

The need for family support networks

Summary

This study focuses on support networks used by the families of children with learning disabilities. In order to find out how families use formal and informal networks, parents/primary care receivers were asked to take part in the research. They completed a questionnaire and a number of them participated in in-depth interviews. The study revealed that parents were most satisfied with educational services. Most of them would also appreciate more informal contacts. It is suggested that professionals should aim to help families of children with learning disabilities widen their formal and informal support networks.

Introduction

The main concern of this study is to focus on what kind of support is currently used by families where there is a child with a learning disability. Support networks may be *informal*, such as those provided by family members and friends, or *formal services* organised by health, education and social services. We are interested in how families use support, what they think of it and what sort of help they consider is lacking for children and carers.

The information was obtained entirely from the carers, parents in all but two cases, of school-aged children (see below for details of the research design and methods). Our objective in focusing on family perceptions is to contrast the formal structures which are in place to provide support with the reality of that support. We also wish to find out who, from the parents'/carers' point of view, are the key professionals involved as well as finding out how much help is received informally from relatives, friends and neighbours. This approach fits with recommendations in the White Paper *Care in the Community* (Department of Health, 1989) which indicates that carers need support, therefore statutory services should be involved in 'providing advice and support and ... practical services such as day, domiciliary and respite care' (para. 2.3), although it also emphasises that 'working together' requires people to take responsibility for their own needs wherever possible (para.2.21). Further, the Children Act 1989 identifies a child as 'in need' if 'he is disabled' (Section 17 (10) (c)) and provides a basis for

working with families who care for children with learning disabilities; yet, while policy and legislative frameworks provide a basis for practice, the grassroots experience of parents and other close family members of children with disabilities is less well understood (National Children's Home, Action for Children, 1994).

It is not only important for professionals to work together in partnership with parents of children in need (Department of Health, 1991) but for researchers to do so in their efforts to gain information which, hopefully, may be subsequently used to help shape family policy and practice. Parents of children with disabilities feel keenly their lack of power and difficulty in getting heard, as we shall show.

There was no intention of getting the views of the children in the study other than incidentally during home interviews where sometimes they were present. Seeking the views of children with disabilities on services received is fraught with difficulties, as Minkes et al. (1994) report in their findings of an attempt to consult children, most of whom had learning difficulties and some of whom had no speech, through getting school staff to interview them about their experience of using one specific service: respite care. The authors conclude that such findings have to be treated with caution.

In sum, then, our view is that, while the child's well-being must be of paramount importance, their care and development carefully attended and all efforts made to understand their wishes, their main carers, usually parents, are the people best placed to give feedback on how families use support networks and on the experience of caring in general.

Seeking the opinions of adults with learning difficulties can be a different matter. Hubert, in her ethnographical study of twenty families where there was a young adult with a severe learning disability, was also concerned 'specifically with the parents' view' (Hubert, 1991, p.14). Earlier, she says 'It is the parents of these young adults, especially the mothers, who understand them best' (p.9). This is not to say that ways of accessing the views of people with learning difficulties should not be sought. This is happening, for example, through the creative involvement of service users in their Independent Personal Profiles, organised by Social Services Departments following the National Health Service and Community Care Act 1990. However, this process often does not go far enough, according to *Advocacy in Action* (1993).

Parents, especially mothers, as the main carers of most children with a disability (see, for example, Ayer & Alaszewski, 1984; Glendinning, 1986; Smith & Brown, 1989; Manthorpe, 1994) are also the users, or potential users, of services and need support of varying kinds in order to carry out their difficult and often stressful task. The well-being of children is closely tied to the well-being of the adults who care for them and, as one father told us, 'parents are experts on their own children'. We agree; and so it is the voices of the parents as family advocates heard in this report, as they talk about their own experiences and the needs of their children.

Terminology

Throughout this report we shall use the term 'learning disability' or, occasionally if the context seems to warrant it, 'learning difficulty'. 'Disability' reflects more accurately the situation of the children in this study, since they have all been identified as being in need of special educa-

tional provision as well as other services such as speech therapy or physiotherapy. It is interesting that many parents still use the term 'mental handicap'; this, as well as 'mental retardation', continues to be North American usage, while the adults of Advocacy in Action (1993) clearly prefer 'learning difficulty'. We concur with Herbert, who provides a useful discussion of definitions, that the terms 'learning disability/difficulty' are less stigmatising than 'mental handicap' (Herbert, 1993, p.86).

Method

Research design

In order to find out how families use formal and informal networks and what they think of them, it was decided to use, first, a self-completion questionnaire for parents/carers using schools as gatekeepers and, second, to follow this up by interviewing roughly one third of respondents in order to obtain more in-depth information about family situations.

To test the questions and format of the questionnaire, a pilot survey took place in January, 1994 (see Burke and Cigno, 1994 for further details of the pilot). Appropriate changes to the questionnaire were made in the light of the response and the final version went out early during the school summer term. The schools, all in one geographical area, were:

1. Ferndale, a special school for children with learning disabilities of primary and secondary school age, in a rural setting, with hostel facilities;
 2. a 'located unit' in Middlefield Infants mainstream school;
 3. a 'located unit' in Middlefield Junior mainstream school.
- (2) and (3) were adjacent to each other but administratively separate, each with its own head-teacher.

The respondents

Most research in this area makes the assumption that mothers are the carers and targets them as informants (eg Ayer and Alaszewski, 1984; Humphreys et al., 1985; Authier, 1987; MacLachlan et al., 1989; Henton, 1989). Recently there has been a move to redress the balance by focusing on fathers as carers (eg Hornby, 1992; Arber and Gilbert, 1993; Herbert and Carpenter, 1994). We were careful, therefore, to make our initial letter of invitation to carers to participate in the study non gender or role-specific, allowing both or either parent to respond. In fact, all but two of the children in the population were living with one or both of their natural parents; and the majority of questionnaires was completed by mothers alone.

The questionnaire

Efforts were made to keep the questionnaire as short and 'user-friendly' as possible so as not to impinge too heavily on parents' time. Parents of children with disabilities often feel that they are asked many questions and are givers, rather than receivers, of information (Glendinning, 1986). We also discovered that, at the time we were delivering our questionnaires to the

schools after much preparation, planning and discussion with headteachers and others, the local authority Social Services Department had, without warning, sent questionnaires to the schools for distribution to parents. We were naturally concerned about this, thinking that these demands could overwhelm parents as well as adversely affect the response to our research. (In the event, we obtained a 70% response rate, perfectly acceptable in research terms.)

The schedules were sent to parents/carers through the home-school book which accompanies each child to and from school and through which information and queries are passed from teacher to parent and *vice versa*. The questions focused on the advice parents sought or were offered from professional and lay networks of care in order to evaluate the need for support and services for families. We also asked for some brief background information about the child's household.

We made it clear that, while the replies would be confidential, respondents need not give their name and contact number or address if they preferred not to do so. Finally, we asked if they would like a copy of the report; and if they would agree to be interviewed: in either case, this, of course, necessitated the giving of name and address.

The interviews

The schedules were numbered as they arrived. Families were selected for interview by taking every third schedule where the respondent had indicated an agreement to be contacted for this purpose. The purpose of the interview was:

1. to explore further the answers given in the questionnaire;
2. to build up a picture of family life of the families involved.

The schedules were to be used as guidelines. Any gaps or uncertainties in answers would be explored, and the interviewees would be encouraged to make any comment they wished on any aspect of help received or not received and indeed to draw our attention to any other matter concerning their child's disability. The researchers, who conducted all interviews themselves in about equal measure, decided to make notes during the interviews, writing down the parents' actual words where possible, and word process the notes as soon as possible afterwards. Twenty interviews were carried out through home visits and a further two by telephone.

We also, unlike Herbert and Carpenter (1994), found it an advantage not to be professionally involved in service delivery but attached to an academic institution and sponsored by an independent research body. Indeed, our assumption, based on experience on previous research with service users (Cigno, 1987, 1988), that parents would talk more freely to independent researchers proved to be well-founded.

One of us also thought that being a parent himself of children with learning disabilities would help him establish immediate rapport. This proved to be the case, although the planned telephone contact to arrange a suitable time, evenings if necessary, for interview was calculated to reassure parents of the nature and confidentiality of the interview, the interest of both

researchers in their views and the importance and 'respectability' of the research. This in fact worked for both researchers.

Quantitative and statistical analysis

With such a small population, statistical testing has a limited use and should be applied cautiously alongside other supporting evidence. Grant, in a paper on researching user and carer involvement in learning disability services, advocates both quantitative and qualitative methods of research (Grant, 1992). Bearing this in mind, we have used the following methods to elicit data which we then use as the basis for further examination and discussion in the light of the respondents' expanded comments and in-depth interviews:

1. simple frequency counts of responses;
2. cross-tabulations of key variables;
3. significance tests (interpreted with caution);
4. chi-square test.

The analysis is reported in full in Burke and Cigno (1996); here we concern ourselves mainly with 1. simple frequency counts.

Response to the questionnaire

The numbers of fully completed questionnaires returned were as follows:

Located units in mainstream schools

Middlefield Infants	11 out of 12 (92%)
Middlefield Juniors	7 out of 14 (50%)

Special School

Ferndale	48 out of 70 (69%)
----------	--------------------

Overall, therefore, the response was 66 out of a population of 96 - 69% or about two thirds of the total sample population of school children and their carers.

We do not know why only half of the Junior school (located unit) parents responded. We are aware that some parents do themselves have learning difficulties and, although the teachers concerned in this study were careful to offer help in completing the schedules in an unobtrusive way, it could be that some parents did not feel able to take up this offer. Given the wariness of such parents towards anyone in authority (Booth and Booth, 1994), a reluctance not to take part in the survey or to feel overwhelmed and humiliated by the written word is not so surprising.

It should also be noted that, if the child was absent from school during the period when the questionnaires were given out, the child's family would not have received the letter of invitation and accompanying schedule.

Results

The families

As mentioned earlier, all but two of the children were being brought up by their parent or parents. 64 families were bringing up between them 158 children, with the number of children per household varying between one and six. Within this variation, the majority of families had two children; several families had only the one child. The ages of the children including siblings of the subject children varied between eight months and 17 years.

The parents

Most parents were aged between 35 and 44. In all cases but one, where the mother was widowed, the lone mothers were either separated or divorced. Older parents, aged 45+, were always conscious of their age, drawing our attentions to the fact that some of their concerns were different from 'most parents'.

'We are older parents-what happens to C when we're no longer here? We are into funerals and illness, caring for elderly relatives - therefore different from other parents' (Telephone interview with mother in her 50s with 12-year-old Down's child).

'As an older mother, I'll have to think of the future - teach her independence, get in touch with Cam-phil...' (Interview with 45+ single mother of 8-year-old developmentally delayed child).

Over half the mothers were full-time mothers and housewives. 22 mothers said they were employed, seven specifying part-time. We do not know what proportion of the rest were in full-time paid occupations. Most were employed in female-dominated work such as care assistant, cleaner, teacher's aide and market researcher. Only two were clearly distinguished as being in higher paid, higher status work as a lecturer and Social Services manger. Interestingly, some mothers wished to tell us what their employment used to be, often as counterbalance to their statement 'I'm just a housewife' or 'I'm a full-time mum'. Baldwin (1985) found that these mothers are less likely to go out to work than mothers of children without disabilities and, if they do work, earn less. Research has shown that some effects, particularly for mothers, of looking after a child with disabilities are the loss of confidence, self esteem and, to a greater or lesser degree, social networks (Ayer and Alaszweski, 1984; Henton, 1989; Smith & Brown, 1989).

Fathers' occupations covered a wide social spectrum and included bank employee, manager, farmer, army personnel, HGV driver, engineer, doctor, labourer and storeman. The effects of having a child with disabilities on fathers' occupation did not emerge as clearly from the responses as it did for women carers, although two mothers during interviews volunteered the information that their husbands coped by immersing themselves in their work and by working part of the time away from home. In her study, Baldwin (1985) considered the effects of a child with a disability on men's work. She reports that this situation affects men's earnings, the kind of work they do and chances of promotion.

Fifteen were single-parent households: in all cases, the lone parent was the mother. The large majority of children therefore were living in two-parent households. Although the questions were not aimed specifically at mothers, they were completed in two-thirds of the cases by the mother alone. The mother was also identified in all cases as the main carer, reinforcing the findings of many studies over the years that, although men participate in some caring tasks and are at times the main carer, especially when the dependent person is a spouse (Arber and Gilbert, 1993; Manthorpe, 1994; McLaughlin and Ritchie, 1994), women continue to do most of the caring of dependent relatives (Equal Opportunities Commission, 1980; Cooke and Lawton, 1984; Glendinning, 1986; Smith and Brown, 1989; McIntosh, 1992, and Grant, 1992).

Only two carers who responded were not parents. One was a nurse in Ferndale's hostel and the other a foster carer. Neither wished to be interviewed.

The Children with a learning disability

Age

Ages were distributed throughout the school - age years between 4-17. As we would expect from our sample, about two-thirds were aged between 4 and nearly 11 (roughly primary school age) with the rest aged between 11-17. The median age was 10. Only 4 young people were school-leaving age (16+).

Sex

There were nearly twice as many boys as girls in the study (42:24). The greater pre- and post-natal vulnerability of males to certain diseases and conditions and the tendency to lag developmentally behind girls right through to adolescence is well-known (Hutt, 1972). Other studies based on population located in one particular geographical area also report a preponderance of males to females with learning disabilities (see, for example, Gun & Berry, 1990; Emerson, 1990; Richardson, Kaller & Katz, 1990). Whether boys are also more likely to be labelled as having learning difficulties due to perceived 'problem behaviour' is another matter which has also been the focus of research (Stone, 1993; Andrulonis, 1991).

The child's disabilities

The diagnoses of the children's learning disability were many and varied, ranging from the specific, such as Down's syndrome, cerebral palsy, microcephalic to the vaguer 'severe developmental delay'. In some cases, the reason for the delayed development was unknown. The disability often could be related to a factor or event which had caused brain damage, such as whooping-cough vaccine, 'drug-related' damage, caesarean or 'difficult' delivery, neonatal hepatitis, high blood pressure and other factors affecting mother's health at the time of the child's birth.

The importance of a diagnosis, however painful, to parents emerged through the interviews. Once the diagnosis had been made, the parents wished for as much information as possible about it. As one parent said:

'I'd never heard of it, but you go to the library, you find out. You become an expert on you own child'
(Father of 8-year-old boy).

All the children had other disabilities to a greater or lesser degree. These were mainly in four areas: speech, sight, hearing and mobility. Mobility problems were by far the most common. A few children were wheelchair users, while many parents reported that their child was a 'poor walker', often requiring special footwear or operations on the feet, legs or hips.

An example of a child with several disabilities is Terry, a seven-year-old Down's child who was born with webbed fingers. He needs antibiotics for his 'chestiness', wears a hearing aid and has weak ankles.

Parents identified problems associated with the difficulties. Incontinence featured widely. Several children had sleep problems, were unable to dress and wash themselves and had no sense of danger. This meant that they might be over-friendly with visitors or strangers as well as not being safe on the roads. One parent reported that her child 'did not notice pain'.

Support and Advice

Main source of support

Respondents named their spouse, the family (especially maternal grand-parents) and the school/teachers in almost equal proportions. The importance of in-house, almost always spouse support was underlined during interviews when parents would say 'we support each other'. The absence of this kind of support for lone mothers and their children contrasted quite sharply. One mother living on a new estate in a small town said:

'My husband left during Anne's first year at school, partly because he couldn't accept her condition (developmental delay and other physical disabilities). He buried his head in the sand and I got little support. Anne was affected by his absence and Colin (Anne's younger brother) had to have counselling'.

The school was mentioned as the main source of support even when distance precluded regular parent-teacher face-to-face contact. It was seen as a good environment for the child and, as another lone parent put it during an interview:

'I can just 'phone and speak to the Head or a teacher. About once a month I can go in the (school transport) minibus. I help in the classroom'.

A few parents indicated that they had no main source of support. These families, whether one or two parent, tended to see themselves as embattled units fighting for justice and resources for their child, although many other families also made the point that they had to 'fight for' resources. Another reason for perceived isolation was geography. One mother of Down's child, now 15, when asked during interview why she had not named a main source of support said:

'There isn't anyone. I used to live in the country and got no help. After a battle, I got the speech therapist and the psychologist to the house. My husband worked away, so it was all left to me'.

Five families named a respite care or hostel facility as their main source of support and, during interviews, expressed a great deal of satisfaction with this resource. The same number of respondents considered a friend to be their main support. One respondent only named the Social Services Community Learning Difficulty Team.

The Services used by Families

The health services were clearly those most known to the families in the survey and used at some time in their child's life. The large majority had used their GP, the paediatrician, the hospital and the speech therapist at the same time as to get help or information for their child. Nearly two-thirds had used their Health Visitor, and half the physiotherapist, for the same purposes. Over a third had used respite care, which was sometimes located in the service, sometimes in education and more occasionally provided by social services.

The other services most known and used by families were the educational psychologist (over two-thirds), social services and nursery school (about half) and Portage Service (over one third). The Family Fund had been used by half the families.

It is perhaps surprising that relatively few families (about one-sixth) turned to voluntary organisations. When they did so, however, they found them useful. Even more surprising was that most parents indicated that they had never used the Education Welfare Service: only six in all had used the Service at any time. The reasons for this were followed up during interviews. The most typical reply was 'never heard of them'. This must be of concern, because the Children Act 1989 consider education services to be an important link in working in partnership for children in need. Sections 4.1 - 4.6 of the Department of Health's document 'Working Together' focus specifically on education services:

Education Welfare Officers and Educational Psychologists also have important roles because of their concern for the welfare and development of children' (Department of Health, 1991, Sec. 4.1).

Long before the Children Act 1989 the Education Welfare Service generally could and did act as a liaison service between home and school, especially where there were children with disabilities requiring special educational provision, often supporting and counselling families through home visits. While educational psychologists from the results of this survey are seen by many parents as a source of help and information, the education welfare service appears to be known to only a handful of families.

Apart from asking if named services were known to, and had been used by families, respondents were also asked to say whether these services had been found to be helpful or not. About three-quarters of those using the various parts of the health service mentioned above found them helpful, with the exception of speech therapy and physiotherapy where the satisfaction of user families was even greater. Speech therapy in particular was mentioned with enthusiasm - and lamented for its scarcity - at other points in the survey as well as in the interviews; possible reasons for this will be discussed below.

Almost all parents used nursery school, Family Fund, Portage and respite care found them helpful. In the case of the Family Fund, this was presumably because their requests for material help were largely successful. During interviews, financial help with holidays and the provision of washing machines were mentioned as making a difference to family well-being. It is therefore a concern that not all parents know of the existence of the Family Fund, a point which emerged during interviews.

The education psychology service was found to be useful by about two-thirds of users; and social services by little more than half. It emerged in later comments and in interviews that parents needed to feel strongly either way about the services, as indeed they did about GP and paediatric services.

Frequency of Advice and Information from Informal and Formal Contacts

We attempted to distinguish between the amount of *contact* families might have with professionals, relatives, friends and neighbours and the amount of *support* they thought they relieved from them. We were not wholly successful in making this distinction, as some parents considered having contact was the same as receiving support, although the majority did make a distinction. For instance, only seven parents thought they received information or advice from the child's escort worker but three times this number acknowledged regular contact with this person. In a similar way, 21 respondents reported weekly contact with friends but less than half that number indicated friends as a source of advice.

Overall, according to the survey indications, families had the most contact and received the most support in the form of advice and information from teachers, with relatives a poor second; half had weekly or more frequent contact with teachers while less than a third said they had this frequency of contact from relatives.

If we consider support from informal networks (relatives, neighbours and other parents) then our findings would seem to differ from those of Glendinning (1986), who looked at where mothers of children with disabilities turn for support. She notes that they are more likely to turn to informal sources rather than professionals for someone to talk to. Only a minority of families in our survey had even once a month contact with informal networks, therefore the lack of availability of these contact must mean that they would have to look elsewhere for support. As we mentioned earlier, the existence for in-house support for most carers assumes great importance.

Cooke and Lanton (1984) found that families could draw on help from friends, relative and neighbours in times of crisis but that one-third of families received no help at all from informal sources. Our results can be summed up as follows:

Frequency of advice or information		
From	At least monthly	None
Friends	19	15
Neighbours	12	13
Relatives	21	13
Other parents	18	19

Some reasons for the low amount of support from informal networks are contained in the following comments obtained during interviews:

Other parents

'Because of the distance (from school) I feel out on a limb with other parents. I don't know them' (Mrs Smith, single parent of 8 year old Anne).

'I see other parents only at school or occasionally at shopping' (Mrs Metcalfe, single parent of Alan, aged 4).

Relatives

'Only distant cousins - I don't see them. I telephone my father but were not close' (Mrs Bell, widow, mother of Penny, aged 15).

'I see my mother but she's not a support for Alan' (Mrs Metcalfe).

Friends

'I have friends but I don't use them for help or advice'. (Mrs Shaw, mother of Katy, aged 8)

I often don't accept invitations to friends' homes because of Helen's behaviour - she picks things up, breaks ornaments'. (Mrs Thompson, mother of 9 year old Helen)

Neighbours

'They're mostly elderly. They complain about the dog, or they don't back me' (Mrs Richardson, single mother of John, nearly 16).

'The neighbours are at work and busy with their own families' (Mrs Price, mother of Sam, aged 10).

This contrast with the large number of families (45) receiving least monthly support from teachers. Only three parents reported no contact (and therefore no support) from teachers.

The professionals indicated as giving this kind of support least frequently are social workers, psychologists and health visitors. The latter appeared to stop visiting families once the child reached school age, although personal communication from health visitors informs us that particularly where there is a child with disabilities, health visitors can continue to visit. Social workers might be expected to give, or organise, psychological support but this appeared to happen only for a small minority of families (5), whereas 33 parents stated that they had no contact at all with social workers. The picture with regard to psychologists appeared to be that they were active in supporting families around the time of educational assessment, but then, on the whole, discontinued contact.

Conclusion and discussion

Tunali and Power (1993), in their study of stress and coping in families of children with disabilities (they use autism as an example) consider that there is a possible correlation between the use of formal and informal networks and family adjustment. They argue that the organised services should encourage goal activity such as information-seeking and the utilisation of professional services because this helps families cope. Since families such as those who took part in our survey may be rejected by outsiders and therefore fall back on the support of their own immediate family, particularly spouse support, it is vitally important that concerned professionals help them to widen their formal and informal support network.

Parents were most satisfied with, although not uncritical of, educational services. Most parents would also appreciate more informal contacts, including contact with other parents of children with learning disabilities. Although we encountered a minority view that parents should help themselves, the more common view was that professionals in authority did have a role in facilitating some forms of informal social networks by, for example, encouraging more parents' meetings, making transport available and providing leisure pursuits for their children during the holidays. We return to the importance of the 'named person', from the social services or health department, whose role might include coordinating the formal support services and facilitating informal networks. The under-involvement by our families in voluntary organisations would also support the suggestion that these could have a more active role in bringing together families where children are 'in need'.

An interesting finding which deserves further comment relates to the benefit families reported from being involved as interviewees in this research. The comment such as 'this is the first time I've really told anyone about our experience' (a mother of a boy with challenging behaviour) demonstrates the need for someone to listen to the tale of the carer; and all those interviewed had a story to tell. This clearly points to the need for a counselling service or a similar role performed by a social worker, where the expectation is not to provide a quantifiable service but rather to listen. The therapeutic value of listening should not be underestimated when mere expression of a situation clarifies within the individual the nature of feelings and difficulties that might never have been expressed.

References

- Advocacy in Action (1993). Review of P. Williams & B. Shoultz (1982, 1991). *We can speak for ourselves: Self-advocacy by mentally handicapped people*. Nottingham: Souvenir Press.
- Arber, S. & Gilbert, N. (1993). Men: the forgotten carers. In J. Bornat, C. Pereira, D. Pilgrim & F. Williams (Eds.). *Community care: a reader*. Basingstoke and London: Macmillan/Open University Press.
- Authier, K.J. (1987). The community basis for protecting handicapped children. In J. Garbarino, P.E. Brookhauser & K.J. Authier (Eds.). *Special children, special risks. The maltreatment of children with disabilities*. New York: Aldine de Gruyter.

- Ayer, S. & Alaszewski, A. (1984). *Community care and the mentally handicapped: services for mothers and their mentally handicapped children*. London: Croom Helm.
- Baldwin, S. (1985). *The costs of caring: families with disabled children*. London: RKP.
- Booth, T. & Booth, W. (1994). *Parenting under pressure: mothers and fathers with learning difficulties*. London: Open University Press.
- Burke, P. & Cigno, K. (1995). A pilot study on children with learning disabilities and the need for family support. *Journal of Health and Social Care in the Community*, 3, 130-132.
- Burke, P. & Cigno, K. (1996). *Support for Families*. Aldershot: Avebury.
- Cigno, K. (1987). *Clacton Family Project: a study*. London: Save the Children.
- Cigno, K. (1988). Consumer Views of a Family Centre Drop-in. *British Journal of Social Work*, 18, 361-375.
- Cooke, K. & Lawton, D. (1984). Informal Support for the Carers of Disabled Children. *Child Care, Health and Development* 10, 67-69.
- Department of Health (1989). *Caring for people: Community care in the next decade and beyond*. London: HMSO.
- Department of Health (1991). *The Children Act 1989: Guidance and Regulations. Volume 6: Children with Disabilities: a New Framework for the Care and Upbringing of Children*. London: HMSO.
- Emerson, E. (1990). Designing individualised community-based placements as an alternative to institutions for people with a severe mental handicap and severe problem behaviour. In W.I. Fraser (Ed.) *op.cit.*
- Equal Opportunities Commission (1980). *The experience of caring for elderly and handicapped dependents: survey report*. Manchester: EOC, March.
- Glendinning, C. (1986). *A single door: social work with the families of disabled children*. London: Allen and Unwin.
- Grant, G. (1992). Researching user and carer involvement in mental handicap services. In M. Barnes & G. Wistow (Eds.). *Researching user involvement*. Leeds: University of Leeds.
- Gunn, P. & Berry, P. (1990). Financial costs for home-reared children with Down Syndrome: an Australian perspective. In W.I. Fraser (Ed.), *op.cit.*
- Henton, P. (1993). Caring. In A. Brechin & J. Walmsley (Eds.) *op. cit.*
- Herbert, E. & Carpenter, B. (1994). Fathers - the secondary partners: professional perceptions and fathers' reflections. *Children and Society* 8, 31-41.
- Herbert, M. (1993). *Working with children and the Children Act*. Leicester: British Psychological Society.
- Hoinville, G. & Jowell, R. (1978). *Survey Research Practice*. London: Heinemann.
- Hornby, G. (1992). A Review of fathers' accounts of their experiences of parenting children with disabilities. *Disability, Handicap and Society*, 7, 363-374.
- Hubert, J. (1991). *Homebound: Crisis in the care of young people with severe learning difficulties: a story of 20 families*. London: Kings Fund Centre.
- Humphreys, S., Lowe, K. & Blunden, R. (1985). Parents' views on mental handicap services: results of a consumer questionnaire. *Mental Handicap*, 13, 95-97.
- Hutt, C. (1972). *Males and Females*. Penguin: Harmondsworth.

- MacLachlan, M., Dennis P., Lang, H., Charnock, S. & Osman, J. (1989). Do professionals understand? Mothers' views of families service needs. In A. Brechin & J. Walmsley (Eds.). London: Open University *op. cit.*
- McGrath M. & Grant G. (1993). The life cycle and support network of families with a person with a learning difficulty. *Disability, Handicap and Society* 8, 25-41.
- McIntosh, A. (1992). *Caring at home for children and young adults with a mental handicap: The impact of service development in North Humberside*. University of Hull: Unpublished MPhil thesis.
- McLaughlin, E. & Ritchie, J. (1994). Legacies of caring: The experiences and circumstances of ex-carers. *Health and Social Care* 2, 241-253.
- Manthorpe, J. (1994). Services to families. In N. Malin (Ed.). *Services for people with learning disabilities*. London: Routledge.
- Minkes, J., Robinson, C. & Weston, C. (1994). Consulting the children: interviews with children using residential respite care services. *Disability and Society* 9, 45-57.
- National Children's Home (1994). *Unequal opportunities: children with disabilities and their families speak out*. London: NCH Action for Children.
- Richardson, S.A., Koller, H. & Katz, M. (1990). Job histories in open employment of a population of young adults with mental retardation. In W.I. Fraser (Ed.) *op.cit.*
- Smith, H. & Brown, H. (1989). Whose community, whose care? In A. Brechin & J. Walmsley (Eds.). *op. cit.*
- Stone, B.J. (1993). Bias in learning disabilities placement. *Psychological Reports*, 72, 1243-47.
- Tunali, B. & Power, T.G. (1993). Creating satisfaction: A psychological perspective on stress and coping in families of handicapped children. *Journal of Child Psychology*, 36, 945-958.