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Making Connections: A narrative study of adult children of parents with learning difficulties

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Parents with learning difficulties are widely presumed to present a high risk of parenting breakdown. Successive studies have reported high rates (40-60%) for the removal of children from the family home (Mickelson, 1949; Scally, 1973; Accardo and Whitman, 1990). Research also suggests that the children of parents with learning difficulties are at risk of developmental delay, maltreatment, neglect and abuse (Schilling, Schinke, Elythe and Earth, 1982). This evidence has contributed to the view that people with learning difficulties lack the competence to provide good-enough parenting, and is often used to support a general claim of parental inadequacy. Oliver (1977:19), for example, asserts that such parents 'continue to be incompetent rearers, whatever supportive treatment is offered' and Fotheringham (1980:35) too claims that few parents have the ability to provide 'conditions of care at the minimal acceptable level'. Accardo and Whitman (1990:70) argue that the only important question 'with regard to parenting failure of significantly mentally retarded adults would seem to be not whether but when'.

The study described, in this chapter arose directly from earlier work, in which we documented the lives and struggles of parents with learning difficulties through personal accounts of their own experience of child-rearing and parenthood (Booth and Booth, 1994). This research showed that blanket judgements of parental incompetence are not grounded in the lives of parents themselves. The statistics on child removal owe as much to the decisions of professionals and the courts as to the behaviour of parents. The fact is that people with learning difficulties frequently fall victim to an expectation of parental inadequacy that is made real through the decisions and actions of those with the power to intervene in their lives. This 'presumption of incompetence' renders parents with learning difficulties vulnerable to discriminatory treatment and prejudicial judgements about their ability to cope with the demands of parenthood. From this point of view, parental competence is not just an attribute of the person but an attributed status that reflects the normative standards

used for defining good-enough parenting by those charged with making the assessments (Booth and Booth, 1996b).

A common response to this research was that we had argued a case for parents that did not take account of the interests or welfare of their children (Schofield, 1996). What, people wanted to know, becomes of children who grow up in such families? This study began as an attempt to address this question.

THE TARGET GROUP

The study¹ was designed to explore what it means to be brought up by parents with learning difficulties through the experience of their adult children. The target group identified for inclusion in the study comprised men and women aged (preferably) between 18 -30 years who had spent the greater part of their childhood living in a family where one or both parents had learning difficulties.

For research purposes, parents were held to satisfy the inclusion criterion if they were known to have received health, education or social services specifically designated for use by people with learning difficulties at some time in their lives or if a professional who knew them personally confirmed that they had been so-labelled. This was the only practical approach in the circumstances given that the parents themselves were not the subjects of the research, many were not seen or contacted and some were now dead. The expedient of using a person's current or former status as a service user as a surrogate for unobtainable test or clinical data in order to establish their learning difficulties has both a theoretical rationale (Mercer, 1973) and an administrative precedent, being the method used by many health authorities to identify those who are eligible for registration with their case registers (Farmer, Rohde and Sacks, 1993)

The decision to target adult children in the 18-30 age range was taken because we wanted respondents who were able to look back and reflect on their own childhood and upbringing from a position in the adult world, but whose memories were not too far distant from the events and experiences they described. Things did not quite turn out as planned. Difficulties in locating willing subjects and the way the introductions and interviews were set up (see below) meant that a number of younger and older people were admitted to the study. All in all, 18 of the 30 subjects

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fell within the prescribed band while 2 were below-age and 10 were over-age.

The research questions driving the study entailed that the adult children who took part had grown up mostly in the care of their parents at home, and had maintained contact with their family during any spell away from home. This requirement seriously limited the pool of eligible subjects. Twenty to thirty years ago, when our prospective subjects were born, it is arguably even less likely than today that the interests of the child would have been seen as best served by remaining in a family headed by parent(s) with learning difficulties.

Many adult children were located who had spent too long away from their parents to qualify for inclusion in the study. In the context of people's family lives it is not surprising that grown up children with relatively secure and stable home backgrounds were hard to find. Crises of family survival precipitated by poverty, broken relationships or official intervention were pandemic. Only half (15) of the study group had remained at home in the care of at least one parent with learning difficulties until they came of age or until they moved out to live independently. Five of our subjects had spent less than two years away from their parent(s), and a further three had been in care for two to four years. Of the remaining seven, all had spent more than four years in children's homes or residential schools but had remained in contact with their parents throughout this period. The majority of this group (5) had spent at least ten years of their childhood with their parent(s). The shortest time that anyone had lived at home was seven years, although in this case the lad went home from his residential school for weekends and holidays.

LOCATING THE SUBJECTS

Adult children of parents with learning difficulties constitute a hidden population for research purposes. There is no register of names through which they can be traced. Tracking them down presents the same problems as trying to trace the children of, say, parents who cannot read or write, or children whose mothers have epilepsy. There are too few to identify them through a general trawl of the population, and in any case such an approach would not be feasible given the sensitive nature of the subject and the difficulties of verifying people's responses. Consideration was given to placing a feature about the study in the local press inviting people to come forward but this idea was rejected because

again there would be no way of validating the parents' status and also for reasons of interviewer safety.

The only practical means of overcoming these enumeration problems was to trace possible subjects through parents known to the services. Even this method was far from straightforward. Some professionals were noticeably reluctant or unwilling to label people as having learning difficulties. Data protection restrictions limit the possibilities for searching the records held by service agencies and in any case information about people's adult children was rarely available on file. No agency was in a position to supply a list of people with learning difficulties known to have children aged between 18-30 years. Legal hurdles aside, such information was usually known only to individual practitioners about individual clients. Accordingly, people working in the learning difficulties services were approached personally and asked if they knew directly or indirectly of any parents with adult children, or knew of anyone else who might know such a parent.

This method of using such 'key informants' (Whitman and Accardo, 1990) has a number of weaknesses. It excludes people who are not known to the service agencies; possibly over-represents the less competent parents or those with greater problems and fewer community supports; and is very time-consuming. Any bias resulting from the first two problems is likely to be small. Most parents with learning difficulties will probably come to the attention of the statutory services at some time when their children are growing up. The other limitation must be seen as part of the price for doing the research at all.

The key informant method took us into twelve local authority areas in search of our target quota of adult children. Enquiries were pursued and leads followed up through social workers and social services teams, adult training centres and social education centres, special schools, special needs tutors in further education colleges, community nurses and community learning disability teams, local case registers, clinical psychologists, educational psychologists, careers officers, Family Service Units, a range of voluntary organisations, and other personal contacts. The task of locating our subjects turned out to be a major logistical venture, and the difficulties we encountered were one of the main reasons why the fieldwork stage of the research took fifteen months to complete instead of the eight months we had initially planned. The process was more like private detective work than research sampling: more Raymond Chandler than Moser and Kalton. It involved tracking down sources, cold

calling, getting a foot in the door, following up leads, checking out information, blundering down blind alleys, cultivating informants, using go-betweens and a great deal of legwork in pursuit of what in research terms were the equivalent of missing persons. Even so, obtaining the names of potential subjects was only the first step to establishing contact.

ESTABLISHING CONTACT

Finding the names of parents with learning difficulties known to have grown-up children was only a point of call on the way to our final destination. The next stage was to find out where the children lived and to arrange for an introduction. This was not so easy as it sounds. The sources who had come up with the parent(s) names were not always acquainted with the children, did not always know their home address and anyway could not usually divulge such information for reasons of confidentiality. In any case, given the nature of the study and the vulnerabilities of the families, we felt it was important that the initial approach should be made via people who were familiar and accountable, and in a way that left the initiative with the subject.

A number of leads fizzled out at this stage or had to be dropped. Some parents were found to have died and their children's whereabouts were unknown, or the children had left home and lost contact with their parents. Other grown-up children had emigrated or now lived in another part of the country. In a few cases the workers involved advised that family circumstances militated against the research (for example, because of a recent bereavement, illness, mental health problems, or a pending court case) or that the individual concerned was unable to communicate well enough to be interviewed. Some professionals refused to act as an intermediary or were instructed not to help us by their line managers. It is not possible to be sure how many potential subjects were lost in these ways, because the number of adult children in the family obviously could not be verified in every case, but at least fifteen families headed by a parent or parents with learning difficulties and known to have adult children slipped through the net before any attempt to contact them could be made.

Putting aside these setbacks, our principal line of approach was to establish contact through the good offices of an intermediary or third party already known to the person. In most cases this was a professional worker, although parents themselves or siblings were also used in this

role. The only occasions when a third party was not used were where the subject was already linked into the researchers' network.

Where the third party was a professional or practitioner they were usually sent a brief outline of the study explaining what it was about and what it would involve, together with some notes aimed at anticipating any questions the subject might ask. They were left to decide when, where and how best to broach the matter. Initially people were simply asked if they would agree to see the researcher to talk about the project. They were told that participation was entirely voluntary and they could pullout at any time. Once consent was obtained the intermediary would either fix up a meeting at a time and place of the subject's choosing or seek permission to pass on the person's name and address to the researcher for arrangements to be made direct. In many cases (12), the third party came along to make the introductions at the first meeting.

The use of intermediaries in this way has its disadvantages. The researcher has no direct control over how the study is first presented and explained; people's feelings towards the third party might act as an uncontrollable source of response bias; and, where a practitioner is involved as the go-between, the researcher may be too closely identified with authority or officialdom. In practice, there was no way round these dangers if the study was going to get done.

Our previous research led us to anticipate that some parents might feel threatened by our enquiries. Most were likely to have experienced long-term surveillance from the statutory services, persistent intervention in their private lives, and various forms of system abuse (Booth and Booth, 1995). These experiences can foster an understandable insecurity and defensiveness. We offered to meet any parents who were made anxious or suspicious by our work, or who just wanted to know more about what we were doing. Third party intermediaries were made aware of our readiness to follow up such concerns. In effect, we allowed the parents a veto over the research: we would not proceed with the interviews if they were opposed even though their son or daughter had agreed to see us. In the event, 16 parents from 11 families were briefed personally about the study of whom 2 exercised their right of veto, in both cases after the first interview.

The process of establishing contact maintained a distance between researcher and subject until the latter's consent had been obtained. The third parties who acted as go-betweens had no cause to put any pressure

on the people they approached and no obvious interest in trying hard to recruit them for the study. Equally the people themselves had no obvious incentive to take part in the study. On the contrary, there are many reasons why they might have preferred not to talk about childhoods that were likely to have been troubled. Both of these considerations pointed to the likelihood of a high refusal rate even when a possible subject had been tracked down. In fact, at least twelve people declined an invitation to participate in the study - around one in three of those approached.

Overall, our best estimate is that two people were located for every one who eventually agreed to be interviewed after allowing for the three main causes of attrition: people who turned out not to be eligible for inclusion in the study (primarily because they were too young or had spent too long away from their parents as a child); people who could not be contacted; and people who refused.

THE STUDY GROUP

Thirty people (16 men and 14 women) were finally recruited into the study. Their ages ranged from 18 to 42 years for the men and 16 to 37 years for the women with a median age for the group of 27 years: over half (57%) were between 20 and 30 years old.

The subjects divide evenly into people with and people without learning difficulties. The men and women are split equally between both groups. The number of people with learning difficulties exceeded what had been planned or expected. Indeed, one of the difficulties which prolonged the fieldwork was the necessity of ensuring adequate representation of unlabelled adults. Finding grown-up children with learning difficulties was relatively so much easier. This fact needs to be viewed in context. It is known that the genetic risk of parents with learning difficulties having a child with a clinically-diagnosable condition is no greater than for the general population (Tymchuk, 1990). Four specific factors, aside from heredity alone, seem to account for the problem. The first is an artefact of the study: adult children without learning difficulties were more likely to have moved away and less likely to be known by local service agencies or practitioners. Second, circumstantial evidence suggests that children are more likely to be removed from their parents if they do not have learning difficulties: partly because the risks to their welfare and development are seen as being that much greater and partly too because they more often present problems of control as they grow older. Consequently, fewer of them can be traced through their birth parents

and more had to be excluded from the study for not having spent the greater part of their childhood with them. Third, the children of parents with learning difficulties face a high risk of developmental delay. Poverty is a major threat to their welfare. It undermines their health, their physical and intellectual development, their educational attainment, the quality of their family relationships and their emotional security. The high proportion who grow into adults with some form of learning difficulties shows what happens in the absence of effective supports designed to compensate for these deficits. Finally, the children in whom we were interested were much more likely to be excluded from mainstream school, channelled into special education and labelled as having learning difficulties because of the stigma attached to their parents.

Twenty-eight of the thirty informants had just one parent with learning difficulties, usually the mother (25 cases). Although most (24) people's parents had been living together when they were born, only 9 partnerships had survived death, divorce or separation and were still intact at the start of the study. Twenty-three informants had a mother or father with learning difficulties who was still alive at the time of interview, of whom all but one remained in regular contact.

The study group included six pairs of siblings. Eighteen people came from families of three or more children; and 8 people had no brothers or sisters. Eleven subjects were either married or divorced - including three women with learning difficulties - of whom all but one had children of their own. The two mothers with learning difficulties both had had their children taken into care. There was one couple in which both the husband and wife were involved in the study in their own right. Twenty-two people were unemployed at the time of interview (including all those with learning difficulties); six of the eight men without learning difficulties were in paid work. There were just three owner-occupiers in the group: 22 people lived in council accommodation and the remainder rented privately. Thirteen people were still living with their parents of whom nine had learning difficulties. Six people with learning difficulties were living independently in their own homes, all with some paid support.

THE INTERVIEWS

Eighty-two interviews were completed with the 30 people who took part in the study. The interviews were based on the narrative method of 'life

review' in which people are invited to reflect on and appraise their past experience from their standpoint in the here-and-now (Birren and Deutchman, 1991; Magee, 1988). An *aide-memoire* was used to provide a framework for the interviews and a checklist for marking off material that had been covered, and for pinpointing topics for discussion and information needing to be collected at a subsequent session. A few direct questions were included which it was felt should be asked in the same manner of all informants. Otherwise the interviews were conducted as free-ranging conversations in which the interviewer's prompting and questioning, though disciplined by the *aide-memoire*, were driven by the storyline determined by the informant.

The interviews were not intended to produce factually accurate or verifiable accounts of lives; narratives whose details would stand up to cross-checking against independent evidence or other sources of information. A distinction must be made between the stories people tell and the lives they lead. The story does not simply 'display the life' (Plummer, 1990). People reconstruct their own past in the light of their present sense of who they are. Memories constitute one of the building blocks of identity and the meanings people give to their own past are intimately bound up with the image they choose to present to others. From this point of view, people's stories about their own childhood provide a way of conceptualising the link between their upbringing and who they have become in adult life. The methodological problems of trying to establish a causal connection between family processes and later outcomes for people brought up by parents with learning difficulties are probably insurmountable. The use of narrative methods opens up the possibility of establishing a bridge through people's subjective interpretation of their own lived experience.

The fieldwork was planned on the assumption that three interviews would be required with each informant in order to cover the ground mapped out by the *aide-memoire*. The form and content of each of these interviews differed

- *The first interview* was about making introductions, clarifying the purpose of the study, outlining what the interviews would be about and how the material would be used, answering any questions the person might have, assessing people's strengths and limitations as informants, finding out who's who in their family, and starting to build up a picture of their background and their life now. The aim was to leave as much as possible of the talking to the informant.

- *The second interview* placed more emphasis on the evaluative aspects of narrative (Kohli, 1981). As well as filling out the details of their life story, people were also encouraged to explore their feelings as a child (about, for example, their parents and grandparents, their schooldays, their family life, the problems they had gone through), to reflect on their experience of growing up, and to assess the significance of their upbringing in terms of their current situation. Information provided in the first interview often served as the cue for raising these topics.
- *The third interview* was used to go through the informant's story as recounted during the two previous sessions, make good any gaps (as pointed out by the interviewee or by reference to the *aide-memoire* material), and address the issues of representation (ensuring the story is true to the person) and ownership (ensuring the person shares the version of their life as reported). More direct questioning was often called for at this stage. Also, people were by now usually a lot easier about the set-up and more trusting of the interviewer so making it possible to raise some sensitive issues that had been passed over in earlier interviews.

A full set of interviews was completed with 23 of the 30 informants (four interviews were necessary in the case of one woman with learning difficulties). A third interview was not obtained with five people: three called a halt after two meetings ostensibly because of new work commitments or starting college courses; one failed to turn up for their last appointment; and another man with mental health problems was evasive about fixing up a third meeting. A single interview only was had with two people: in both cases it was the informant's parents who decided to withdraw on their behalf.

The interviews were carried out in small batches of 7-8 informants at a time so that the interviewer could keep up with each person's story as it unfolded and grew more detailed. Although part of the initial fieldwork plan, such a staggered approach was in any case made inevitable by the difficulties encountered in locating and contacting subjects. No more than three weeks were allowed to elapse between successive interviews in order to maintain people's interest and commitment, and usually the gap was closer to two weeks. Almost all (79) of the 82 interviews were tape-recorded with the informant's consent and later transcribed. The one person who refused to be recorded readily agreed to notes being taken. Two sisters asked to see the text of their story, and another man agreed to having his interviews recorded after being offered a copy of the tapes.

All informants were promised a summary of the findings once the study had been finished.

A number of ploys or devices in addition to direct questioning were used to unlock people's memories, gain access to their lives, elicit information and encourage them to talk.

Photographs

Asking to see people's family photos was an effective way of finding out about family members and family relationships, bringing back the past, triggering recollections, facilitating self-reflection, stimulating conversation, focusing discussion, and easing informants into their role. Photographs are useful to the interviewer in three ways. They help to take the spotlight off the informant (who is made to feel less self-conscious and more in control). They help to legitimise the asking of questions and the interviewer's curiosity. They also have a totemic significance by providing a visual representation of the nature of people's family ties: compare, for instance, the son whose sparse collection of family photos pictured no-one outside his immediate family unit, the woman who brought out five hefty albums full of snaps of family gatherings, group holidays, celebrations and set-piece wedding portraits, and the five people who had no photographs at all of their parents.

Writing Stories

Eleven people were asked to write a short story about an episode in their life of their own choosing, and seven of them delivered. The purpose was to see if people were prepared to reveal themselves through writing in ways they would not using the spoken word (Rowland, Rowland and Winter, 1990). The stories were not intended to present a complete picture or set of facts in themselves, but to open up the perspectives through which people made their own experience comprehensible and to identify topics which might become a focus for further enquiry. They also helped to verify or develop points raised in interview.

Shared Interviews

Ten interviews were conducted involving two sets of brothers and sisters, a pair of sisters and a married couple in which both informants were seen at the same time. These came about for reasons of design and necessity, including the wishes and convenience of the people themselves, the

impracticality of meeting them alone, and the promise of better rapport. Shared interviews brought a number of benefits. They helped to give some people the confidence to talk more freely; allowed them to spark off each other; encouraged disclosure through mutual prompting and cross-questioning; made possible verification of factual data; and provided a measure of emotional support when talking about sometimes painful events. They also helped to illuminate the effects of such variables as birth order, gender and personality on people's experiences and their resilience in the face of adversity (Booth and Booth, 1997a). Bertaux (1981:39) says that 'a good life story is one in which the interviewee takes over the control of the interview situation' (italics in original). Such an occurrence implies a measure of self-assurance and fluency rarely encountered among most informants, least of all those with learning difficulties. However, shared interviews did tend to empower informants by making them feel less vulnerable to the interviewer's attention.

Switching Off the Tape-Recorder

Putting aside the tape-recorder for a spell during an interview was often a useful gambit, especially in the case of more reserved informants. Doing so served a variety of purposes: to relax the informant; to check whether the recorder was having an inhibiting effect; to mark the shift to a new and perhaps sensitive topic; and to give both parties a breather. Switching off made it possible to see if the person felt any easier about talking, and helped to 'break the ice' on a new topic before recording was started again. Issues that might require careful handling could be approached in an 'off-the-record' fashion. Also, though rarely acknowledged in the literature, the practice of recording puts a lot of strain on the interviewer, who is constantly aware of being 'on air' and playing to an audience (including the transcriber and any research colleagues). This knowledge exerts a subliminal pressure to say the right thing, keep the conversation flowing, stick to the point, phrase the questions appropriately, attend to leads and generally deliver a good performance. Switching off may be done several times during an interview for any number of these reasons.

ISSUES FOR NARRATIVE RESEARCH

People organise their experience and their memory mainly in the form of narrative (Bruner, 1991). This study set out to make use of this human capacity for 'storying' experience in order to capture something of what it

means to be brought up by parents with learning difficulties. Stories invite the listener 'to imagine, and in imagining to experience, the worlds created in the words' (Scheppelle, 1989:2074). Connelly and Clandinin (1990), for instance, suggest that a good story is one that can be lived vicariously by others. Our aim was to harness the power of narrative in order to depict the lives of our subjects at the level of feeling as well as understanding. The success of this venture obviously depended on the responsiveness of our informants. A number of inhibiting factors limited some people's ability to talk freely.

Inarticulateness

Inarticulateness refers to an inability to communicate fluently in words that goes beyond mere shyness, anxiety or reserve. It originates with restricted language skills, but is generally overlaid by other factors such as lack of self-esteem, learned habits of compliance, loneliness and the experience of social exclusion. Although more commonly encountered among our informants with learning difficulties, it was not confined to them. Inarticulateness does not present an insuperable barrier to people telling their story (Booth and Booth, 1996a). However, it does have implications for the role of the interviewer (who must expect to work harder) and for the way stories are turned into text (where the hand of the editor will be more apparent). Sometimes there was simply not enough direct speech to render a person's story in their own words. But third-person accounts of lives usually lose the immediacy and authenticity of the subject's own voice. In order to ensure the important emotional dimension of narrative is not lost with inarticulate subjects, researchers must be prepared to experiment with methods of reporting that allow more scope for the play of what George Eliot called 'the veracious imagination', including the fictional form (Booth, 1995; Clough, 1996).

Temporality

Talking about experience, as Clandinin and Connelly (1994:417) point out, 'is to talk temporally'. Time is what holds a life story together and gives it both structure and meaning. The self as narrator, however, exists only in the present. Language is necessary in order to abstract the self into the past (or an anticipated future). It is only through language that the self has a sense of itself in the past. For people with restricted language skills, like some of those with learning difficulties in our study, the inability to objectify the self found its expression in a strong present

orientation and a concrete frame of reference that countermanded the tick-tock essentials of good storytelling.

The Reticence of Young People

Many of the younger adults in our study struggled to find a voice. Such reticence did not come about because they were unable to express themselves. They were just not sure they had anything worth saying. Lack of confidence in the validity of one's own experience is a characteristic of youth. People must first know what they know before they can begin to narrate their own stories. Informants who had less to say tended to be younger people (with or without learning difficulties) whose lives were still closely bound up with their parents or who, irrespective of age, had not yet fully negotiated the transition into adulthood. Dickerson and Zimmerman (1993) have conceived adolescence as a time when young people are living stories in which they are the protagonist rather than the narrator. Building on this insight, it may be that establishing an identity of one's own is a prerequisite for carrying off the role of narrator in the story of one's life.

Poor Recall

Some people seemed to have scant memories of their childhood. Why this should be is not immediately apparent although Bruner (1987) provides a possible clue. He suggests that story-telling provides recipes for structuring experience itself and for laying down routes into memory. The stories that constitute children and young people's lives are usually told for them by others. Autobiographical memories of childhood come from the sharing of such stories, primarily between parents and children. It is possible that parents with learning difficulties engage in less 'memory talk' of this kind with their children so limiting what their children know about their own past. The absence of family photographs may serve as one clue that such a store of remembering has not been laid down. People who lack fully storied lives may not be able to access their own experience through memory or know they have a story to tell.

Interview Cuckoos

The researcher was not always able to control who was present during an interview. Aside from the shared interviews, where two informants were seen together, twelve interviews involving ten people were conducted

with someone else in the room for all or part of the time. Usually this was a parent, spouse or partner, although cuckoos also included a friend and various practitioners. Family members were present for two of the interviews with two people; in all other cases supernumeraries were only there for one of the three sessions. The other person was always present on the express wish of the informant. Although better avoided if possible, having an informed other occasionally sit in on an interview was not always a bad thing, especially given the problems of reticence and poor recall mentioned above. Parents in particular were sometimes useful for triggering early memories or raising issues that could be explored later when the subject was next seen alone. The essential flexibility of the narrative method provides a check against possible bias from this source: the same material can always be revisited at a later date or a further interview added to make good one spoiled.

'Writing about the past', Steedman C 1990:245) says, 'must always be done out of a set of current preoccupations'. This study developed from our interest in the process of parenting by people with learning difficulties. We set out to investigate the link between family upbringing and family outcomes in families containing a parent or parents with learning difficulties through the experience of their adult children. The focus of the study was on their presently remembered past. A full account of the findings can be found in Booth and Booth C1997b; 1998).

The relevance of the study, however, extends beyond the immediate group of parents to which it refers. Looking at out-of-the-ordinary families throws new light on taken-for-granted assumptions about the process of parenting. Parents who break the rules help to define them more clearly. Observing children under pressure shows up the extent of their adaptability. Studying parenting on the margins of competence provides a new perspective on the limits of parental adequacy. From this point of view, the study highlights what is common to all parenting rather than what is different about parents with learning difficulties.

REFERENCES

- ACCARDO, P. and WHITMAN, B. (1990) 'Children of mentally retarded parents', *American Journal of Diseases of Children*, 144,69-70.
- BERTAUX, D. (1981) 'Introduction', in D. Bertaux, ed. *Biography and Society: The Life History Approach in the Social Sciences* London: Sage Publications pp.5-12.

- BIRREN, J. and DEUTCHMAN, D. (1991). *Guiding Autobiography Groups for Older Adults*. London: The John Hopkins University Press.
- BOOTH, T. (1995). 'Sounds of still voices: issues in the use of narrative methods with people who have learning difficulties', in L. Barton, ed., *Sociology and Disability*. London: Longman.
- BOOTH, T. and BOOTH, W. (1994). *Parenting Under Pressure: Mothers and Fathers with Learning Difficulties*. Buckingham: Open University Press.
- BOOTH, T. and BOOTH, W. (1995). 'Unto us a child is born: the trials and rewards of parenthood for people with learning difficulties'. *Australia and New Zealand Journal of Developmental Disabilities*. 20 (1): 25-39.
- BOOTH, T. and BOOTH, W. (1996a) 'Sounds of silence: narrative research with inarticulate subjects', *Disability and Society* 11 (1): 55-69.
- BOOTH, T. and BOOTH, W. (1996b) 'Parenting in context: policy, practice and the Pollocks', *Child and Family Social Work*. 1 (2): 93-96.
- BOOTH, T. and BOOTH, W. (1997a) 'Risk, resilience and competence: growing up with Parents who have learning difficulties', in R. Jenkins, ed. *Culture Classification and (In)competence*. Cambridge: Cambridge University Press.
- BOOTH, T. and BOOTH, W. (1997b) *Exceptional Childhoods. Unexceptional Children*, London: Family Policy Studies Centre.
- BOOTH, T. and BOOTH, W. (1998, forthcoming) *Growing Up with Parents who have Learning Difficulties*, London: Routledge.
- BRUNER, J. (1987) 'Life as narrative', *Social Research* 54 (1): 11-32.
- BRUNER, J. (1991) 'The narrative construction of reality', *Critical Inquiry*. 18(1), 1-21.
- CLANDININ, D. and CONNELLY, F. (1994) 'Personal experience methods', in N. Denzin, and Y. Lincoln, eds. *Handbook of Qualitative Research*. London: Sage Publications.
- CLOUGH, P. (1996), "Again Fathers and Sons": the mutual construction of 1 self, story and special educational needs', *Disability and Society*, 11 (1): 71-81.
- CONNELLY, F., and CLANDININ, D. (1990) 'Stories of experience and narrative inquiry', *Educational Researcher*, 19 (5): 2-14.
- DICKERSON, V. and ZIMMERMAN, J. (1993) 'A narrative approach to families with adolescents' in S. Friedman, ed. *The New Language of Change: Constructive Collaboration in Psychotherapy*. New York: Guilford Press, pp 226-50.
- FARMER, R., ROHDE, J. and SACKS, B. (1993) *Changing Services for People with Learning Disabilities*, London: Chapman and Hall.

- FOTHERINGHAM, J. (1980) 'Mentally Retarded Persons as Parents', Department of Psychiatry, Queen's University, Ontario, Canada (unpublished).
- KOHLI, M. (1981) 'Biography: account, text and method', in D. Bertaux, ed., *Biography and Society: The Life History Approach in the Social Sciences*, pp.61-75. London: Sage Publications.
- MAGEE, J. J. (1988) *A Professional's Guide to Older Adults' Life Review*. Lexington, USA: Lexington Books.
- MERCER, J. (1973) *Labeling the Mentally Retarded: Clinical and Social System Perspectives on Mental Retardation*. London: University of California Press.
- MICKELSON, P. (1949) 'Can mentally deficient parents be helped to give their children better care?', *American Journal of Mental Deficiency*, 53: 516-534.
- OLIVER, J. (1977) 'Some studies of families in which children suffer maltreatment', in A. Franklin, ed. *Challenge of Child Abuse*. London: Academic Press.
- PLUMMER, K. (1990) 'Herbert Blumer and the life history tradition', *Symbolic Interaction*, 13 (2):125-44.
- ROWLAND, G., ROWLAND, S. and WINTER, R. (1990) 'Writing fiction as inquiry into professional practice', *Journal of Curriculum Studies*. 22 (3): 291-293.
- SCALLY, B. (1973) 'Marriage and mental handicap: some observations in Northern Ireland', in F. de La Cruz and G. LaVeck, eds. *Human Sexuality and the Mentally Retarded*. New York: Brunner/Mazel.
- SCHEPPELE, K. (1989) 'Foreword: telling stories', *Michigan Law Review*, 87: 2073-98.
- SCHILLING, R. F., SCHINKE, S. P., BLYTHE, B. J. and BARTH, R. P. (1982) 'Child maltreatment and mentally retarded parents: is there a relationship?', *Mental Retardation*, 20 (5): 201-209.
- SCHOFIELD, G. (1996) 'Parental competence and the welfare of the child: issues for those who work with parents with learning difficulties and their children. A response to Booth and Booth', *Child and Family Social Work*, 1: 87-92.
- STEEDMAN, C. (1990). *Childhood. Culture and Class in Britain*. London: Virago.
- TYMCHUK, A. (1990) 'Parents with mental retardation: a national strategy', *Journal of Disability Policy Studies*, 1(4): 44-56.
- WHITMAN, B. and ACCARDO, P., eds. (1990) *When a Parent is Mentally Retarded*. Baltimore: Paul H. Brookes.