LEARNING THE HARD WAY: PRACTICE ISSUES IN SUPPORTING PARENTS WITH LEARNING DIFFICULTIES

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SUMMARY. Parents with learning difficulties from an underserved needs group whose numbers are steadily increasing as a result of deinstitutionalisation, community care and the acceptance of the principle of normalisation. This paper presents a case study of one such family in order to highlight the strengths and weaknesses of current service responses to parents, the inhibiting as well as the enabling character of the support offered, and the importance of the values and attitudes that inform practice. It concludes with a detailed 'service audit' of the case.

INTRODUCTION

In 1991 Lancashire County Council were censured by the United Kingdom 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).

This presents a new challenge for practitioners. As Whitman et al. (1986) have observed, parents with learning difficulties constitute 'an invisible and underserved special-needs population.' There has been scant research into such families and practitioners have little to guide them except hunch and intuition. One fact on which researchers are agreed, however, is that the numbers of parents with learning difficulties are steadily increasing and will continue to do so as a result of deinstitutionalisation, decreased segregation, changing attitudes towards sexuality and wider opportunities for independent living and participation in the community (Attard, 1988; Rosenberg and McTate, 1982; Haavik and Menninger, 1981).

A number of points stand out about the research that has been done so far. Most is American in origin and so throws little light on the adequacy of the support services in this country, or on the problems and pressures faced by the parents themselves. The small British literature shows a greater interest in the welfare of the children and in child protection issues than in the needs of the parents. The great majority of studies have focused on just four areas of interest: issues of genetics and the intellectual functioning of children born to parents with learning difficulties; fertility and family size; parental competence and parenting training; and the risks of maltreatment and abuse. Most of this research has been conducted from a clinical, developmental or behavioural perspective which has tended to treat the parents as little more than dependent variables in the analysis rather than to credit them with any integrity as people. There is virtually no research which shows respect for them as individuals by according them the same status of actors in the drama of their own lives.

The focus and origins of much of this research do not readily permit the findings to be translated into practice in ways that would help social workers in this country to clarify their aims when working with parents with learning difficulties. Instead, they illuminate the differences in context and approach that distinguished social work intervention in this field in Britain and America. In the USA, practitioners are mostly psychologists, working from a perspective rooted in the psychology of learning, following behavioural programmes of instruction or training, primarily with mothers along, in improving competence in parenting skills. By contrast, in the UK, intervention is less targeted on parental training and reflects the emphasis within the learning difficulties field generally on inter-professional collaboration in the delivery of community-oriented, generic services within the home.

This paper sets out to bring research and practice into closer alignment by drawing on material from an ongoing study of parents with learning difficulties to highlight some of the lessons that emerge from their experiences.

THE STUDY

The Study (funded by the Nuffield Foundation) is designed to explore the experience of child-rearing and parenthood by mothers and fathers with learning difficulties with a view to framing a set of 'good practice principles', grounded on parents' perceptions of their own needs, for the guidance of service providers and practitioners. It aims to rectify some of the omissions in the existing research literature by giving pride of place to the views and feelings of the parents, by listening to 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 in which the parents as people make no appearance. The study comprises a two-stage design.

Stage 1 has been completed and involved unstructured interviews with a selection of parents or sets of parents in different circumstances aimed at providing comparable information on their experiences of parenthood from becoming pregnant, through pregnancy, confinement and labour, to baby care, child-rearing and being a mother / father. Twenty families (containing 33 parents of whom 25 have learning difficulties) agreed to participate in the study (another 4 declined) including 8 married and 3 cohabiting couples, 5 single parents, 4 divorced mothers and one separated couple. Between them they have had a total of 50 children whom 2 are now married (one of the married couples are also grandparents), 25 are living at home with their parents, 1 is living with grandparents, 3 have been adopted, 8 fostered, 1 has been placed in temporary care, 1 lives independently, 2 with separated partners and 1 was killed in a road accident. The remaining 6 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 2 are owner occupiers, 2 live with their own parents, 1 couple live in a caravan, and 1 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 into new relationships. Similarly some children have left home or been taken into care while others have been reunited with their families.

Six couples and one single mother have been chosen from this group to go forward into the next stage. Stage 2 involves the compilation of in-depth personal accounts of people's ongoing situation as parents. As Plumber (1983) has stressed, 'biographies are in a constant state of becoming' and the guiding purpose of this stage of the research is to capture something of this ebb and flow of experience by presenting a picture of 'a year in the life' of these families.

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. Parents were mostly located using the 'key informant method' (Whitman and Accardo, 1990) although a few were traced from 'grapevine' information picked up in the course of fieldwork. The main danger of relying on key informants in service agencies is the risk of bias towards the people with problems. As the primary focus of this study is on parents who have more severe learning difficulties, and who are likely to experience problems in living that call for surveillance or support or otherwise bring them into contact with the statutory services, this risk did not present a serious worry.

A 'social systems perspective' (Mercer, 1973; Budd and Greenspan, 1984) was adopted as the main diagnostic criterion for determining whether parents were eligible for admission to the study on account of their learning difficulties. We felt the only practical decision rules we could follow were to select parents (single parents or couples living together where one or both partners have learning difficulties), with children of any ages, in the care of their parent(s) or living away independently or in the care of others, *who at some time in their lives, not necessarily currently, have been in receipt of health, education or social services specifically intended for people with learning difficulties.* A fuller account of the research methods and the conduct of the interviews can be found in Booth and Booth (1993).

This paper focuses on just one of the couples in the study. Julie Beckett and Neville Fletcher's story illustrates many of the common themes and issues that emerge over and over again in the accounts and experiences of other families. It also shows up some of the strengths and weaknesses of current service responses to parents like them, the inhibiting as well as the enabling character of the support offered, and the importance of the values and attitudes that practitioners bring to their work. Their story might not be representative in any statistical sense but it is certainly typical of the experiences of parents in the study. As Ferrarotti (1981) has argued, the 'effort to understand a biography in all its uniqueness....becomes the effort to interpret a social system.' This entails 'listening beyond' (Bertaux-Wiame, 1981) people's spoken words or, in this case, the parents' own accounts, to catch the resonance of the structural forces in the wider society that help to shape their lives. This is the true meaning and significance of Julie and Neville's story.

JULIE AND NEVILLE'S STORY

Julie spent much of her childhood in care at residential schools and with foster parents ('They kept moving me every time I go to bed at night.'). When she was 18 years old she met and fell in love with Neville at an Easter fair at the social education centre he attended. Neville had lived with his mother until he was in his twenties when, after a short spell in a hostel, he and his brother were given a flat. He gradually became 'fed up' with social workers calling on them and eventually moved in with a friend's mother. Both Julie and Neville have learning difficulties.

They had been courting for two years when Julie became pregnant. For a while she stopped in a homeless person's hostel but after the birth of their son the local Housing Department gave them a house and, when Julie came out of hospital, they moved in. Suddenly, Julie and Neville found they had to learn how to budget their money for food and clothes, pay the bills, prepare meals and cook, wash and iron, do the shopping and keep the house warm and clean. This was difficult enough without also having to adjust to living together and caring for a new baby.

When their baby was just two weeks old, the health visitor became concerned about him not gaining weight. The midwife called round to weigh him, and dropped him (in front of witnesses). He was taken straight to hospital. Soon afterwards Julie and Neville were told he could not be returned to them. A Place of Safety order was taken out and he was made a ward of court.

There was a long delay of nearly two years between the baby being warded and the date of the custody hearing. The Court decided to leave him with foster parents on the grounds that Julie had no insight into the needs of a young child. Julie and Neville were allowed regular access.. Julie was told she was being put on Depo-Provera injections: 'My mam said to a social worker, 'Why can't Julie have any more' and they told my mam, 'She cannot look after them'. However, after a few years she began using the contraceptive pill. At some point she stopped taking it.

The issue of their son's adoption arose at the same time as Julie found herself pregnant again. He was nearly six when the court ruled that he should be adopted. Julie recalls, 'They were making me to have him adopted but I didn't want to, but I like went through it'. Thereafter, all contact between him and his parents ceased, apart from a photo which Julie and Neville are sent once a year and the birthday and Christmas presents they are allowed to leave for him at the social services office. Julie and Neville had to accept they had lost him, at least for the time being. As Julie said:

> I'm just waiting. I'm going to wait till he knocks on the door, that's all. You see, if I have him back I'll be a family, a proper family. He knows I'm his mam: his first mam and his first dad.

They continued to nurse concerns for their son. On one occasion they had seen him in town with his new parents and his lip had been swollen. The adoptive parents told Julie that he had fallen off his bike. Julie was not so sure: 'I don't know if they're hitting him or not'.

Julie gave birth to a second boy, Jeremy, who is now almost 18 months old. ('I said to them if you take this kid off me I'd just kill myself'.) After Jeremy was born the social services and the CMHT (Community Mental Handicap Team - multidisciplinary services) decided to draw up a visiting and support programme for the family. A social work assistant was introduced to Julie while she was still in hospital and both parents took to her immediately. (As Julie said later: 'She's been all right with us. She's like a mam to us'.)

The house the family lived in was on a run-down council estate smitten by tell-tale signs of vandalism, poverty and neglect like boarded-up windows, overgrown gardens and broken fences. Support workers refused to visit at night and the police had advised those attending the local women's group not to venture out alone after dark. Julie suffered a lot of abuse from local children. ('They call me a gyppo; they call our Jeremy's not clean'.) Occasionally a window would be smashed by stones or she would find her washing-line cut through. Sometimes she saw other women on the estate maltreating their children and could not understand why only she and Neville had been singled out to have social workers checking on them and their son taken away. ('Why've they took my kid off me, not Barbara's'.) They were not happy living here.

When Jeremy was small, Julie and Neville had twice daily visits from care workers or community nurses. According to their social worker, these were intended to 'motivate' them. Neville would mix the feeds and do the feeding charts, while Julie fed the baby. As he grew older, checks were made on whether he had been fed the appropriate food for breakfast, on the state of the house, and to sort out the finances.

During the course of a week, five different workers would call at the house to check on the baby. All visits were recorded in a book kept in the living room. The entries were often derogatory in tone and praiseworthy comments were rare: for example, 'Julie was in a bad mood today and I had to tell her off for not hoovering the carpet'. Julie and Neville cannot read, and the book annoyed them intensely: 'If they keep writing in that book I'm going to put it back on the fire. I'm sick of seeing it. They're not me mam to make me do'.

They saw these visits as interference and a restriction on their independence. As Julie said on one occasion:

> I just want them to leave me alone, let me get on with my life. I don't want anybody telling me what to do. Only your mam should tell you off, not social workers. They treat me like I was one year old and I'm twenty six. I can't go out when I want 'cos I have to wait in for them. When I clean the place up for them they don't turn up. They want me to get my house perfect but I cannot get it perfect. I'm not like other people, them posh people. It's just like other houses round here. With Tessa you've to wipe your feet when you come out.

Julie and Neville felt themselves to be under constant criticism, although the baby was thriving and his needs always came first. A persistent fear was that Jeremy too would be removed if they failed to live up to the expectations of the authorities. Julie confessed to being frightened that he might still be taken away from her 'if I argue with social workers'. Her sister reinforced the point: 'Sometimes they say to her: Your baby's not clean enough. If you don't clean him up we'll have to take him off you'. Julie added defiantly, 'I tell you now, they're not taking him off me.'

Julie and Neville had always enjoyed going out during the day, meeting some of their friends or other members of their extended family. They still managed it most days, after their daily visit. Julie had a sister who attended the local SEC (social education centre) and they saw each other regularly She too had given birth to a baby boy who had been fostered.

On the advice of a social worker, Julie joined a women's group in town where, once a week, the women talked over their problems and gave each other support. All the women that attended were mothers and poor. They were also clients of social services. Run by social workers, the group sessions were held in a dilapidated building, also used as a youth club, covered in grime and graffiti. In winter it was cold enough inside to force the women to keep their coats on and their babies well wrapped-up. There was a hole in the roof through which the rain leaked. Most of the seats and tables had been vandalised, the floor was unclean and the toilets a mess. Although Julie liked some of the women, she was very critical of the surroundings: 'I know it's not decent.... and they tell us about cleanness'. Nevertheless, here she started to learn the same way most mothers do about bringing up a baby - by observation and by asking questions.

Julie and baby Jeremy also attended a family centre and Neville accompanied them. They looked forward to these afternoons and the staff gave them considerable practical support and encouragement. The centre had a number of community functions but the purpose of their particular session was to bring together families who had difficulty fitting into larger mother and toddler groups. It was attended by couples with learning difficulties, single mothers and a few with post natal depression. In contrast to the woman's group, it was warm inside, clean, friendly, brightly decorated and with much to occupy the children. The staff's efforts to make the surroundings attractive showed they valued the people attending. They also made sure the time spent there was lots of fun. Julie and Neville have little social conversation and found it difficult to mix with the other parents and their children. Little Jeremy, however, had no such problem.

As time went on, the visits by support workers became more erratic. Some days Julie and Neville would be waiting but no-one would call. For whatever reason, their minders failed to notice the huge debts they were accumulating until the court orders started to appear.

People had spotted their vulnerability and abused their good nature. Julie used a catalogue from which others would order and not pay for the goods. Neighbours borrowed money and equipment and failed to repay or return it. Their gas meter was broken into; other women made use of Julie's washing machine; distant relatives lodged with them without contributing to their own keep. Even her stepfather borrowed money from them. Eventually things caught up with them. They defaulted on their gas bill, were fined for not having a TV licence and had their TV and video repossessed.

Once the full scale of their financial problems was realised, a new programme of intensive support was drawn up using a 'core and cluster' team. This entailed one of three workers being present in the house five to seven hours a day, every day, including some evenings. The support workers set out to get Julie and Neville into a routine with Jeremy; to help them budget, cook and shop (with the accent on buying nutritious foods); to arrange the home and keep the fire well stocked; and to make sure they were aware of the hazards now that Jeremy was crawling. In time, the team thought their hours in the home would be reduced. Julie and Neville were involved in all the decisions that had to be made, except one. Fat stains on the ceiling showed evidence of a few cooking fires and the chip pan (i.e. french frier) was thrown into the dustbin. Neville complained bitterly, having dealt competently with the fires, but chips are still off the menu.

Jeremy was now just one year old. He was placed with a child minder on Tuesdays while Julie, accompanied by her careworker, went dry skiing, ten pin bowling, swimming and ice skating. On Wednesdays, Neville attended the SEC to work in the agricultural unit. He was pleased to be back again, and enjoyed seeing his old friends, although he would have preferred a place on a job training scheme.

Meanwhile, arrangements were being made to offer Julie and Neville a way out of their debts. Social services owed a semi-detached house in the grounds of one of their elderly person's homes in the next town. Three young men with learning difficulties, one being Neville's brother, occupied one half and the other side was vacant. Julie and Neville were given the change of living there for a very small rent, including gas and electricity costs, until they had paid off their arrears. They were both anxious to move away from the council estate and agreed readily to the suggestion, although their old tenancy was kept on for a month in case they changed their minds. The house was fully furnished and centrally heated with a gas fire, in place of the coal fire they had at the moment, and a telephone. They also liked the fact that one of the careworkers and her family lived just up the road and would be available in emergencies.

Before they moved into their new home, some of the carpets were replaced and a new three piece suite was installed. A freezer was ordered and the support team applied for money to have the house redecorated. Most of the furniture and furnishings in their old house were tossed out. It was to be a new beginning.

Both Julie and Neville liked their three careworkers. Shortly after moving in they went on a week's holiday with two of them at a holiday camp. Julie had only ever had one holiday before, with her foster parents. The careworker's family living close-by have also become involved with Julie and Neville - visiting them, baby-sitting occasionally and passing on toys, clothes and equipment.

Neville used to mention how intrusion by careworkers into their private lives caused problems between them. Julie used to get very upset by them always being there and, as he once put it, 'sulks a lot'. Now she has stopped getting angry. 'It's different now'. she explained. The careworkers are there 'because we need help'.

Julie no longer attends the family centre - it is too far away - and the women's group has closed down. She joined the local mother and toddler group and a new childminder is being found for Jeremy.

Three months on, the house is immaculate and the garden is kept tidy by the council. Julie is not one to enthuse and gives little sign of what she really things about their new home. Neville on the other hand, is quite adamant that, 'You won't get me back down there. Even if Julie goes back, I'll stop here'. Now, instead of spending money eating out in cafes as they once did, Julie and Neville are being shown how to prepare their own meals. Julie does the washing and Neville the ironing. Child care is mainly Julie's responsibility while Neville mops, sweeps and hoovers the floors. Jeremy, a happy child, is just about walking and explores his surroundings with tireless energy. Recently they have been told that he is no longer a ward of court.

While the careworkers are around, Julie and Neville seem to look to them for prompting about what jobs need doing, whether it is making a cup of coffee for visitors, ironing or stopping Jeremy from touching the record player. On their own, Julie and Neville do things when it suits them. At some point Julie's fiercely independent streak has dimmed and she has ceased to resist the tendency for the services to take over. From persistently expressing her desire before their move to 'manage on my own' and for 'social workers' to stop coming ('I want to get rid of them though. I don't like them being on my back. I don't know why they don't leave us two alone to get on with our life'), she is now much more passive and accepting. Both she and Neville have realised that in order to keep their little son they have to cooperate.

So far the quality of life for Julie, Neville and Jeremy seems to have improved although new tensions in their relationship are beginning to emerge as a result of the focus and intensity of support going into the household. Their isolation is more evident than it was before. Jeremy too is reaching an age when he needs more stimulation and supervision, and this will place new demands on his parents. How these tensions and challenges develop and are resolved remains to be seen.

Julie and Neville's story has been recounted not because they are unusual but because it illustrates a number of common points in the experience of parents in the study and also because it highlights both strengths and weaknesses in current practice with such families. For this reason, it is instructive to undertake a 'service audit' of their case.

SERVICE AUDIT AND PRACTICE IMPLICATIONS

Tucker and Johnson (1989) provide a useful framework for such an exercise. They argue that *environmental strain* (caused by poverty, bad housing, illness, personal crises etc.), the parents' *actual level of competence*, and the support system's *perception of parental competence* each have a direct impact on the type and level of social support provided to families. Such support may be either *competence-promoting* or *competence-inhibiting* in character. In turn the kind of support offered loops back to influence the parents' actual level of competence which then reinforces how they are perceived by the support system.

Applying this model to Julie and Neville's case produces the following 'service audit'.

Environmental strains

- Victimisation in a poor neighbourhood.
- Poverty and deprivation.
- Poor housing on an impersonal estate.
- Little practical support from extended family or neighbours.
- Segregated and inadequate education including lack of teaching in life skills.
- Socialisation deficits resulting from a childhood spent mostly in institutional care and providing little experiences of family life or lacking parenting models.
- No holiday or respite from daily grind.
- Social isolation and harassment.
- No phone or immediate transport.

Actual level of parental competence

The parents have shown over the past six years:

- The capacity to function as a family unit with complementary skills - sharing the load in caring for the child, cooking, cleaning, shopping, ironing, etc.

- The capacity to recognise their own skills and the ability to learn new ones with appropriate training.
- The ability to learn about child rearing from other mothers and fathers by observation and by asking questions.
- The ability to learn skills by example from care workers.
- The ability to form close loving relationships.
- The capacity to put their child's needs before their own.
- A continuing concern and love for their first child and the strength of this parent / child bonding.
- The ability to learn (friendship, practical skills, child care) from community groups.
- A willingness to accept support in the home even though it is sometimes seen as an intrusion and a limitation on their independence.

Perceptions of parental competence

The service and support provided for the family have revealed:

- A tendency to assume too easily that problems are caused by the parents' learning difficulties.
- Too little acknowledgement of the impact of environmental factors on the parents' coping skills.
- An assumed lack of nurturing skills coupled with too little acknowledgement of the parents' capacity for learning (evidenced by the removal of their first child when only two weeks old).
- Judgements about the adequacy of homemaking and parenting that are informed by inappropriate comparisons with middle class norms (as shown by an emphasis on standards of tidiness and cleanness out of keeping with the neighbourhood).
- Inadequate recognition of the emotional boding between parents and child, and the trauma of separation.
- An undervaluation of the parents as people (illustrated by workers who fail to turn up when expected and services that diminish rather than enhance self-esteem).
- More positively, a readiness to consider the needs of the (second) child within the context of the family unit.

Competence-inhibiting support

- Manipulation of the parents' ever-present fear that their child might be taken away in order to ensure their compliance,
- Level of day-to-day surveillance that threatens to undermine parents' independence and reinforce their feelings of inadequacy.
- Failure to involve parents fully in all decisions (as instanced by enforced contraception, the adoption of their first child against their wishes and the dumping of all their furniture in the move to the new house).

- Failure to provide counselling to assist them to cope with the emotionally disabling loss of their first child.
- Sporadic supervision which allowed them to build up large debts.

Competence-promoting support

- Intense support given at crisis point.
- Necessary and appropriate long-term practical support offered and maintained.
- Practical training opportunities given, leading to self-reliance.
- Grants applied for and received for furniture, furnishings and domestic equipment.
- A comprehensive check made on social security benefits available to the family (including exemption from poll tax).
- Holiday arrangements made and family support maintained in unfamiliar surroundings.
- Day care for child.
- Practical help for coping with debts.
- Introduction to family centre.
- Introduction to women's group.
- Stress eased by second child no longer being a ward of court.
- Support workers' liking for the family.

CONCLUSIONS

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. Competence too is socially constructed in terms of the normative standards and evaluative judgements enforced by the wider society, official agencies and their front-line representatives.

Julie and Neville have lived much of their lives in segregated settings cut off from the opportunities for learning that come with participation in mainstream society. They have always been poor. Their problems as parents cannot be separated from these facts of life. At the same time, they have shown that with the right kind of support they can shoulder new responsibilities. The challenge for the support services and for practitioners is to ensure that they promote rather than inhibit such competence. While it is not possible to change what has happened in the past to Julie and Neville, there are ways of consolidating their hold on the present:

1. By reducing the problems that cause stress. Care workers can give help with: money management; reading letters and filling in forms; emotional traumas; fear of losing their child; counselling for abuse or harassment; rehousing if necessary; education on birth control methods to allow choice.
2. By improving access to resources such as: Family Planning Clinics; Samaritans (telephone helpline for people in distress); Citizen's Advice Bureau; a crisis

volunteer or telephone number; adult education; leisure and sports outlets; respite; baby-sitting services; skill acquisition sessions; self-help groups and community networks; employment opportunities; and, if possible, other parents in the same position.

3. By looking into the possibility of linking the parents with another family to learn the art of child-rearing. It could be that the care worker's own family or friends may choose to get involved or someone from the local church.
4. By encouraging health awareness and explaining the importance of regular visits by all the family to their GP, dentist and optician.
5. Tackle poverty by explaining the state welfare benefits system, their family's entitlement and the use of money. Apply for grants covering equipment, furnishings, clothes and shoes, to improve their living situation. Holidays too are a necessity for most people, even for short breaks, and funding is available for such needs.
6. By reducing the number of professional workers involved with any one family. Three is perhaps ideal to provide backup for the family and workers alike. It is important to match service workers who are sympathetic with the family's particular needs and who promote individual abilities without losing sight of people's limitations. It is also important that service workers and families who spend so long in each other's company should actually like one other.

By building on their strengths, parents too can be made to feel good about their achievements and are more likely to accept help and advice with their difficulties. Julie and Neville were lucky. Very few parents with learning difficulties are given a second chance.

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