schools. Three of the remaining five parents were recruited via community nursing teams during a second recruitment phase designed to increase the representation of children with severe learning disabilities and complex health needs. In addition, one mother was recruited through a parent support group, and one through another parent. The sampling strategy adopted should have ensured that most parents living in the areas covered were aware of the study. Nevertheless, the sample was unavoidably self-selecting, and therefore not necessarily representative of those who did not participate in the study. For example, parents with more positive attitudes to caring for a child with severe learning disabilities may have been more likely to volunteer. However, the research does document one existing approach to risk management, regardless of its typicality.

Most of the twenty primary care-giving parents who participated in the study, were mothers (n=18, 90%). Participants came from seven countries. Eleven respondents were White British in origin, and the remainder were Asian (5), White European (2), African (1) or Middle-Eastern (1). Translation and interpreting services were offered, and utilised by one respondent. Few (n=4, 20%) parents were in paid employment, all part-time. This employment pattern was undoubtedly associated with the time demands involved in caring for a highly dependent child. Most were married (n=15, 75%).

The children whose parents participated in the study included 13 girls and nine boys aged 4-19. These children could be located in two groups. One group (n=14, 67%) had physical disabilities. Two of these children were recruited inadvertently, despite not have a learning disability. They were included in the study at the request of their parents, providing useful comparative data. Of these 14 children, seven (50%) had cerebral palsy, and six (43%) rare serious conditions. They were all wheelchair/pushchair bound, and had limited, if any, communicative ability. They tended to be incontinent, and heavily dependent upon their parents for meeting their basic living needs. Most required developmental physiotherapy, which parents often provided on a regular basis. The extensive health problems of this group included, epilepsy, constipation, chest infections, muscle spasm, bowel and bladder dysfunction, and skeletal problems. Their parents took responsibility for a wide range of complex care, including seizure management, wound care, chest physiotherapy, suction, oxygen therapy, catheterisation and gastric or naso-gastric feeding and medication delivered orally, rectally, via a gastrostomy or through injection. Most of the children (n=12, 86%) had been hospitalised at least once, predominantly for surgery or emergency treatment, such as resuscitation or intravenous therapy. Three children had life-limiting conditions.

The other group of children (n=7, 33%) had severe learning disabilities without major physical disabilities, although two had significant additional health problems. They were fully mobile, and possessed some communication ability. Of these children, two had Down's syndrome, three had an autistic spectrum disorder, one a rare genetic condition and one no specific diagnosis. Their main problems were associated with their severe learning disabilities, for example challenging behaviour.

#### Data Analysis Methods

Data from fully transcribed individual and focus group interviews were analysed through constant comparison (Morse & Field 1996) in three overlapping stages of open, axial and selective coding (Strauss & Corbin 1998) undertaken concurrently with data collection. Open coding involves grouping data extracts into one or more thematic categories, axial coding the analysis of category properties and relationships to other categories, and selective coding the identification of one central theme around which subsequent data collection and analysis were structured. The analysis presented below focuses on parental adoption of undelimited responsibility for the well-being of their child. This attitude will be explored in relation to two mutually reinforcing drivers, parental vocation and heightened risk consciousness. Important related issues, namely mistrust/trust, the autonomy *versus* safety balance and the child's projected future will also be considered. The analysis will be presented in retrospect rather than in terms of its evolution during the intertwined processes of design, data collection and analysis.

## DATA ANALYSIS

### Undelimited parental responsibility

Whilst parental carers, mostly mothers, located their sense of undelimited responsibility in a negative risk framework, discussed below, their primary orientation was one of devoted dedication.

*You give 100% all the time, you give your all. Whatever happens, I just do it ... As a mum you are there for whatever your child needs (Helen, mother of 14 year old son with severe learning and physical disabilities).*

This orientation could lead parents to focus their attention exclusively on the child.

*Once Mark is in [from school], that's it. It is totally him, and it is all-consuming ... Everything revolves around Mark (Caroline, mother of 15 year old son with severe learning disabilities).*

Parents rarely mentioned areas of responsibility they felt did not belong to them. In consequence, they could not place temporal boundaries around their caring role. One parent who had worked as a carer for adults with learning disabilities compared her role in caring for her son with that of being employed.

*It's a bit like having a job. It's full-time. There's no days off. You're on duty, constant. There's no going out and saying, 'Wee that's it. I've done it. I've done my day. I can get out of this situation'. No sign out and forget it. You're with it 100% (Helen,*



mother of 14 year old son with severe learning and physical disabilities).

Acceptance of undelimited responsibility precluded the division of daily time into segments allocated to varying activities, a central feature of the psychosocial economy of modern life. Similarly, carers of children whose life expectancy extended into adulthood could not anticipate the probable termination of the parental project in the future when their child became independent. However, this indefinite extension of the parenting project could be valued positively.

*Whereas having a normal child as well, they sort of, as they grow up, of course they still need ya, they want to do their own thing. Whereas Olivia [daughter with severe learning disabilities], I don't know, perhaps I'm so used to her being dependent on me. Perhaps I'd miss that now. I don't know* (Karen, mother of 14 year old daughter with severe learning disabilities).

The meaning of caring for a highly dependent child could extend beyond heightened fulfilment as a parent, taking on cosmological significance as a vocation involving a trial from God.

*I can't see myself, my personality. There is no Susan as a mum, no Susan, just a dummy with the test of mum. I forget my future, my studies, my MPhil. I forget my parents, my brother and sister. It happen automatically ... I do this sacrifice happily 'cos I feel child is my test in each and every way. This is my test from God.* (Susan, mother of 14 year old daughter with severe learning and physical disabilities).

The sense of willing personal abandonment of self conveyed in this quotation resonates with the discipline of a religious order. The following powerful quotation frames caring for a child with severe learning disabilities positively in terms of the limits of Western secular society.

*There aren't many opportunities in twentieth century life in England to be a good person unless you seek it out. And, like a missionary or something, so caring for somebody, and the experience of loving somebody who is different, and damaged, and has certain problems is a very rewarding experience for me personally ... It's a bit like Calvinism. You actually begin to feel as if you're of the elect, and of a very small banded set of special people who are different from everybody else ... It's very dangerous to feel superior to other people. That's why you have to fight it. (David, father of a daughter with severe learning and physical disabilities).*

By viewing his caring role as offering the opportunity for a '*terrific personal journey*', this father completely inverted the medical interpretation of the birth of a child with severe learning disabilities as a highly adverse event. Other parents valued their child's progress for its own sake, in effect recalibrating culturally normal notions of child development in favour of valuing those accomplishments that their child could achieve.

*Her every little step she makes is just so phenomenal. And what grace she's got. And, ah, she's just a complete delight all the time (Shannon, mother of a daughter with severe learning and physical disabilities).*

If their child's life expectancy was seriously reduced, as was the child of Shannon, parents might seek to share their child's life as much as possible within the limited time available.

*I want to give my attention to Heidi and Sarah because I'm always thinking they are going to die, you know. Once they've gone, I'll give my time to my other kids*  
(Frances, mother of two daughters with severe learning and physical disabilities).

In order to ensure that she experienced her time with these children to the full, this mother suspended the parenting project for her non-disabled children, hoping to compensate them subsequently.

As well as worrying about the riskiness of sharing responsibility for the care of a child with severe learning disabilities, as discussed below, parents were concerned that they might be asking too much of others, who could not be expected to feel their own level of commitment.

*I was a bit concerned with the fact that this lady didn't really have to put up with it. I feel that because she's mine, she's my responsibility. She's [paid carer] been kind enough to open up her house and ... all of a sudden she's taken on this six-and-a-half boisterous, into everything, destructive child. And I think, 'Well, she doesn't really have to do that'. (Clare, mother of 6 year old daughter with severe learning disabilities).*

This parent went on to say that she worried about the situation throughout the entire time when her daughter was away, which, as her husband pointed out, prevented her from enjoying a proper break from her caring responsibility.

Risk and undelimited responsibility

Parental adoption of undelimited responsibility was driven by risk concerns as well as devotion. Parents of independently mobile children with severe learning disabilities worried about their child's inability to sense the many diverse dangers lurking in the modern world, such as traffic and sexual predators. Where a child's life and well-being depended upon the correct application of complex medical technologies, parents saw themselves as guardians against the risk of these technologies being misapplied. This section will firstly illustrate the relationship between parental concern about their child's vulnerability and their acceptance of undelimited responsibility for their safety. The related issues of consideration of the child's lifespan, concern about sharing risk ownership, itself linked to mistrust, and balancing autonomy with safety will be discussed.

With respect to children who lacked mobility and suffered from serious, complex medical conditions, parents' main risk concerns involved the fragility of their child's health.

*I think that a lot of my feelings about Niamh are tied up with the fact that she has such a poor prognosis. All the time you're on tenterhooks thinking, 'Is this the thing that's going to lead to pneumonia?' Living with fear all the time ... You never have a day when you just forget (Shannon, mother of a daughter with severe learning and physical disabilities).*

Many parents slept with their child every night in order to prevent them from choking, having an epileptic attack or falling out of the bed.

*I don't want to go in my own bed. I always go in Bethany's bed because I can't trust each and every moment ... I never take a risk Bethany sleep alone a single*

*moment. And he [husband] always want to come and spend time alone, but I always deny [him].* (Susan, mother of 14 yr old daughter with severe learning and physical disabilities)

This mother's prioritisation of her daughter's safety was associated with constraint on the marital relationship, which subsequently altered. The father left the family home to return to his native country, only to return sporadically for short visits.

Parents who were directly in charge of care could experience major risk concerns because complex activities which are normal in the modern world were further complicated by problems associated with the child's disabilities. One parent described the impact that her daughter's habit of removing her seatbelt, climbing around the car and opening the doors and windows had on the entire family.

*It is just one nightmare, and it just isn't worth it, because you can't concentrate on your driving. It's not worth even going there, putting her in the car and putting everybody at risk* (Clare, mother of 6 year old daughter with severe learning disabilities).

This respondent felt that she sometimes had no option but to accept this risk because she did not have anyone available to care for her child when she needed to go out, for example when collecting siblings from school. Conversely, by seeking to avoid such risks as much as possible, parents inevitably accepted limitations on their opportunities to interact with others, as otherwise everyday activities were transformed into dangers. These two features of risk management for children with severe learning disabilities, namely the transformation of the routine into the dangerous and the isolating potential of

risk avoidance, spread into every aspect of parental life, even sleeping, as illustrated above.

Parents worried about the risk of their child suffering injury, poor management of health problems and abuse. The all-pervading scope of their risk concerns is well-illustrated by the following quotation.

*The responsibility just feels so intense, it is **so** intense. With Mark, what if they don't give him his medication on time? What if he has a fit and falls in the road? What if, what if, what if? So it is probably the same feeling of responsibility, but a million times more powerful* (Caroline, mother of 15 year old son with severe learning disabilities).

The combination of devotion to their child with severe learning disabilities and heightened risk consciousness made mothers reluctant to accept care from others, or afraid to do so.

The parent quoted below felt that others could not achieve her standard of care.

*I wouldn't want it [short term care] anyway, 'cos I don't think anybody else could be good enough to look after him ... I'd just rather get off my backside and do it* (Helen, mother of 14 year old son with severe learning and physical disabilities).

The image of getting off her backside conveys this respondent's sense of ultimate backstop responsibility for remedying service deficiencies. Her views were coloured by her experience of short-term care provision, from which her child had returned with bruises on his legs. In this and other cases, a single adverse experience triggered rejection of service support, since the parent was not willing to risk its recurrence, a significant emergent finding. Subsequently, the only outside support which this mother accepted was a monthly

visit from a carer whom she could not leave alone with her child. In consequence, parent and child frequently spent periods of days without leaving the house. In this and other cases, parents retained 'risk ownership' through constant monitoring, severely limiting the benefit to themselves of sharing care.

Children with medical conditions often depended upon carers meeting their more or less complex care needs. Failure to do so could have serious consequences. One parent explained how her daughter's collarbone had been broken on the journey to school, an accident which she believed had happened because the driver had not strapped her daughter in her wheelchair correctly. Another had discovered that her child had experienced hours of pain at school because teachers had been unable to ascertain that her toe was bent completely backwards in her shoe. Both parents became more anxious about entrusting the care of their child to others in the future. Even close relatives might not be trusted to meet a child's special needs. The parent cited below had declined her brother's offer of help with medicine giving.

**Comment [BH1]:** Not sure why you changed this. 'Unable to ascertain implies, to me anyway, a systematic enquiry whilst did not realise is more neutral.

*He [brother] came to me, and said, 'Sister you sleep. I'm looking after Bethany'. I said, 'Don't go in her room. Don't give her medicine. I'll do it' ... I don't want to take any risk ... I feel it is best we [parents] give medicine because we can check the label, everything. If we ignore these things, then everyone can ignore it, because relationship is more touchy and more emotional (Susan, mother of 14 year old daughter with severe learning and physical disabilities).*

This respondent placed so little confidence in the caring abilities of others, that she wanted her child to die before her, reversing the usual desire of parents to be outlived by their children.

*I pray Bethany have life end before me ... because I can't give Bethany to another person [respondent distressed]. It's very difficult to say to anyone to take Bethany and I am now going to die now. It is a big responsibility (Susan, mother of 14 year old daughter with severe learning and physical disabilities).*

Concern about the commitment of other carers was magnified when caring tasks required complex skills and knowledge.

*I had terrible worries about one night nurse, and I just got into my head that she didn't know anything about medication. I ended up going up and clearing out the medication cupboard. I just thought she wasn't clocking what she had to give Niamh. I don't want her giving her 10 mgs of Vallergran or whatever. Its only 2.5 mgs. Do they know things about syringes? Do they know about gastrostomies? Do they know about flushing? ... It's that kind of thing it makes me quite nervous (Shannon, mother of a daughter with severe learning and physical disabilities).*

This parent's concern was not assuaged by the other carer's status as a qualified nurse. She perhaps felt, as illustrated below, that the nurse would lack the specialist knowledge she possessed about her child's particular needs. Although parents described many positive experiences of hospital care, the occurrence of any problems could devastate their trust in the overall system.

*They [nurses] gave her an overdose of sedative. Even though I told them she has two mills they didn't believe me. They looked in their book, and looked up dose for a child her age, and no consideration for [her weight]. She nearly fell into a coma ... I*



*am never going to leave her in hospital again* (Shannon, mother of a daughter with severe learning and physical disabilities).

This parent cared for her child mostly at home, with varying levels of support from the community nursing team. Again a single adverse experience, not necessarily representative, could cause a parent to avoid services which might have proved beneficial overall.

Parents of older children were particularly worried about the risk of them being abused by carers.

*You wouldn't let someone you don't know look after a million pounds would ya? I just like to make sure that she's well-protected. I would rather she just stays here with me ... These kids are a target, aren't they? ... It's just paedophiles. I know it sounds really far-fetched, but I always worry about things like that* (Karen, mother of 14 year old daughter with severe learning disabilities).

This parent stopped using short-term care services on account of this concern, despite having no access to a car and being unable to take her daughter on public transport. As a result, she spent most of the school holidays isolated to the house with two children. The metaphor of not leaving a million pounds unguarded vividly articulates the association between parental vocation and risk avoidance.

Although parents adopted highly protective approaches towards risk management for their child with severe learning disabilities, they faced the usual risk management dilemma of

balancing safety with autonomy, albeit at a level where only limited autonomy could ever be contemplated.

*You have to allow them a certain amount of freedom. You can't keep them cooped up* (Joanna, mother of 5 year old son with a severe learning disability).

A few parents of children with a normal life expectancy adopted a longer time perspective, linking the need to promote autonomy, and therefore accept risks, to the time-limited nature of the support they could offer.

*She's going to come to a point where we're not going to be around. She can't rely on us to do everything all the time. She's got to let other people do things for her. I know she's never going to be independent, but there's got to be a degree of independence* (Diane, mother of 14 year old daughter with severe learning and physical disabilities).

This parent felt that delimiting her current responsibility by giving her daughter opportunities to become accustomed to being cared for by others would benefit her in the future when her mother was no longer able to care for her.

The next quotation illustrates the complex interweaving of concerns that could underlie parental reluctance to transfer risk ownership even for a limited period.

*This woman would hug my daughter when she came into school in the morning. And it was like, 'Do you do that with the other pupils?' 'No.' 'Don't do it to mine.' She would get her dressed after swimming. Why? Because it speeded things up. Lucy*

*was quite capable of dressing herself. In fact, for her own independence, she needed to. 'Please do not dry and dress my child. It is inappropriate touching her, apart from anything else'* (Melissa, mother of 19 year old daughter with severe learning disabilities).

This mother's concerns encompassed discriminatory treatment, deskilling and violation of norms about age-appropriate bodily contact. Mistrust could, thus, be fuelled by parental concern that paid carers would not allow their child appropriate autonomy.

Risk as an outcome of accepting undelimited responsibility

Acceptance of undelimited responsibility, either voluntarily, or because no alternatives were available, created new risks for parents, particularly in relation to lifting and handling, supervision of siblings and administering medication. The respondent quoted below would have welcomed help with giving her child mobility.

*She's become heavier. She still can't stand or walk. She is totally dependent on someone's - on me mainly ... No-one is going to lift her up. Even we can't lift her up, but we have to lift her up because we haven't got any choice ... Most of the time I had back problem, backache, and sometime, I had wrist pain and worries. So, if I said I can't lift her up she looks sad ... They [carers and family] don't put their backs or their lives on risk just for my daughter* (Rachel, mother of 13 year old daughter with severe physical disabilities).

As a result of struggling to move around the house unaided, the daughter had acquired painful knees and bleeding knuckles. The emotional impact on both mother and daughter

of living with the conflict between the daughter's desire for mobility and the mother's problems with lifting was apparent, as the mother became distressed when discussing this topic in the interview.

Another parent had to supervise her other young children at the same time as taking and collecting her two disabled children from the school bus. Whereas escorts had previously carried her two children to and from the school bus, they no longer did so because of the risks associated with lifting and handling.

*If anything within those couple of minutes went wrong in the home, I would be arrested or done by social services you know ... I mean my son [child without disabilities] could even just put the gas on, or put the kettle down, or, you know, strangle the little one ... I know that is a big risk (Frances, mother of two daughters with severe learning and physical disabilities).*

The above respondent was caught between the needs of her disabled children and placing her other children at risk. In order to minimise these risks, the mother called on the help of her older daughter after school. But this risk management strategy prevented the latter from socialising with friends and taking part in extracurricular activities, causing the mother to feel guilty and sad.

Rather than eliminating the physical risks associated with lifting and handling, the regulatory practice protecting workers merely transferred them onto the family. In turn, non-disabled siblings could be exposed to new physical, emotional and social risks. Similarly, a parent explained that her carer was not allowed to give her son rectal diazepam if he experienced uncontrolled epileptic seizures. The parent, however, despite

being untrained, was allowed to administer the life-saving medication her son needed. She felt that it was unfair to leave the carer alone with her son, and therefore frequently spent up to ten days at a time without leaving the house.

#### Delimited Responsibility

Although parents mostly took undelimited responsibility for the welfare of their child with severe learning disabilities, exceptions require careful consideration. Some parents did rely on carers whom they had learned to trust through long acquaintance, and who knew their child well.

*I've got a carer I really, really like now, I've had for years, and I'll pay her out of my own money sometimes. And I just think she's fantastic. She knows her every single move. (Shannon, mother of a daughter with severe learning and physical disabilities).*

Willingness to share responsibility was mediated by trust in the secondary carer in this and other cases. In order to earn such trust, the other carer needed to have built up detailed personal knowledge about a child.

Parents sometimes delimited zones of responsibility because they felt that the requirements of medical or other unpleasant procedures conflicted with their mothering role.

*It used to take two people to hold her down while she had her blood tests ... They were quite surprised when I refused to be party to this holding my daughter down thing. It was, like, 'Well, we've only got the school nurse'. And I was, like, 'I'm sorry,*

*but I don't actually want to collude with that which she sees as being painful. I will be there and give her a cuddle afterwards, but I am not pinning my daughter down' ... There is an expectation that you will do those things because you are there (Melissa, mother of 19 year old daughter with severe learning disabilities)*

Unusually, this mother felt able to fend off the expectation that she would assist with her daughter's medical care, excluding the necessary infliction of pain from her parental remit. Others accepted help only because they felt that they could not manage on their own.

*Before I used to refuse to have carers ... But recently I have to get carer due to own ill health ... I refuse to give my son to go to their place. Only the carer come to my house. I don't trust them to take my son out of the house, just in the house (Ingrid, mother of son with severe learning and physical disabilities from research advisory group who attended one of the focus groups).*

This parent's limited and reluctant use of services was driven by her lack of 'trust' in other carers who might put her child at risk. Our final quotation powerfully evokes the 'responsibilisation' thesis and its ramifications.

*In hospital I do everything for him, but we need to learn to let someone else to be responsible because otherwise they use us. If they think we take all the blame, all the responsibility, they see a different way. The people who pay the carers they say, 'Okay, the parent is responsible. We can just send anyone.' ... If they know they are going to get responsibility they will have to think twice if they are going to get somebody to do that. You need to let go to teach them something (Trudie, mother of a son with severe disabilities).*

This respondent limited her own responsibility in order to avoid contributing to a process in which her parental devotion would unintentionally facilitate withdrawal of paid caring resources. Her action, unusually, was oriented towards the wider political agenda in which responsibility is allocated and owned.

## DISCUSSION

Relatively little research into the lives of people with severe learning disabilities and their carers has been undertaken, perhaps because the former comprise a small proportion of the population of people with learning disabilities, and because their perspectives are difficult to investigate. As noted in the Introduction, most extant research has adopted an epidemiological approach, documenting the substantial absolute and relative levels of risk facing these children. The present paper has focused on parental risk management for children with severe learning disabilities living at home. These families are worth careful consideration because of the seriousness and complexity of the difficulties which they face. Moreover, medical advances will lead to ever more children with severe learning disabilities surviving for longer, increasing the number of families affected.

The research discussed in the present paper is affected by the usual limitations of qualitative methodologies. Sample representativeness should not be assumed. For example, more highly motivated parents may have been overrepresented. Qualitative interviews lend themselves to the relating of anecdotes, potentially overemphasising poor practice. The depiction of service deficiencies in the present paper should not obscure the many examples of good provision also discussed. Although qualitative research offers only

weak generalisation, it can illustrate complex social processes in rich detail. The present research documents caring and risk management problems faced by parents, mostly mothers, which the rest of the population, including service providers, have never experienced and can scarcely imagine.

Our starting point for understanding carers' experiences was that many viewed their role as a positive vocation, rather than seeing themselves as managing an adverse event. This stance undermines, however unintentionally, the taken-for-granted values of Western medicine, and implicitly challenges a wider culture which emphasises beauty, intelligence and achievement. Caring for children with severe learning disabilities also challenged implicit assumptions about the normal life course, as when parents treasured the shortened time available to a child with a life-limiting condition, or were concerned about who would care for a permanently dependent child after they died.

Parents also saw their child as vulnerable to a range of unacceptable risks, a belief validated by the epidemiological evidence. Their sense of vocation and protectiveness mutually reinforced each other, pulling them towards the safety pole of the universal autonomy *versus* safety risk management dilemma. However, a few parents did value increasing their child's autonomy within the radically shifted scale of possibility, on the grounds that their child would have to cope without them after their death, or that safety constraints such as mobility restrictions were too damaging to the child's quality of life.

When parents did share caring responsibilities with others, they often retained risk ownership, supervising or auditing the activities of other carers. In consequence, their opportunities to take breaks from the physical and emotional labour of caring were seriously limited. Moreover, their protective approach caused some parents to abandon



sources of support immediately if they were found wanting. Although understandable in view of the potential for harm to their child from even a single adverse event, this risk management strategy prevented parents from testing out the representativeness of poor practice. A single bad experience could thereby block access to urgently needed sources of support. This process exemplifies a type of prevention paradox in which the adoption of an avoidance strategy removes the inductive evidence which might demonstrate that it was unnecessary. Despite such concerns, parents sometimes felt reluctantly compelled to accept support which they lacked confidence in simply because nothing better was available, and they could not cope without it. In contrast, parents could value care received from persons with whom they had built up a trusting relationship, and who understood the particular needs of their child. Thus, the relationship between devotion and risk management was mediated by variations in trust, the bestowal of which required long-term proof of commitment and demonstrable idiographic knowledge of the child.

As suggested in the Introduction, these parents' experiences can be understood in relation to the related concepts of individualisation (Beck, 1992) and responsabilisation (Rose, 1999) the farther limits of which they illuminate. These two rather clumsy terms usefully reference two complementary processes: the hollowing out of the welfare state in response to global economic pressure; and the attribution of moral responsibility to families for meeting the needs of people with long-term disabilities. Families, almost invariably women, may take on demanding and enduring care duties in the absence of alternatives, and are expected to feel an obligation to do so. They did not consider state care as an alternative. It was absent from the current ecology of care, and would probably have been rejected if it had been considered as an option. Parents accepted and embraced undelimited responsibility for the care of their child.

These processes of individualisation and responsabilisation were intensified by an unintended consequence of another recent societal shift, the strengthening of the risk regulatory control over the world of work (Power, 2007). Excluded risks such as lifting and handling older, heavy children and providing routine medical interventions outside the healthcare environment were simply shifted onto parents, *faute de mieux*. Unlike commercial companies which can simply go into administration when risks which they have bought from the state prove unprofitable, parents would find such shedding of responsibility unthinkable. They retained risk ownership, reluctantly accepting consequent risks such as personal injury or being forced to leave other young children unsupervised.

## CONCLUSION

The research outlined in this paper has explored parental risk management for children with severe learning disabilities and other serious health problems in relation to the emergent core category of undelimited responsibility and the associated themes of trust and managing the autonomy *versus* safety balance. The research suggests that a number of difficult risk-related issues need to be addressed in order to improve the fitness for purpose of support services for children with severe learning disabilities and their parents. Firstly, the increasing regulation of organisational safety, designed to reduce the risk of litigation and to protect employees, has had the unintended consequence of privatising health risks which must then be taken up, if at all, by parents. The consequent risk management issues have received little consideration. Secondly, parents often feel that their expert, idiographic understanding of their particular child, and general, nomothetic knowledge about complex and unusual medical conditions are discounted. Their accounts suggest that professionals, constrained by power relations such as medical dominance, may try to impose general rules which should not be applied to a particular child because

of their condition. Thirdly, parental concerns, well-founded in epidemiological evidence, that their child might be abused or accidentally injured by carers, need to be addressed.

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