

## Parenting with Learning Difficulties: Lessons for Practitioners

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### SUMMARY

Parents with learning difficulties form an underserved needs group whose numbers are steadily increasing and are likely to continue to do so as a result of deinstitutionalization, community care and the acceptance of 'ordinary life' principles as a basis for service provision. This article reviews the research literature on parenting by people with learning difficulties in order to draw out the lessons for practitioners and to assist them in developing a clearer view of their aims and approach when working with these families. Case vignettes from an ongoing study of mothers and fathers with learning difficulties are used to illustrate the common themes. The authors conclude that service providers still have much to learn about how best they can secure and uphold the citizenship rights of these parents as well as protect the welfare of their children.

The true prevalence of parents with learning difficulties is unknown and possibly unknowable. At the moment, as Whitman *et al.* (1986) have observed, 'the mentally retarded parent represents an invisible and underserved special-needs population'. Most researchers agree, however, that their numbers are steadily increasing and will probably continue to do so as a result of changing attitudes towards sexuality, deinstitutionalization, decreased segregation and wider opportunities for independent living and participation in the community (Haavik and Menninger, 1981; Rosenberg and McTate, 1982). This trend calls for recognition in the planning and delivery of services and in the approach of practitioners working in this field. Already, for example, Lancashire County Council have been 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. 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). In this paper, we set out to review some of the main practice principles that emerge from the literature on parents with learning difficulties, and to illustrate the pressing need for a new deal for these families by drawing on case material from an ongoing study of their experiences of child-rearing and parenthood (Booth and Booth, 1992).

## THE EPIDEMIOLOGY OF PARENTHOOD

There are no reliable estimates of the numbers of parents with learning difficulties. Moreover, the methodological obstacles to undertaking a sound epidemiological study in the community seem to be insurmountable (Whitman and Accardo, 1990). What evidence there is about the extent of childbearing among people with learning difficulties comes mostly from follow-up studies of formerly institutionalized populations or from administrative censuses of official records.

Brandon (1960) surveyed 200 women discharged from the Fountain Hospital between 1922 and 1958 and found that 70 of them had given birth to a total of 160 children. Laxova *et al.* (1973) report that 53 women out of a total of 991 female patients (5.3 per cent) admitted to Harperbury Hospital between 1961 and 1971 were known to have become pregnant one or more times before, during or after their stay in hospital, and to have produced 95 children (including 6 stillbirths). Of 214 former hospital residents, Floor *et al.* (1975) found that 80 had subsequently married forming 56 couples with 32 known children between them.

Shaw and Wright (1960) identified 242 married people from the 2887 case records of all people since 1915 formally ascertained as having learning difficulties in Sheffield. Of this number, 197 people were eventually traced and found to have produced a total of 377 children. In a similar fashion, Scally (1973) examined the case records of all 4 631 people with learning difficulties known to the public authorities in Northern Ireland and identified 342 people who were married or who had at least one pregnancy (32 men and 310 women, representing 10 per cent of all people with learning difficulties over the age of 16). Among this group, Scally counted a total of 887 pregnancies leading to 791 live births. Finally, Whitman, Graves and Accardo (1986) report the results of a community-based survey of the numbers of parents with learning difficulties known to agencies providing services in the city of St Louis. They found 402 referred parents of 1 096 children.

These data are best treated as indicative only and must be interpreted with caution. Their comparability suffers from variations and changes in the definition of mental retardation both over time and cross-nationally (Tymchuk, 1990). Lacking a standardized method of criteria of assessment, it is impossible to be sure that like is being compared to like. This problem is compounded by inconsistencies in the use of terminology. Also, they undoubtedly underestimate the true prevalence of parenthood, not least because of the undernotification of fathers. Nevertheless, for all their limitations, the data do support a few summary points.

First, the research shows there are significant numbers of adults with learning difficulties in the community who are parents. Parenthood is a choice and consequence of ordinary living. As the acceptance of 'ordinary life' principles (King's Fund Centre, 1980) spreads so the number of parents can be expected to rise (Gillberg and Geijer-Karisson, 1983).

Second, the research demonstrates that when people with learning difficulties are freed from the invasive control over their sexuality exercised within institutions more of them will have children. Decreased segregation widens the opportunities for people to form personal relationships, to meet a partner, to fall in love, to live together, to get married and to start a family (Attard, 1988).

Third, the evidence shows that parenting by people with learning difficulties is not a new phenomenon and probably was more widespread in the past than has ever been officially recognized or acknowledged. Any significant increase on this historical base as a result of changes in attitudes and policies now underway will add yet more urgency to the already pressing need for service providers to develop forms of education, training and support for parents with learning difficulties.

### RESEARCH ON PARENTING

There has been scant research on parents with learning difficulties (Feldman, 1986). Most is American in origin: there have been fewer than a dozen reported British studies in the past thirty years. The work that has been done has focused on just four main areas of investigation (Tymchuk *et al.*, 1987): issues of heredity and familial handicap; fertility and family size; parental competence and parenting training; and child maltreatment or abuse.

There are a number of dangers in using this research uncritically to inform policy and practice in this area. The parents who have been reported on have not been representative. Most have come from an institutional background and have lacked adequate social supports in the community (Feldman, 1986). Consequently, they have generally had little experience of family life or of parenting models on which to base their own behaviour (Gath, 1988; Donaldson, *n.d.*). They have usually been drawn from those known to the services, often the child protection agencies, precisely because they were experiencing serious difficulties of one sort or another (Andron and Tymchuk, 1987). Also, virtually all the information currently available refers to mothers only; the role of fathers, with or without learning difficulties, has been neglected (Llewellyn, 1990). Indeed, most research has focused on the problems and failings of parents without giving due attention to their competencies and the more positive side of their experience. Moreover, the concept of parental adequacy is generally not clearly defined and parents are assessed against implicit middle class standards on the basis of little more than anecdotal evidence about their abilities (Tymchuk, 1990). This weakness is compounded when, as often been the case, no attempt is made to separate the effects on family life of social class, poverty and deprivation from the intellectual limitations of the parent(s) (Brantlinger, 1988). Finally, research so far has signally failed to listen to the parents themselves and to represent their own views and experiences of the rewards and demands of parenthood (Booth and Booth, 1992). For all these reasons, it would be a mistake to assume that research to date presents a true account of the limitations and potential of parents with

learning difficulties. It should always be borne in mind that our understanding is confined to people who were born, brought up, have lived and had their children during a time of repressive treatment and pervasive discrimination. As Andron and Tymchuk (1987) say, we may have to wait until a whole generation of people has lived in the community with adequate supports before we can begin to fully appreciate their qualities as parents.

Despite these shortcomings, enough is now known to correct a few common misapprehensions about parents with learning difficulties and, following the recommendations of the Local Government Ombudsman, to assist practitioners in developing a clearer view of their aims and approach when working with these families. This section draws on the research literature to identify some of the broad principles on which practice should be based.

The locus of fears concerning reproduction and people with learning difficulties has shifted. Formerly linked to eugenic alarms about the supposed threat to the national gene pool posed by the excessive fecundity of the mentally unfit, these fears now focus more on the risks to children's welfare and development as a result of inadequate parenting (Budd and Greenspan, 1984). On this point, however, the research evidence is consistent and persuasive. There is no clear relationship between parental competency and intelligence (Kanner, 1949; Brandon, 1957; Shaw and Wright, 1960; Galliher, 1973; Mira and Roddy, 1980; Haavik and Menninger, 1981; Schilling *et al.*, 1982). A fixed level of intellectual functioning is neither necessary nor sufficient for adequate parenting (Whitman *et al.*, 1989), and the ability of a parent to provide good-enough child care is not predictable on the basis of intelligence alone (Rosenberg and McTate, 1982). Parenting behaviour rather than IQ should be the criterion by which parental competence is assessed (Budd and Greenspan, 1985), and this can only be done on a case-by-case basis.

The practice implications of these findings are clear-cut. When working with parents, practitioners must beware *the presumption of incompetence*; approach each case *with an open mind*; and avoid what might be called *the mistake of false attribution* or seeing all the problems parents may be having entirely in terms of their learning difficulties.

One factor working against the application of these principles is the growth of specialization within social work and the resulting organizational division between services. Ever since the Maria Colwell tragedy there has been a steady shift in emphasis from care to protection in the child welfare services. The 1989 Children Act has reinforced this development by bringing neglect as well as abuse under the purview of child protection teams. As a result, parents are at risk of being referred for investigation under the 'duty to enquire' clause because the presumption of incompetence provides sufficient cause to suspect significant harm. Equally, the danger of them being assessed as incompetent is heightened when the practitioners involved have little or no experience in the learning difficulties field.

'Good parenting' is a vague concept in need of more precise definition (Brantlinger, 1988). Although there is a reasonable consensus on the specific dimensions of parenting that are important for child development (Dowdney *et al.*, 1985), there is no agreement of what constitute minimal acceptable standards of adequate child care. While children are known to need care, supervision, nurturance and stimulation, the minimal requirements defining parental competence in these skills are unspecified.

Assessments of the childrearing skills and practices of people with learning difficulties appear to show a number of common 'parenting deficits'. These include the failure to adjust parenting styles to change in their child's development, a lack of verbal interaction with the child, insufficient cognitive stimulation especially in the area of play, a tendency to overgeneralize instructions, inconsistent use of discipline (and in particular, a reliance on punishment at the expense of praise), and a lack of expressed warmth, love and affection in relationships. Once again, however, these findings must be treated cautiously. They are prone to selection bias (Tymchuk, 1990); some have been derived from clinical studies of 'extreme cases' (Llewellyn, 1990); most are based on subjective judgements of third party reports of parental competence rather than direct observation using standardized assessment procedures (Feldman, 1986); and, crucially, very few studies have used matched comparison groups to control for other variables apart from intelligence that might have an effect on parenting skills.

It is important to distinguish the influence of socio-economic effects on parental competence from the effects of having learning difficulties. What little research there is in this area strongly suggests that the problems of parents with learning difficulties living in the community are similar to those encountered by other parents of the same socio-economic status (Unger and Howes, 1986), and that their parenting styles also do not seem to differ from other parents in the same sort of circumstances (Andron and Tymchuk, 1987). After allowing for the effects of previous institutionalized living (Dowdney *et al.*, 1985), much of the inadequate child care among parents with learning difficulties may be seen as the product of poverty (Fotheringham, 1980, 1981). As Schilling *et al.* (1982) have observed, 'mentally retarded parents are relegated to the socio-economic circumstances that foster child maltreatment'. Consequently it is not surprising to find that parents with learning difficulties who come to the attention of child protection services share many characteristics with parents in the general population who experience similar caretaking problems. Foremost among these characteristics are inadequate incomes, unemployment, poor vocational skills, a disadvantaged childhood, isolation from their extended family, an insufficiency of social supports, stressed marital relationships, large families, and a lack of ordinary living experiences (Mickelson, 1949; Rosenberg and McTate, 1982). In short, the factors that make it hard for parents with learning difficulties to cope are mostly the same as those that make it hard for people who do not have learning difficulties to be good parents (Gath, 1988).

A number of good practice principles emerge from these observations. Practitioners must avoid *blaming the victim* (by ascribing poor childrearing to the limitations of the parents where it owes more to the constraints of their social situation); *avoid making value-laden judgements* about the adequacy of parenting on the basis of unfair comparisons with middle-class standards; *be sensitive to the similarities* between the parenting problems of people with learning difficulties and other at-risk families and *respond in a like-minded way*; and *beware of underestimating* the contribution which practical supports can make to helping families under pressure.

For most parents with learning difficulties, family life is constantly under threat. Shortage of money, debt, unemployment, chronic housing problems, fraught relationships, the hardships of single parenthood, personal harassment, victimization, and skill deficits all contribute in part to their vulnerability. As long as families or preoccupied by such crises of day-to-day survival their capacity for dealing with the demands of parenting and child development will be reduced (Espe-Sherwindt and Kerlin, 1990). It is against this criterion, however, that their 'fitness for parenthood' is judged. Consequently, overarching all the other pressures, parents live with the ever-present fear that their children may be taken away (Andron and Tymchuk, 1987). Usually under close surveillance from the statutory services, families feel their every move is under scrutiny and any mistake risks punitive consequences. One effect can be to foster a suspicion of the motives and intentions of professionals that may in turn lead to a reluctance to seek or use help.

Within the psychology of learning, stress is generally presented as a form of overload on an individual's adaptive resources. Lazarus (1966), for example, suggests that environmental pressures are perceived as more stressful for people with fewer available resources and supports. Parkes (1971) also notes that those with poor coping skills are particularly vulnerable to the traumatic effects of stress: decreased functioning, depression, withdrawal, anger and fear. In this light, parents with learning difficulties appear to face a sort of double jeopardy. More likely to experience parenting under conditions of adversity, they are also more susceptible to its strains. If so then, as Feldman (1986) has commented, given the range and variety of pressures these parents encounter their adaptability and durability is often extraordinary (Feldman, 1986).

The general lessons for practitioners are threefold: look for the *strengths and positive qualities* of families (and how they can be reinforced) not just for their weaknesses; explore practical ways of *reducing the pressures on the family* from environmental threats so lightening the parenting load; be ready to respond to *early signs of stress* instead of waiting for a crisis to occur; and ensure that they have *access to independent, informed and sympathetic advice* whenever issues relating to parental responsibilities and the care of the children arise.

The research evidence shows that, like other parents, people with learning difficulties have the potential for growth and their parenting skills can be improved by

training (Thompson, 1984; Budd and Greenspan, 1984; Feldman *et al.*, 1986; Tymchuk and Andron, 1988; Feldman *et al.*, 1989; Whitman *et al.*, 1989). This broad finding needs to be seen in context. Most of the work in this field has been done in North America where concerns about the risks of cultural retardation have encouraged a focus on training in personal and interactive skills rather than practical ones. Programmes have tended to use the techniques of behaviour modification and to concentrate on training in the clinic rather than in the home. Training has been directed almost exclusively to mothers and virtually no information is available about its impact on family functioning. Lastly, the target groups have been skewed towards the more able people and there is a need for further research into the receptivity of parents at various levels of ability.

Putting aside these specific points, there are two main areas of uncertainty within the literature about the effectiveness of training. The first concerns whether the skills acquired are maintained over time after training is discontinued. Rapid learning may be followed by quick forgetting without ongoing reinforcement. Peterson *et al.* (1983), for example, found that positive benefits disappeared quickly whereas Feldman *et al.* (1989) report that most (but not all) newly acquired skills were sustained over a 3-18 month follow-up period. It is not possible to tell whether these different outcomes were related to parental or programme differences. The second area of mixed evidence concerns whether people are able to generalize from their learning in the sense of transferring the lessons across settings (for example, from clinic to home) or applying them in new situations. Although further work is needed on both these questions it is clear that the parenting skills of people with learning difficulties can be improved by intervention. For training to be effective, however, it must be carefully developed, targeted, delivered and evaluated (Tymchuk *et al.*, 1990).

Practitioners must address these findings. In particular, they must *never assume that parenting deficits are irremediable*, or that problems cannot be overcome, without firm evidence for such a judgement; they must accept responsibility for ensuring that parents are given *the opportunity of acquiring adequate child care skills* and learning appropriate parenting behaviour; and they must *never seek permanently to remove a child from home* for reasons of neglect, inadequate care or abuse by omission before every effort has been made to equip the parents with the skills they need to cope. In order for practitioners to act on these last two points, a new priority will need to be given to the development of formal training and ongoing support for parents.

Just as adequate parenting is not a simple function of intelligence neither is there a simple relationship between parental competence and child outcome (Tucker and Johnson, 1989). One reason is that the support system may compensate for shortcomings in the skills of the parents to ensure satisfactory care for the children. Indeed, a significant predictor of child well-being is the adequacy of supports that parents have 'regardless of their own level of knowledge and skill' (Tymchuk, 1992).

The presence of a benefactor has been found to be crucial in enabling parents to continue looking after their children (Kaminer *et al.*, 1981). The one feature that has consistently been shown to distinguish families where the children remained at home from families where the children were removed is the presence of another adult able to give extended daily support or possibly several people able to help as required with matters beyond the parents' own coping resources (Seagull and Scheurer, 1986; Andron and Sturm, 1973; Espe-Sherwindt and Kerlin, 1990). Edgerton (1967) defined a benefactor as someone without learning difficulties who helps with the practical difficulties of coping with everyday problems. The role may be filled by a relative, neighbour, employer, landlord, social worker, community nurse or, indeed, by a spouse or partner. Seagull and Scheurer (1986) typify the level of help needed by families as approximating 'that offered by a well-functioning extended family system.'

The value of support to parents with learning difficulties is determined in large measure by the attitude of its providers (Tymchuk, 1990). Social support may be either 'competence-promoting' or 'competence-inhibiting' and the perception of parental competence directly affects the nature of the support provided (Tucker and Johnson, 1989). Benefactors must believe in the parents' ability and provide the opportunities for competence to emerge. Espe-Sherwindt and Kerlin (1990) found that families whose children were removed permanently typically had only limited support, lost their support at a crucial time or were viewed as incompetent by key figures within their support system. So far as professionals in particular are concerned, this suggests that their values and attitudes towards parents with learning difficulties are just as important in providing effective support as their knowledge and skills. As Andron and Tymchuk (1987) have said, a 'professional must be really committed to working with these families and be able to see their strengths as well as their problems.'

Working with parents with learning difficulties is a challenge for professionals. Often the framework of supportive services is lacking (Crain and Millor, 1978). Public prejudice and discrimination serve to deter or exclude people from using mainstream services such as family planning clinics, ante-natal classes, adult education, voluntary groups for single parents, etc. (Madsen, 1979). The inability to read or write may further reinforce their isolation by limiting access to services and to information about their rights and entitlements. Moreover, many parents have had such bad experiences of the services that their main aim becomes one of avoiding them in the future so further cutting themselves off from potential sources of support or help in a crisis (Whitman *et al.*, 1989). Together these factors often push families into overtaxing their informal support network (Rosenberg and McTate, 1982): a consideration which may also help to explain why they appear to get so little physical support from their own extended families (Andron and Tymchuk, 1987). The corollary of such a breakdown (or the absence of informal caretakers) may be a level of demand on the case management system enough to produce professional burn-out (Whitman *et al.*, 1990). Indeed, there may be a level at which it becomes

impracticable to deliver the support necessary to enable parents to go on looking after their children but 'the existence and location of that cutoff point needs to be proven on a case-by-case basis, and not presumed' (Whitman *et al.*, 1989).

Responsible professional involvement in the families of parents with learning difficulties calls for a long-term view, a long-term commitment and a genuine appreciation of the parents as people (Miller, 1981). Practitioners should adopt *an enabling approach*, aimed at creating opportunities for parents to develop and exhibit their competence, within a *user-centred framework* that gives parents a sense of control over their own and their children's lives.

## PARENTS AS PEOPLE

The research evidence reviewed above challenges many prevalent stereotypes about people with learning difficulties but it lacks a living pulse. Presented in impersonal terms it fails to convey any impression of the parents as people or of the lives they lead. This section seeks to give the discussion a human face by drawing on the case material from an ongoing research study of parents with learning difficulties.

The study is designed to explore the experience of child-rearing and parenthood as recounted by mothers and fathers with learning difficulties. The aim is to rectify some of the gaps and shortcomings in the existing research literature by giving attention primarily to the parents, by listening too what they have to say about the rewards and demands of parenthood, and by using the biographical method and life history as an 'antidote to accounts which come from other quarters' (Atkinson and Williams, 1990) and a counterweight to research in which the parents as people make no appearance. The study comprises a two-stage design.

Stage 1 involves interviews with a selection of parents or sets of parents aimed at providing comparable information on a range of families in different circumstances. Many factors seem likely to shape their experiences. Among them are marital status and household composition, the number and ages of the children, the presence of additional physical disabilities, whether the mother or father or both parents have learning difficulties, where they are living, the measure and type of support they have received, the attitudes of their own families, whether they have been enabled to bring up their children themselves or have had them taken away and so on. The intention is to achieve a spread of life-stories which encompasses as many of these factors as possible.

Twenty families have agreed to participate in the study (another four declined) including eight married and three cohabiting couples, four single parents, four divorced mothers and one separated father. Between them they have had a total of 50 children of whom two are now married (one of the married couples are also grandparents), 25 are living at home with their parents, one is living with grandparents, three have been adopted, eight fostered, one has been placed in temporary care, one lives independently, two with separated partners and one was

killed in a road accident. The remaining six children were born to other people and are not living in the household. The great majority (14) of the households live in rented council accommodation: of the remainder two are owner occupiers, two live with their own parents, one couple live in a caravan, and one mother lives in a social services hostel. In fact, this rough breakdown presents a static picture of a moving scene. In the course of the study to date, some parents have split up, some have got together again and others have entered new relationships. Similarly some children have left home or been taken into care while others have been reunited with their families.

A small number - possibly 6-8 - of willing parents or couples will be chosen from this group to go forward into the next stage. Stage 2 will involve the compilation of in-depth personal accounts of people's experiences of parenthood from becoming pregnant, through pregnancy, confinement and labour, to baby care, child-rearing and being a mother/father. The method used will draw on a combination of the 'life story' approach (Bertaux, 1981) and the *vox populi* style of oral documentation (Plummer, 1983).

The study design has been chosen in order to provide as full a subjective view as possible of what it means to be a parent with learning difficulties. The purpose is not generalization. There is no sampling frame for this group of parents. The 'life story' approach of depth interviewing is intensive, time consuming and precludes a large sample. Furthermore, the number of parents is relatively small, while the variations in their characteristics and circumstances are relatively large, so compounding the selection of a representative sample. As Erikson (1973) says, sampling is 'a strategy of plenty'; doing life stories demands a more frugal approach. Instead of generalization, the study sets out to penetrate the subjective realm of the lived life, and to produce person stories that are typical if not representative of parents with learning difficulties. A fuller account of the research methods and the conduct of the interviews can be found in Booth and Booth (1992).

The following three case vignettes have been selected from the material collected as part of Stage 1 of the study to convey something of the varied circumstances and experiences of the parents and to illustrate the general points from the literature review. These stories also serve to highlight some of the themes that are beginning to emerge from the early phase of the research.

### DEBORAH AND DEREK'S STORY

Derek's family separated when he was thirteen and he and his mother moved address nine times within a few short years, sometimes sleeping in condemned properties and once in an outside toilet. They finally settled in a small council house opposite to where Deborah's family lived. Deborah has severe learning difficulties.

It was a long time before Deborah and Derek started going out together. She remembers their first date clearly. He took her to a disco. She borrowed her sister

Pamela's fur coat and Pam did her hair and make-up for her. After they had been seeing each other for a year she discovered she was pregnant and they decided to get married. Deborah's mother urged her to have an abortion and Derek's mother was also against their marriage. Deborah through had no doubt that she wanted to keep the baby. They married when she was five months pregnant and moved into her mother's two-up two-down terraced council house.

A son was born and, two years later, a daughter. By now there were ten people living in the house: aside from Deborah and her family there was also her mother, her brother, and her divorced sister with her own three children.

In some ways this arrangement suited Deborah and Derek. Help was always available during the day, and when Derek returned home from work he would make up the feeds for the baby's bottle, do the shopping and help with the washing. Sometimes, missing a good night's sleep before he went off to work the next day, Derek found the routine exhausting. But with their family around them they seemed to cope quite well.

Six years after getting married they moved into their own council house some distance from Deborah's mother's. Within a few weeks Derek's mother decided to move in tiwh them and she provided the support previously given by Deborah's family. She did the cleaning, made the meals, helped with the children and kept Deborah company. In 1984 Deborah, unexpectedly pregnant again, had another son. Three years later Derek's mother died and their troubles began.

Until Deborah was left on her own, Derek had not fully realized that she could not manage a domestic routine. The house began to show signs of neglect. Meals became hit and miss affairs, rubbish accumulated, and Derek had to do the ironing and washing because Deborah could not understand the dials.

Derek himself had become very depressed after his mother's death and thought about splitting up the family. Deborah and the children would go back to her mother's and he would go it alone. He found it more difficult to go to work worrying about what was happening at home and, if he stopped at home to help out, he worried about losing his job. In the end he was made redundant.

Round about this time their eldest boy began to mix with the wrong crowd. He was caught breaking into houses and damaging property by the police and was fortunate to be let off with a stern warning. When finally he left school this behaviour stopped. Their daughter, too, started to truant and keep company with a gang of girls who were always getting into trouble. Sometimes she would go missing for a day or two at a time. She began to vandalize her own bedroom, making holes in the walls and writing on the wallpaper. She also starter with an enuresis problem. Much more disturbing though, her father began to suspect that she had become the victim of a paedophile ring.

Fearing for his daughter, Derek began to keep her at home instead of sending her to school. At least then he knew she was safe. She stayed at home for many months without schooling until the Education Department took action. A social worker was

attached to the family and she visited regularly but her main concern seemed to be the truanting from school.

To cap it all the family itself became the victim of intimidation. Throughout her life Deborah had been abused by young lads picking on her and calling her names, and she even had stuff thrown at her including a bottle of urine which spilt all down her coat. Occasionally she would go to the local school and complain to the headmaster. Now things had become a lot worse. Eggs were thrown at their windows, threats were made to set their old car on fire, toys and equipment disappeared from the garden, two windows were broken and they no longer dared to put their washing out on the line.

After their daughter was accused of theft (but never charged) she was taken into care and placed in a children's home. She was still not attending school full-time and, after being assessed in an adolescent unit, there was talk of her going to live with a foster family. She refused and the subject was dropped. Deborah and Derek were only allowed to visit two days a week, but could phone whenever they liked. After one visit they discovered that all the downstairs windows in the children's home had been broken and were now boarded up. Instead of feeling their daughter was being cared for they began to fear she might come out even worse than when she was admitted. She was still being visited by the friends her parents believed had led her astray.

Soon after all this upset in their lives, a support worker was introduced to the family. She visited twice a week for two hours at a time mainly to help Deborah develop the skills she needed for coping with everyday life. But she also took the youngest child out swimming and shopping, and suggested jobs that Derek might do while he was at home. Deborah had started to attend the local adult education college to learn cooking, literacy and home economics and she had begun to make a few friends there. In addition, their social worker had recently helped Deborah to apply for a Severe Disablement Allowance and was actively pursuing a claim for some more bedding, a new cooker and some flooring for the kitchen and bathroom.

Derek, on the other hand, had become more worried about his daughter's future and could find no relief or satisfaction in what the professionals were telling him. He took himself off his Employment Training Scheme but then had his income support temporarily stopped. With Christmas approaching, the family finances were rapidly getting into a mess. Derek began to lose confidence in himself and, seemingly unable to help his daughter break free of the corrupting influences in her life, to doubt his worth as a parent. The talk of placing her with foster parents only served to reinforce these feelings. Deborah was phoning her daughter every day at the children's home and when the quarterly bill came through it was over a hundred pounds. They could not pay and their phone was disconnected.

Derek has put their names down for a transfer to a house nearer Deborah's mother. His hope is that when their daughter comes home they might be able to start afresh in another part of the city away from her old friends. He has been told that a transfer

might take anything from four to ten years. Deborah, however is reluctant to leave the area because the college she attends has become a very important part of her life.

Meanwhile they have just been informed that a review panel has decided their daughter will be allowed back home soon after her sixteenth birthday. Although this was the fourth review they attended during her six months in care it is the only time they have received a written report on the proceedings and decisions. Delighted at the prospect of her coming home, they are still aware that nothing has really changed except her age. They face the future with some trepidation.

### MOLLY AND KEVIN'S STORY

Molly was mostly brought up in a children's home and has no recollection of her mother who died after the birth of her fifth child. Molly has two sisters and two brothers and all of them were abused by their father. She had an unhappy childhood and remembers a few disastrous foster placements where she felt picked on and blamed for any mischief or wrong-doing. At 17 she became pregnant after being raped. After seeing her pregnancy through for the full term the baby was removed at birth. When finally she left the children's home she lived for a while in a hostel for people with learning difficulties and attended the local SEC. The only training she ever received for marriage and bringing up children was to learn sewing and how to make buns. Only once did she cook a full meal.

Today she lives with Kevin on a bleak caravan site at the head of a long, unmade lane in a despoiled area close to a power station: a place where social workers visit only in pairs and after leaving their cars out of sight. Molly and Kevin met at the unemployment drop-in centre and decided to live together. They now have a four-year-old daughter and a two-year-old son. The site has no facilities. A store and a social centre were vandalized so often they were closed some time ago. Now a mobile grocery van visits once a day. There is no bus service, Molly spends a lot of her time watching television to relieve the boredom.

Unlike many of their neighbours, Kevin has got a job but he works long hours, and often nights. He sleeps much of the day and it is difficult in a caravan for Molly to keep her two small children quiet. Consequently, they play outside whenever the weather permits, getting muddies up and creating a great deal of washing and mess. As the caravan only has one sink, and much of the washing has to be done at a launderette which costs 50p a load and 70p for drying. Any toys left out are stolen.

The caravan itself is very damp and one of the bedrooms is unusable during the winter. Clothes become mildewed after a few days, and both children regularly suffer bad colds caused by the draughts and damp. At present the only heat they have comes from a one-bar electric fire as they are waiting for the site owner to mend a broken pipe to their gas fire. Molly worries about the dangerous siting of their gas cooker next to the outside door. Apart from the risk of wind blowing out the flame, it creates a hazard when she is cooking and the children are running in and out. Last Christmas

the water pipes under the caravan froze and the whole family had to go and stay with friends in a one-bedroom flat. The strains of living under these conditions make the children fractious and demanding and their persistent whining eats at their parents' patience.

The police are often on the site and most residents have learned to keep themselves to themselves. Kevin has a brother living in a nearby caravan and Molly a sister with a new born baby. Molly and Kevin have received only minimal support from the services. They expect to be visited once a month by a community nurse but quite often this will stretch to three months. Even if they request a visit, it usually takes a number of phone calls over a period of weeks before anyone comes to see them.

Molly and Kevin have had their ups and downs in the past. When the children were younger Kevin took a job in London for a year. While he was away he asked the local social services department to keep an eye on Molly and to make sure she paid the rent every week (for which he regularly sent her the money). Social services said they would but, in fact, nobody ever checked. Molly accumulated huge rent arrears and, shortly after Kevin returned they split up. Molly went to live with friends and Kevin took the children. After various temporary home, he and the children were finally placed on the caravan site. Kevin's name was put down as a priority on the housing list and he was told he would be rehoused in six months time. Meanwhile, the social services asked him and Molly to try and get back together again. Eventually Molly moved into the caravan.

Meanwhile, Kevin has said he would pay off Molly's rent arrears so as not to jeopardize their chances of a house in the future. He wanted Molly to sign over the tenancy to his name. Molly refused. Unable to read or write except for her own name, she feared she might be signing away custody of the children. At one point she went to the social services and asked for someone to come out to the caravan and read the document for her. They said they were too busy.

Recently they had a visit from a housing officer who told them that Kevin's name had been taken off the emergency housing list. As Molly went back to living with him, he no longer qualified for priority as a single parent. They would now have up to two years to wait. Understandably, they felt as if they were being forced to separate again in order to get a house. To add to their troubles, they were also told by the LEA that their daughter would not be allowed to start school as a 'rising five' because, with the prospect of them moving house, a change of school would be disruptive.

When, soon afterwards, Kevin was laid off work with a pulled back muscle, Molly could take no more. She left him and the children and disappeared without a word. Four weeks later she returned to find them installed in a new caravan. Kevin had contrived to put his foot through the floor of the old one and, after complaining, had been given a better equipped model with separate bedrooms, a larger kitchen, an

inside toilet and more space. Whether Molly finds this makes her life any easier remains to be seen.

## MARY AND TOM'S STORY

Mary's first child was the result of rape at the age of sixteen. A friend of the family forced his way into her bedroom at home while she lay asleep. After the birth she stayed at home with her parents until her daughter was two years old when she met Tom and fell in love. Tom had spent most of his life in care. His mother had thrown him out when he was quite young after accusing him of being responsible for letting his brother drown. While in care he was placed in a special school but attended very infrequently. When he left the children's home, he lived for a while on the streets.

Tom is eight years older than Mary and, before they took up together had already lived with two other women who had borne three children by him. He admits he has a violent temper and, when angry, has kicked holes in doors and ripped the wallpaper. Once he was put on probation for breaking the nose of an eleven-year-old-boy.

Mary and Tom married quite quickly and, after Mary found herself pregnant, they moved into their own home where her second daughter was born. Tom had wanted Mary's first child to stay with her grandparents as he did not care for the little girl but Mary wanted her to live with them.

Mary has severe learning difficulties and, after living at home with her parents, suddenly found she had to manage the household budget, prepare meals and cook, wash and iron, do the shopping and keep the house warm and clean as well as care for a husband with mental health problems and two small children.

When the first daughter was four years old, suspicions concerning her welfare were voiced by a neighbour and staff at the nursery she attended. Evidence suggested that she had been the victim of sexual interference by a man and, although she had been in regular contact with her five uncles as well as her stepfather, the police did not directly accuse anyone of the abuse. A place of safety order was taken out and she was removed from the family home and placed with foster parents.

At this time, the second daughter was attending a registered childminder five days a week and sometimes weekends as well. She was also taken from Mary and Tom because of concerns about physical and emotional development. There was no evidence of abuse. Both children were originally placed with the same foster family, but soon afterwards they were separated.

A few days before their daughters were removed, Mary gave birth to a son. He remained at home until he was four years old when he too was taken into care for failure to thrive. He was placed with a third foster family.

At present Mary and Tom are no longer allowed to see their daughters and have only limited access to their son.. He has stopped calling them mummy and daddy and now uses their christian names. He also cries when he sees them and says he wants to come home.

Their health visitor advised Tom to have a vasectomy. She said it was best because, 'You know when they all get to a certain age they're going to disappear'. The social worker made the appointment at the clinic for Tom and accompanied him while he had the operation.

At present, Tom is seeing a psychiatrist and Mary has just begun to receive counselling from a clinical psychologist about her relationship with Tom and the possible effects of her rape. They are both attending adult literacy classes for half a day a week, and Mary is also learning to cook. She has applied for a divorce. Neither of them have ever been given any support to help them cope with the loss of their children.

### CONCLUDING REMARKS

Although the research still has a long way to go, these brief case stories illustrate a number of broad themes that are beginning to recur in the experiences of other parents in the study and were also brought out in the review of the wider literature.

- Parents with learning difficulties do not form a homogeneous group with a common history of family pathology. There are big variations among them in their characteristics and circumstances. Their experiences of parenthood and child-rearing show more similarities than differences with other ordinary families from the same social background, and the problems they encounter or present tend to mirror those of other 'at risk' groups.
- Parental competence is not just a matter of possessing adequate parenting skills. It is an attributed status which owes as much to the decisions of professionals as to the behaviour of parents. It is situationally determined by the quality or poverty of the environment in which people live (it is hard to maintain socially acceptable standards in a dilapidated caravan lacking basic amenities). Parental competence is also socially constructed in terms of the normative standards and evaluative judgements enforced by the wider society, official agencies and their front-line representatives.
- Many of the problems faced by parents with learning difficulties derive more from poverty, poor housing, harassment, victimization, social isolation and lack of support than from deficits in their own parenting skills.
- Family problems are too easily viewed in terms of the parents' learning difficulties rather than in the context of their own upbringing. Growing up without good parenting models, possibly without direct experience of ordinary family life, perhaps subjected to abuse themselves as a child, excluded from mainstream society, denied any sort of preparation for adulthood does not provide a sound foundation for good parenting. This has important implications for practice. Problems rooted in the inability to learn may seem intractable. Problems rooted in failures of socialization can be remedied.

- Social isolation and lack of support stretch the coping resources of parents and contribute significantly to their everyday problems of living. Having a benefactor without learning difficulties (who may be a spouse, partner, family member or friend) is one of the single most important factors influencing their ability to manage.
- Professionals occupy a problematic status in the lives of parents with learning difficulties. For some they are an essential and valued source of support and guidance. For others they are a major cause of upset and trouble. Overall, perhaps the signal feature of much professional intervention is its inconsistency. Some families receive intensive support where others are left to fend for themselves until they can no longer cope. Blatant disparities exist in the access conditions granted to parents whose children have been removed from home. Some families are required to maintain prescribed domestic routines and standards of cleanliness which are ignored in the case of others. The statutory services still have much to learn about how best they can secure and uphold the citizenship rights of these parents as well as protect the welfare of their children.

Stepping back from all the detail, the simplest and most instructive reading of the material presented in this article is that it bears out Mickelson's (1949) observation almost fifty years ago that parents with learning difficulties are properly seen 'not as different kind of parent but as a more vulnerable one'.

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