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# Parents with learning difficulties, child protection and the courts

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# Background

The number of parents with learning difficulties<sup>1</sup> is unknown, though the numbers who are known to the health and welfare services are widely acknowledged to be rising steadily (Gillberg & Geijer-Karlsson, 1983; Hoffman et al., 1990; Ray, Rubenstein, & Russo, 1994; Whitman & Accardo, 1993).

Genders (1998), for example, reports that almost two-thirds (62%) of the 266 community nurses she surveyed had parents with learning difficulties on their current or recent caseload. Likewise, Stevenson (1998) found that most social work practitioners in the Children and Families teams she studied had experience of working with such parents, and two-thirds of them were currently involved with at least one family headed by a parent or parents with learning difficulties. McGaw (1997) estimates there are 250,000 parents with learning difficulties known to health and social services agencies in the UK.

<sup>&</sup>lt;sup>1</sup> The term 'learning difficulties' is used in this proposal in place of other labels for which it is a synonym, such as mental retardation, mental handicap, intellectual disabilities, cognitive impairment etc., in line with the preference of the self-advocacy movement in the UK.

The reasons for this trend are complex and it is not easy to tell if more referrals really mean there are more parents. On the one hand, policies that reduce controls over the sexuality of people with learning difficulties might be expected to lead to more of them having children (Attard, 1988; Haavik & Menninger, 1981). The fact that increases in the number of parents have been reported in all countries which have moved towards services based on 'ordinary life' principles (King's Fund Centre, 1980) and community living would appear to support this interpretation (Danish Ministry of Social Affairs, 1996).

On the other hand, families on the margins of competence might be finding it harder to manage in an increasingly competitive society. Greater intervention by the state in family life, closer surveillance of parents and their children and the widening of the child protection net (Thorpe, 1994; Thorpe, 1995) may have brought more parents to the attention of the public services.

Whatever the reasons for the apparent increase in families headed by a parent or parents with learning difficulties, they now represent a sizeable population whose special needs have so far not been adequately addressed by the health and social services (Booth & Booth, 1994b; Llewellyn, McConnell, & Bye, 1995; Tymchuk, 1990).

There is a small but growing body of international research on parenting by people with learning difficulties. Reviews of this literature (Andron & Tymchuk, 1987; Booth & Booth, 1993; Dowdney & Skuse, 1993; Llewellyn, 1990; Sheerin, 1997; Tymchuk, 1990) show that these families often receive a raw deal from the statutory services characterised by an 'over zealous' approach to the assessment of risks (Social Services Inspectorate, 1999) and an underinvestment in the kind of services and supports that might enable them to bring up their children.

#### The Support Gap

An accumulation of well-documented failures in the service system point to the existence of a yawning support gap which threatens the capacity of mothers and fathers with learning difficulties to cope with the parenting role. Key features of professional practice and service organisation that undermine parents in their parenting and heighten their vulnerability include:

- The presumption of incompetence or the belief that parents' innate limitations make them unfitted for parenthood and then only seeing the evidence that supports this preconception.
- A deficiency perspective or a tendency always to focus on people's deficits and on what they cannot do instead of their strengths and how to build on them.
- System abuse meaning policies and practices that harm the families they are supposed to support or protect. System abuse is the unacknowledged scourge of families (see, for example, Booth and Booth, 1998, chapter 9). It is rampant, pervasive and destructive of family life. The evidence presented below regarding the discriminatory

treatment of families involved in care and related proceedings serves as a case in point. Lily's<sup>2</sup> experience (see boxed insert) offers another.

 Competence-inhibiting support - meaning support that deskills parents, reinforces their feelings of inadequacy and undermines their independence.

# System abuse: Lily's story

Lily is 23. She has three children, a boy aged four and two girls aged three and two. All three children had been placed on Care Orders because of their father's violent behaviour towards Lily. In desperation, she upped and moved 150 miles from her home city in order to escape his brutality, leaving behind her family and friends to start a new life. But she found it hard to manage three young children on her own in a strange city with no-one to turn to for support. The children also missed their father. Unsettled by the move, their behaviour became more difficult and Lily finally approached Social Services for help. When workers found bite marks on the youngest child, her sister was identified as the culprit and removed from the family home. A support worker was put in but the elder boy had been further upset by his sister being taken away and his behaviour became more aggressive ('They're not coming for me', was his constant refrain). Other incidents - a hospital report that Lily had taken the twoyear old to A&E with a black eye and a referral from the nursery saying that she had told them her son had swallowed some medicine - led to an Emergency Core Group meeting being convened at which it was decided to withdraw family support to see how she managed. A week later Lily was informed both children were being taken that day. Her son was taken out of nursery and it was a week before she knew where he was or was allowed to see him. Setting mothers up to fail in this way is a common example of system abuse.

<sup>&</sup>lt;sup>2</sup> Pseudonyms have been used throughout this article to preserve anonymity.

- Top-down priorities meaning that the professional as trained expert is usually in control and running the show. The Social Services Inspectorate (1999) comments on finding assessments and outcomes influenced by a ' "professional knows best" culture', in which only a 'tokenistic acknowledgement' is given to the views of parents, contrary to the emphasis which the Children Act 1989 puts on working in partnership with parents.
- A child-centred focus the primary focus of attention for practitioners is usually the welfare of the children. Too often the needs of the parents are overlooked even though they may be unable to do their best by their children until their own problems are sorted out. The Social Services Inspectorate (1998) found that 'the majority of disabled parents we saw did not consider their needs had been recognised' and workers rarely looked at how 'to support and help the parents in the discharge of their parental duties' (Goodinge, 2000).
- Poor assessments the Social Services Inspectorate found demonstrable evidence of 'shortcomings in the assessment of the needs of children and their disabled parents' (Goodinge, 2000).
- *Conflicting responsibilities* there is a constant tension between the 'policing' and 'enabling' role of social workers. As Harris (1990)

observes, families in difficulty 'typically turn to the very professionals who have the main statutory responsibility for child protection.'

- Organisational barriers the needs of parents with learning difficulties cut across service boundaries which too often leads to them being owned by no-one. As parents they come under Children and Families Teams but as disabled adults they are dealt with by Learning Disability Teams. Glennie et al (1998), for example, observe how parents in Nottinghamshire who presented 'grave concerns to the children's service because of child neglect, did not meet the threshold for adult service.' As the Social Services Inspectorate (1998; 1999a; 1999b; 1999c; 1999d; 1999e; 1999f; 2000) found, this results in a fragmented service response, lack of co-ordination, inadequate record keeping, difficulties in applying eligibility criteria, poor management information, a failure to take a holistic view of the family's needs, and budgetary inflexibility.
- Blaming the victim family and child care problems are often ascribed to the limitations of the parents when they owe more to environmental pressures or deficiencies in the support services. Jackie's story (see boxed insert) provides a personal example to illustrate the point.
- Crisis-driven services families often have to wait until a crisis erupts before the services will respond.

- Lack of trust many parents have had bad experiences of the services in the past and are often reluctant to seek help even when they need it for fear of where it might lead.
- High drop-out rates keeping families interested and involved in early intervention programmes, parenting training programmes, support groups and the like is a recurring problem.

### Blaming the victim: Jackie's story

Jackie, who is now thirty, had her first baby when she was fourteen and a second a year later. Both were adopted. Five more children followed in quick succession. Jackie has never lived with the father: he has remained permanently in the background although they have maintained a long-standing relationship. As a lone parent, Jackie found it increasingly difficult to control the children's behaviour as they got older and, when she again became pregnant, all five children were taken into foster care. Only then, with all her children gone, was Jackie allocated a family support worker. Her new baby too was removed at birth despite her insistence that she'd have no trouble just managing the one: after all, she said, she'd brought up five on her own until the oldest was ten. The baby, she was told, would be freed for adoption. Later she learned that social services were looking to have the three youngest of her other children adopted also. Currently the children have been split up. Jackie thinks she may be pregnant again.

Throughout this time, Jackie has been treated as the problem rather than a person with problems. The whole sorry cycle seems set to repeat itself unless someone looks beyond her learning difficulties at how she can be supported as a mother.

#### **Child Removal and Parenting Failure**

A common finding running through the international research is the high risk parents face of losing their children. This finding appears to hold in all countries with an infrastructure of child protection services, although the rates of removal vary from study to study and country to country (reflecting both geographical variations in policy, practice and service provision, and the problems of collecting this sort of data for what is, in research terms, a hidden population).

The New York State Commission on Quality of Care for the Mentally Disabled (1993a) found that '(a)Imost one out of every two families....had at one time lost the custody, at least temporarily, of one or more of their children'. On the basis of a review of agency records in St. Louis, Accardo and Whitman (1990) report that 103 of 226 children (45.6%) born to 76 parents with learning difficulties had been removed from the family home. Feldman (1998) goes so far as to suggest that, in 'the United States and Canada, as many as 80% of these parents have their parenting rights terminated'. In Denmark, Faureholm (1996) puts the figure of children permanently placed away from home at 30%, as does Pixa-Keltner (1998) in Germany. Van Hove and Wellens (1995) give the proportion of children living away from their parents as 40% in Belgium. A prevalence study in Australia identified 77 parents with 116 children of whom one third had been taken into care (McConnell & Llewellyn, 1998). In Britain, Scally reported in 1973 that only 30% of the children of parents with learning difficulties in his administrative study were 'being reared....in their own homes'. More recently, Cross

and Marks (1995) found that a total of 13 children from 18 reported pregnancies and 16 live births were subject to child protection proceedings: 'In 7 cases proceedings were started within 1 week of birth, 6 of those 7 starting at birth itself.' In our own study of 20 parents (Booth & Booth, 1994b), 14 had had one or more of their children placed in short-term or permanent care.

These facts appear to indicate widespread parenting failure among this group of parents. However, as Dowdney and Skuse (1993) have pointed out, a child's reception into care is an unsatisfactory criterion of parental inadequacy in the case of parents with learning difficulties. A number of variables mediate the relationship between parental adequacy and child outcomes (Booth & Booth, 1994a). As Czukar (1983), for instance, observes, parents with learning difficulties 'are especially vulnerable to losing custody of their children in child welfare adjudications because of prejudicial attitudes, unfounded assumptions about inadequate parenting, lack of appropriate support services, and other problems.' Gilhool and Gran (1985) are supported by Hayman (1990) in arguing that US law governing the rights of mentally disabled parents is so laden with stereotypes about their abilities and potential as to 'prejudice decisionmakers' and lead to a judicial bias against these families.

#### **Barriers to Justice**

According to McConnell and Llewellyn (2000b) existing research shows that parents with learning difficulties receive a raw deal in child protection court proceedings and they are led to the stark conclusion that 'unnecessary harm is being done'. Bray (1999)

echoes the point. She argues that, 'Law, policies and practice are often based on outdated beliefs and assumptions, while the real needs and abilities of these parents are ignored. Ultimately, children and parents suffer.' Evidence, mainly from Australia and North America, is beginning to accumulate that parents with learning difficulties are:

#### Disproportionately represented in child care proceedings.

A survey by the Family Support Services Association in NSW, Australia found that parents with 'identified cognitive limitations' were almost twice as likely as non-disabled parents to have involvement with the NSW Department of Community Services in matters of child protection (reported in McConnell & Llewellyn, 1998). More recently, the same researchers concluded a prevalence and outcomes study of families headed by parents with disabilities who appeared in care proceedings before the NSW Children's Court. They found a 'substantial over-representation of ...parents with intellectual disability compared to the estimated prevalence figures for these parents in the community' (McConnell & Llewellyn, 2000a).

 Less likely to have received support in their parenting – or to have received inadequate support – before care proceedings are initiated.
 Research from around the world continues to affirm Gilhool and Gran's (1985) conclusion that 'adequate support systems for retarded parents do not exist'.
 Child protection agencies are 'ill-equipped to address the needs of (these) parents' (New York State Commission on Quality of Care for the Mentally

Disabled, 1993b). On the one hand, staff in these agencies lack training and expertise in working with parents who have learning difficulties. Mandeville (1990) reports that 'agencies with the most expertise in developmental disabilities are the least likely to be involved with families'. On the other hand, child protection agencies are not funded to provide intensive services nor 'organized to provide help to parents who will need support over the long term.' (ibid.)

# • At risk of having their parental responsibility terminated on the basis of evidence that would not hold up against non-disabled parents.

In most American states, 'the statutory and common law...treats disabled and nondisabled parents unequally' with the result that 'it is easier to terminate a retarded parent's rights than those of a nonretarded parent guilty of the same neglect.' (Gilhool & Gran, 1985) Levesque (1996) also concludes that the 'rights of mentally disabled parents are, in practice, being terminated when states present evidence which, if used against nondisabled parents, would not be enough to sever the parental relationship.'

# • Likely to have their competence as parents judged against stricter criteria or harsher standards than other parents.

Greenspan and Budd (1986) observe how parents with learning difficulties often live under the close scrutiny of child protection agencies and that such scrutiny 'sometimes results in the application of stricter standards of accountability.....than might be applied to "normal" parents.' Levesque (1996), too, concludes that 'mentally disabled parents essentially are being held to a higher standard of parental performance......more seems to be expected from mentally disabled than from nondisabled parents.' According to Payne (Payne, 1978), parents with learning difficulties are more likely to be judged inadequate and deprived of their parental rights than homosexual parents, incarcerated parents or parents with a diagnosed mental illness. Worse still, as Painz (1993) has pointed out, parents are often left striving to meet standards that are never made explicit.

# More likely to have their children removed and their parental rights terminated.

Hayman (1990), for example, observes that the 'presumption with mentally retarded parents is that physical removal of the child is most consistent with the child's best interests.' In a study of 206 consecutive referrals for protective services to the Boston Juvenile Court, Taylor et al (1991) found that parents with learning difficulties had less prior court involvement and greater acceptance of court-ordered services but still had their children permanently removed more often than nondiagnosed parents.

 Disadvantaged in the child protection and court process by rules of evidence and procedure, their own limitations and inadequacies in services.

An Australian study (Keyzer, Carney, & Tait, 1997) suggests that legal services are poorly equipped in both resources and training to represent parents with

learning difficulties. Hayman (1990) surveyed cases reported in the USA since 1965 and concludes that 'the fact of mental retardation, once established, often has the effect of shifting the various burdens of proof from the state to the parent....(O)nce a court is satisfied that it is in fact dealing with a mentally retarded parent, it often insists that the parent bear the burden of proving her fitness or potential for fitness...'.

Other factors working to the disadvantage of parents are the lack of experience on the part of most child protection workers in dealing with people who have learning difficulties (New York State Commission on Quality of Care for the Mentally Disabled, 1993b); lack of co-ordination among services which results in many families 'falling through the service net' (Whitman & Accardo, 1990); lack of independent advice and legal representation; legal representatives who are not skilled at communicating with people who have learning difficulties and who may share the presumption of inadequacy (Hayman, 1990); and parents' own difficulties in understanding the adjudicative process and how best to present themselves.

# Less likely to receive support in correcting the conditions leading to termination.

The belief that the innate limitations of people with learning difficulties make them unfitted for parenthood leads to the view that any parenting deficiencies on their part are irremediable and, consequently, that the provision of training or rehabilitative services will avail nothing. As Gilhool and Gran (1985) comment,

'few courts (in the USA) have been persuaded to order such services be provided as an alternative to severance of the retarded parent's relationship with a child.'

#### **Bringing These Findings Home**

What we know about the barriers to justice facing parents with learning difficulties involved in care protection cases derives mostly from the evidence of international research. There has been no research in England that examines how such are handled by social services and the courts, explores what factors are weighed in the balance when making decisions about the best interests of children from such families or offers any direct evidence as to whether parents with learning difficulties encounter similar discriminatory biases

However, evidence from a number of sources, including the DoH's 'Messages from Research' programme (Department of Health, 1995), recent work by the Social Services Inspectorate (Goodinge, 2000), newspaper reportage of individual cases (see, for example,Marchant, 1995; Pragnell, 1994; Valios, 1995; Whitely, 1995) and user studies of parents' own experiences of the child protection system suggests that the kind of rough justice evident in the findings of international research may have its parallels in this country. For example:

Lancashire County Council were censured by the Local Government
 Ombudsman for maladministration in failing to provide the level of counselling
 and support needed by a mother with learning difficulties whose child had been

taken into care. The Ombudsman recommended that the Council 'need to ensure that their social workers have a clearer view of what their aims are at any one time when working with such clients.' (Report by the Local Government Ombudsman, 1991) The failure to provide the right kind of timely, co-ordinated support is known to pitch families into crises that trigger intervention by child protection (Jackson, 1998). Evidence shows that 'where professionals fail to provide adequate support in the early stages of intervention there is an increased likelihood of the child becoming looked after' (Department of Health, 2000b).

- The work of professionals tends to be focussed on child protection, narrowly understood, rather than on the provision of compensatory support services (Gibbons, 1995) with the result that 'Section 47 enquiries dominate at the expense of Section 17 services.' (Little, 1995) The Government's efforts to refocus children's services nationally in order to promote and strengthen family ties have so far shown that it is easier to review policies and change priorities than it is to alter social work practice.
- The existence of a support gap, documented above, means that parents are frequently pitched into the child protection process while being denied the kind of support they are known to need in order to succeed. The SSI have expressed 'particular concern' about the 'lack of awareness' on the part of social services staff in some areas (see, for example, Social Services Inspectorate, 1999d) of

the kind of specialist help that a mother or father with learning difficulties might require in order to succeed as a parent.

- Critical decisions about the children of 'learning disabled parents' (such as decisions about them being placed on or remaining on the child protection register and/or being removed from the family) are being made 'on inappropriate or inadequate information' (Goodinge, 2000). Standards of case recording and of files generally for this group of parents are reported as causing 'concern' with key information missing (to a degree likely to have 'a direct impact on the quality of assessments undertaken'); no way of 'bringing together the key findings of different staff working with a family'; evidence of judgemental decision-making; and the omission of material about the impact of the parent's disability (see Section 7 in the various Social Services Inspectorate reports on individual local authorities).
- Disabled parents are reported to view social workers in Children and Families teams as 'insufficiently knowledgeable about either disability or how to enable disabled adults to parent' (Social Services Inspectorate, 1998).
- The principle of permanency planning appears to be pressing workers into using adoption as the preferred alternative form of care in cases involving parents with learning difficulties even when the needs of the children suggest that 'a more open model....which encourages continuing contact with parents may be more appropriate' (Glennie, Cruden, & Thorn, 1998). This outcome mirrors

experience in the United States where the 'new national adoption policy, with its briefer time period before termination of parental rights, has heightened concern about discriminatory practice' (Kirshbaum & Hansen, 1999).

 Too often parents with learning difficulties lose even when they win. Anecdotal evidence abounds of parents who have received court judgements in their favour only to face a local authority which runs away from the decision. A letter I received recently, extracted in the boxed insert below, illustrates the dilemma.

#### Endnote

These issues are best seen against the background of the Government's commitment to improving the quality of services for supporting children and their families and, particularly, in the context of the Quality Protects Programme (Department of Health, 1998) and the new framework for assessing the needs of children and their families (Department of Health, 2000a).

'Quality Protects' is concerned with 'getting decisions right about when (children) will benefit from public care and when services should be provided to them while living with their families.' (Department of Health, 1998). All the signs are that we are still a long way from achieving these objectives in respect of the children of parents with learning difficulties, never mind ensuring them and their parents equal treatment under the law and securing their basic human rights.

One of the objectives the Government has set for improving children's social services is 'to ensure that children whose parents have specific needs arising out of disability or health conditions enjoy the same life chances as all other children in the locality' (Department of Health, 1999).

### The support worker's story: A plea for help

'I apologise for writing to you out of the blue. I used to be a support worker for a couple where the woman had moderate learning difficulties and the man was classified as "borderline". I was their support worker throughout the woman's pregnancy and the first few months of their son's life. They have had "extensive" involvement with social services and the courts, much of it somewhat less than helpful.

Their son is now two years old and the courts have decided to allow them to keep him, as long as they have support. Now they live in a shared home with another family, where the parents are their support workers. They share most amenities in their new home and get round-the-clock support with parenting and life skills from their support workers. The support workers are extremely experienced in this home-based support work. It is on behalf of all of them that I am writing to you.

The local authority has, until very recently, argued that the difficulties of the parents meant they could not look after a child. Various independent assessors submitted evidence to the court which made the judge disagree with this. He ordered that their son should live with them and their support workers. During the course of legal proceedings, which have gone on for two years, there has been a great deal of confusion as to who should be paying for the support of this family. Communication within social services, between adults and children's services and between middle management and director levels had not been good or swift. For the parents and for support workers this has been exhausting, particularly as so much about the legal system is intimidating and confusing. For this borough the placement is setting a precedent, both in terms of the principle of supporting parents with learning disabilities and in terms of finances, and their response to the situation has not been well organised.

I have maintained a close friendship with the family since I stopped working with them. I am contacting you to see if you could give me/us any information about the

"normal" or "reasonable" levels of funding that I could pass on to the lawyers of the parents and the support workers.'

We shall not come close to meeting this objective in the case of families headed by a parent or parents with learning difficulties until we begin to close the support gap that makes worse their social exclusion, prejudices the outcomes of later intervention and contributes to the persistence of stereotypical thinking about their competence.

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