

Chapter 5: Children and Young People with a Learning Disability and their Families.

Overview

In many instances a child with severe learning disabilities will be identified at birth or soon after and nearly all are diagnosed by school entry age. The main policy shift has been a complete move away from any form of institutional provision for these children. Nearly all children now grow up in families, either with their natural families or in a small number of instances, with foster or adoptive families.

There are however a very small number of older children and adolescents who need alternative provision away from the family and at present their needs are not well met in Northern Ireland.

The importance of early intervention to promote the child's development is well attested internationally although its implementation is far from universal.

Moreover in recent years the focus has shifted from a focus solely on the child to that of providing supports to the family. However this too has yet to find expression in many of the services currently provided.

A major unresolved issue is the coordination of professional inputs and services to these children and families. Greater involvement of parents in service planning and delivery is also required alongside greater opportunities for young people's views to be heard and acted upon.

This chapter is in three main sections.

Section 1 is recent review of Northern Irish research and policy undertaken by Berni Kelly and Marina Monteith on behalf of the National Children's Bureau and published in 2003. This is reproduced in this report with permission of the Bureau and any quotations from this should acknowledge the authors and publishers.

Section 2 is an Appendix to the Kelly and Monteith review with more details given of additional or pertinent recent research findings in learning disabilities and autistic spectrum disorders within Northern Ireland.

Section 3 is a synopsis of international research that highlights the implication for service developments and practice.

Section 1: Supporting disabled children and their families in Northern Ireland: A research and policy review

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Summary

- The prevailing focus on protective rather than preventive services has limited the development of support services for disabled children and their families.
- Research suggests that parents experience poorly coordinated systems and inadequate services especially at particular stages, such as diagnosis or post-school transitions.
- Respite care services hold potential benefits for disabled children and their families but need to be more flexible, comprehensive, family based and focused on the needs and wishes of disabled children.
- There is a need to develop more integrated recreational, social and leisure opportunities for disabled children to help combat their social exclusion.
- The provision of accessible and inclusive education for disabled children needs to expand alongside initiatives to address bullying on the grounds of disability discrimination in schools and the local community.
- The development of more flexible work patterns and community or school based child care services would be useful for working parents of disabled children.
- Parents should have greater access to professional advice on eligibility for social security benefits or grants for home adaptations, and assistance with application processes.
- Service providers need to more actively involve parents and children in the planning process and listen to their views, especially for children who do not use conventional methods of communication.
- New developments, such as the appointment of a Children's Commissioner and the current review of community and hospital services, should improve support service provision for disabled children and their families in Northern Ireland.

Introduction

Over the past decade there have been major policy reforms regarding service provision for disabled children and their families in Northern Ireland. This legislative progression promised the development of more effective support services for these children and increased recognition of their rights and needs. While there have been some positive service developments, researchers have reported fragmented implementation of these policies and identified outstanding support needs of disabled children and their families in Northern Ireland. These include the need for more flexible short breaks, service coordination, consultation, adequate housing, appropriate postschool transitions and social inclusion. Recent research has provided indications of how support services can be further developed to meet the needs of disabled children and their families. In addition, it is hoped that new developments, such as the appointment of a Children's Commissioner and the current review of community and hospital services, will improve support services for disabled children and their families in Northern Ireland.

Policy and disabled children in Northern Ireland

The Policy Planning and Research Unit (PPRU) surveys of disability in Northern Ireland (1990) remain the main source of detailed statistical information on disabled children in Northern Ireland (PPRU 1992, 1994, 1995; Monteith *et al.* 2002). The absence of a clear and consistent information base on the prevalence and circumstances of disabled

children in Northern Ireland inevitably has a detrimental impact on the planning, delivery and evaluation of services provided to meet their needs (Monteith *et al.* 1997; McConkey and McAteer 1999; Monteith *et al.* 2002). Schedule 2 of the Children (NI) Order 1995 requested the establishment of a register of disabled children. The two-year project on the development of this register has just been completed and the first wave of implementation will begin shortly. It is hoped that the future establishment of this register will in some way address this lack of information. Policies relevant to disabled children in Northern Ireland include the Disabled Persons (NI) Act (1989), the Disability Discrimination Act (1995), the Northern Ireland Act (1998), the Education (NI) Order 1996 and the Children (NI) Order 1995. The Disabled Persons (NI) Act (1989) requires Boards or Trusts to identify the needs of young disabled people leaving school and provide appropriate services. It also established disabled people's right to information, representation, assessment and counselling and recognised the needs of carers to have an assessment of their ability to care. The Disability Discrimination Act (1995) seeks to eradicate discrimination against disabled people and promote equal opportunities. Priority is given to equal opportunities in relation to facets of adult life, such as employment or buying property, rather than issues more relevant for children. Section 75 of the Northern Ireland Act (1998) includes a requirement for public authorities in

Northern Ireland to promote equality of opportunity in policy and practice between individuals and groups, including potential inequality related to age and disability and between people with dependants and people without. This legislation requires wide consultation on policy implementation to provide opportunities for individuals and organisations to highlight potential breaches and this should include consultation with disabled children and young people on policies that affect their lives.

The Education (NI) Order 1996 established legal duties for the identification and assessment of children who have special educational needs and issuing of a statement outlining how their educational needs will be met. Parents were granted a legal right to participate in the decision making process about their child's special educational needs and under the associated Code of Practice parents may appeal a decision about the statementing process at the Special Educational Needs Tribunal. The Children (NI) Order (1995) follows most of the provisions set out in the Children Act (1989) of England and Wales and the Children (Scotland) Act (1995). This legislation recognised disabled children as children first and firmly embraced the inclusion of disabled children within the broad definition of 'children in need' (Article 17). Article 18 and Schedule 2 outlined a range of support services to safeguard and promote the welfare of children in need. There is also an emphasis on multidisciplinary

teamwork, working in partnership with families, ascertaining the views and wishes of children, minimising the effect of impairment and providing support services for young disabled people making transitions. Each Health and Social Services Trust also provides policy and procedures handbooks. The 'Children in Need' policies and procedures handbook provides operational indicators of need. However, these operational indicators minimise the original definition in the Order of a child with a disability as a child in need to 'a child with a disability who may require social services care' (SSI 1995). The Children (1995 Order) (Amendment) (Children's Services Planning) Order (NI) 1998 also placed a requirement on Health and Social Services Boards to produce Children's Services Plans every three years in collaboration with other key agencies in Northern Ireland.

Regarding services for disabled children, these plans have highlighted the need for early intervention, advice and support for parents following diagnosis, transitional planning and improved coordination between agencies and professionals. However, it is also recognised that greater levels of funding for social services is required to meet the department's strategic aims in relation to disabled children (Monteith and Cousins 1999; Monteith *et al.* 2002). With regard to international policy, the Human Rights Act (1998) allows individuals to claim their rights under the European Convention on Human Rights (ECHR) in courts in Northern

Ireland. The ECHR was ratified in 1951 by the UK. Children's rights were not prioritised, however, it recognises rights related to private and family life, protection, liberty and freedom of speech which are also relevant to disabled children. In addition, Articles 12, 13 and 23 of the United Nations Convention on the Rights of the Child, ratified by the UK in 1991, refer to the participation rights and provision for children, including disabled children specifically. The Convention recommends that policies that facilitate a full expression of the child's view in any decisions made about their lives should be developed.

In particular, Article 23 describes rights for disabled children including their right to care, education and training that promotes self-reliance and active participation in society. Disabled children should also benefit from recent developments in policy for children in general in Northern Ireland. Despite the suspension of the Northern Ireland Assembly, work has continued regarding the development of an all embracing children's strategy for Northern Ireland. This 10-year strategy for children and young people addresses issues such as improving children's services and ensuring children's rights and needs are coordinated, monitored and promoted within government. This is closely linked to the appointment of a Commissioner for Children and Young People in June 2003, who is responsible for safeguarding and promoting the rights and best interests of children and young people. In addition, the Children's

Social Services Strategy is currently in the early stages of development with plans for consultation underway for 2003. While having links with the Children's Strategy and the Children's Commissioner, the Children's Social Services Strategy will have the aim of promoting cohesion in the planning and provision of children's services in Northern Ireland. This will also address issues such as those covered by the Quality Protects Initiative in England and Children First in Wales with its emphasis on meeting the stability needs of looked after children. These policy advances for children in general, alongside new legislation addressing the needs of disabled children (SENDA (NI) Bill and Carers and Direct Payments Act (NI) 2002) and the review of community and hospital services for disabled children led by the Social Services Inspectorate, should improve the provision of services for disabled children and young people.

Health and social service provision

The Health and Personal Social Services (NI) Orders (1991) and (1994) placed responsibility for assessment of health and social welfare needs and provision of services on Health and Social Services Boards in Northern Ireland. This established the purchaser/provider organisation that meant Health and Social Services Boards purchase services for their populations from Health and Social Services Trusts so that services are

sensitive to the needs of local communities. However, Monteith *et al.* (1997) noted that, although the PPRU survey estimated there were 14,600 disabled children in Northern Ireland, during the year ending March 1995 only 2,883 disabled children were in contact with a Health and Social Services Trust.

The needs of families with disabled children

Much research has revealed that the pattern of service development in Northern Ireland has prioritised protection and restricted levels of family support services for children (Higgins *et al.* 1998; Geraghty 1999). McCrystal (2000) found that in contrast to the commitment to disabled children in the Children (NI) Order (1995), the key operational indicator of a child in need was a child in need of protection. This narrow interpretation of need ignores the diverse needs of disabled children and their families that should be targeted by service planners and providers (Monteith and Cousins 1999; Kelly 2002a).

Many researchers have discussed the ongoing practical and emotional needs of parents of disabled children (McKeever 2000c; McKeever and Griffiths 2001; Kelly 2002a). However, much of the stress experienced by these parents is directly related to discriminatory barriers and poorly coordinated service systems rather than inevitable effects of caring for a disabled child. For example, the technocratic social security system makes it difficult for parents to successfully complete application

processes. In addition, some parents still feel they must argue with professionals and agencies for access to appropriate levels of service provision for their family (McKeever 2000c; McKeever and Griffiths 2001; Family Information Group and Contact a Family 2001; Kelly 2002a). Authors have emphasised the need for support services at diagnostic stages (Mencap 1997; McKeever 2000b; McKeever and Griffiths 2001; Family Information Group and Contact a Family 2001; Kelly 2002a). Such research has found that professionals informed parents about diagnoses in unsympathetic and inappropriate ways, and follow up services were inadequate and uncoordinated. Many parents researched their child's impairment themselves rather than being given adequate levels of information from professionals. Parents not only need information on diagnosis and prognosis but also on the availability of local services, support networks and the roles of different professionals and agencies relevant to disabled children and their families (McConkey 2003). In addition, researchers have found that many families did not receive professional counselling following diagnosis, although parents suggested this would have been of benefit to them (Mencap 1997; McKeever 2000b, 2000c; McKeever and Griffiths 2001). Parents who were not given a diagnosis of their child's disability also experienced problems persuading medical professionals to take their concerns about their child seriously and were often accused of being over-protective parents (Mencap

1997; Kelly 2002a). Researchers have concluded that professionals should receive more training on family dynamics, listening, advocacy, counselling, and conveying positive images of disability while providing accurate information about impairment.

Inter-agency and multi-disciplinary coordination

There is much evidence that, despite legislative intent, there is a lack of inter-professional and inter-agency coordination (Mencap 1997; McConkey and McAteer 1999; McKeever 2000a; Family Information Group and Contact a Family 2001; Kelly 2002a). Monteith *et al.* (2002) found that even within the public sector disabled children often fall between gaps of internal planning and service boundaries. Researchers have indicated that one of the best ways to avoid this is to provide a keyworker for families (DHSS 1996; Mencap 1997; McKeever 2000a, c). Sloper (1999 p91) defined a keyworker as: *a named person whom the parent approaches for advice about any problem related to the disabled child. The key worker maintains regular contact as needed with the family, and has responsibility for collaborating with professionals from a range of services, and coordinating support for the family. Particularly important aspects of the service are the key worker's knowledge of and ability to access information and services from a range of agencies.* However, McConkey and McAteer (1999) found disagreement about

which profession should undertake this role. Similarly, Kelly (2002a) found that staff changes and challenges related to interdisciplinary, multi-disciplinary and interagency working can undermine the potential benefits of keyworking.

Respite care services

Researchers have found that the most frequent service provided from social services is respite care, sometimes termed 'short breaks' (Monteith *et al.* 2002; Kelly 2002a). There are potential benefits of respite care for families of disabled children, especially when it is part of an overall package of support services for families rather than the only service (Kelly 2002a). Parents can enjoy opportunities to rest, do household chores or go on family outings. When delivered appropriately respite care can also offer opportunities for disabled children to develop increased independence, have a wider range of social experiences and become more involved in the community. Generally, the literature suggests that respite care works best for families when it is locally based, provides good quality child care with age appropriate enjoyable activities for disabled children and flexibly responds to needs as required over short periods (McKeever 2000b; Kelly 2002a). However, Mencap (2003) recently conducted a survey of respite care provision involving 76 families, with children or adults who have learning disabilities, from England and Northern Ireland. The study found that six out of ten

families were not receiving a short break service or were receiving limited respite care provision that did not meet their needs. Mencap (2003) also discovered that six out of ten families who were on a waiting list for short break services had been waiting for at least six months. This study revealed many carers of children and adults who have severe or profound learning disabilities feel they are driven to breaking point because they cannot access necessary support services. McConkey *et al.* (2003) argued that increased respite care services and appropriate residential services would help alleviate stress that some families experience. The author emphasised this is particularly relevant for families of adolescents who are dependent on technology or those with autistic spectrum disorders and challenging behaviours. Research has also demonstrated that parents prefer family-based respite care rather than accommodation in residential or hospital units (McConkey and Adams 2000). However, Prewett (1999) and McConkey and Adams (2000) found that, although they were popular and most cost effective, social and leisure services and family based respite care services were marginalised within social services provision. Prewett (1999) expressed concerns about inadequate preparation and training for family carers, lack of consistency in re-approving carers annually and insufficient monitoring of placements. Kelly (2002a) also discovered that respite care was often provided to meet the needs of parents, rather

than children, and disabled children were rarely involved in decisions about the type and frequency of stays at respite care. In addition, Monteith and Cousins (1999) and Kelly (2002a) expressed concern that tools for assessing and reviewing respite care provision provided limited opportunities to include the views of disabled children.

Disabled children and social exclusion

Monteith and Cousins (1999) reported improvements in service provision for disabled children since the enactment of the Children (NI) Order (1995), however, they also revealed limited access to mainstream services for disabled children. This restricted access to common sources of support for parents of disabled children means they must rely on specialist facilities that isolate their child from their peers in the community (McKeever 2000a; McConkey and Adams 2000; Kelly 2002a). Many studies in Northern Ireland have found that disabled children have restricted social opportunities within local communities, especially for children who have learning disabilities (Monteith and Cousins 1999; Educable 2000; McConkey and Smyth 2000; Kelly 2002a; Monteith *et al.* 2002). Contact a Family's survey of the United Kingdom, including Northern Ireland, highlighted the extent of social exclusion that disabled children experience (73 per cent did not go on outings, 70 per cent cannot attend a youth club and 55 per cent

of parents must travel out of their local area to access suitable leisure facilities for their disabled child).

McConkey and Smyth (2000) found that young people who took part in leisure activities usually did so in the company of their parents. Monteith *et al.* (2002) also discovered that even when disabled children did have contact with peers in the community they often had negative experiences of bullying. In addition, social contacts at special schools were usually not accessed outside school hours because they lived long distances away and most children did not have opportunities to develop friendships with both nondisabled and disabled children (Kelly 2002a; Monteith *et al.* 2002). Monteith *et al.* (2002) discovered that a lack of established friendships caused young people to become withdrawn and self-reliant. These authors suggested that strategies should be developed to provide safe, accessible play areas and more integrated social activities. However, this would require more adequate ring-fenced funding for services that enable disabled children and young people to access mainstream play and leisure facilities.

Educational services

The first DENI study of provision in mainstream schools in Northern Ireland for pupils with special educational needs revealed serious inadequacies in the implementation of the Education (NI) Order 1986 and a higher rate of 'statementing' of children in Northern Ireland than in other areas of the United Kingdom (DENI 1998). Monteith *et al.* (2002) found that parents felt alienated by the assessment process and

insufficiently informed to make a genuine contribution to their child's education. Although legislation promotes inclusive education and the use of mainstream schools for children who have special educational needs, Geraghty (1999) noted that few mainstream schools provide facilities for disabled children. The majority (74 per cent in 1996/7) of disabled children in Northern Ireland in the 1990s were still being educated in special schools or in special units attached to mainstream schools. McConkey and Bhurgri (2003) found that, although mainstream preschool facilities were committed to enrolling children who have autism, staff had inadequate training or lacked knowledge of the skills required to meet the particular needs of these children. Monteith *et al.* (2002) drew attention to particular issues for disabled children in school including difficulty with regard to maintaining friendships and bullying. They recommended that additional funding should target the needs of disabled children in mainstream schools and address physical access problems to facilitate the inclusion of disabled children in mainstream settings. The authors also suggested that initiatives to address racial and sectarian bullying in schools should be extended to include discrimination on the grounds of disability.

The Educable (2000) study, carried out by a group of young disabled people with Save the Children and Disability Action, investigated the educational experiences of over 50 young disabled people in Northern Ireland. They discovered some

mainstream schools were inaccessible or did not provide essential specialist services. Children attending segregated schools often felt socially isolated and rarely had social networks outside their own family. Young disabled people felt they were not encouraged to undertake serious study and were restricted by lack of access to computers and other essential aids. In addition, negative teacher attitudes meant that some young disabled people felt they were not treated with respect and not encouraged to develop aspirations for post-school education or employment. Many young disabled people in this study would have liked to have learnt more about living independently and been more actively involved in decisions about post-school training and employment. The study recommended the provision of disability awareness training for teachers, more accessible mainstream schools and transport systems, alternatives to examinations for assessment, increased subject choice, counselling services within schools and the involvement of young disabled people in school councils.

Post-school transitions

Monteith and Sneddon (1999) examined the needs and experiences of 76 young disabled people between the ages of 16 and 21 making transitions to adulthood in Northern Ireland. Although the authors discovered that many young disabled

people accessed valued activity for future employment, such as youth training programmes or higher education, the availability of future employment for these young people was limited. In addition, while most young people interviewed did have active social lives, there were concerns for young people who had learning or multiple disabilities who felt more isolated. The authors reported poorly planned and uncoordinated transitional services with limited access to appropriate professionals, especially social work services. In addition, young disabled people were not involved in assessments or reviews and had limited access to information on options or sources of available support. McConkey and Smyth (2000) interviewed young disabled people aged between 18 and 21 and their parents separately about their educational experiences, lifestyles and aspirations for the future. The majority of young disabled people were dependent on their parents for personal care which restricted opportunities for them to become self-reliant. Parents had limited access to social work services and at transitional stages required information about social security benefits and services, respite care breaks, leisure activities for young disabled people and practical assistance in the home. An interesting finding in this study was the difference between the views of young disabled people and their parents. Although almost all of the

young people wanted to access employment, only half of their parents agreed this was possible. Parental views contrasted even more with their child on the subject of sexuality and marriage. The authors emphasised the importance of parents, professionals and young disabled people working together on a risk-taking strategy to promote self-reliance.

Employment and social security

Monteith *et al.* (2002) noted that childhood disability was strongly associated with reduced income levels. Several researchers have noted how mothers often give up paid employment to care for their disabled child and fathers are also restricted in their choice of employment and opportunity for promotion (Kelly 2002a; Monteith *et al.* 2002). Reduced income has a detrimental impact on the ability of families to cover extra costs related to caring for their disabled child such as home adaptations, specialised diets or equipment. Difficulty in accessing local child care provision for families of disabled children is of particular concern and demonstrates the need for implementation of the duties and powers within the Children (NI) Order 1995 to integrate disabled children into mainstream child care provision (Kelly 2002a). The development of more flexible work patterns, community or school based child care services and adequate access to support systems for working parents would also be useful for families of disabled

children (Monteith *et al.* 2002). Given the fact that some parents of disabled children experience difficulties related to employment, findings by Monteith *et al.* (2002) that a third of families rely totally on social security benefits for income is hardly surprising. In addition, the authors found that lone parents of disabled children were more than twice as likely to be dependent on social security benefits than twoparent families. Despite the importance of state benefits for these families, researchers have found that complex benefit systems often result in inadequate financial support for parents. It was estimated in 2001 that nearly 300,000 families in the United Kingdom were not receiving the benefits they should have been (Contact a Family 2002). Mencap's (1997) report recommended that parents should have access to professional advice on eligibility and the application process. Since benefits are entitlements, and can improve quality of life and wellbeing, they should be easily accessible (McKeever 2000c; Monteith *et al.* 2002).

Housing services

McKeever (2000c) acknowledged that the housing needs of children with disabilities and their families can be complex and change as children grow older. Appropriate housing for disabled children is crucial to ensure their basic needs, such as safety and space, are met. However, McKeever (2000c) and Monteith *et al.* (2002) commented on the difficulty of obtaining grants for home adaptations and the high levels of bureaucracy involved.

Based on the PPRU data, Monteith *et al.* (2002) found that in 1990 families of disabled children in Northern Ireland were less likely to afford their own home. In addition, these authors noted that there is no public finance available for families who need to move to a new home with more adequate space for their disabled child and recommended increased disability awareness among those designing new homes. Hopefully, implementation of the Housing Support Services Bill should recognise more fully these housing needs of disabled children and their families.

Listening to disabled children and young people

Much research has identified the need for policy makers and service providers to work in partnership with children and parents and harness their expertise to develop effective services for families (Higgins *et al.* 1998; Pinkerton 2000; McKeever 2000b). The fundamental right of disabled children to be listened to and understood is reflected in current policy, such as the Children (NI) Order 1995, and the United Nations Convention on the Rights of the Child. Yet there has been little effort to include these children in crucial decisions that affect their lives or the services provided to meet their needs. This is particularly the case for children who have learning disabilities and those who do not use verbal communication (Kelly 2002a). Monteith and Cousins (1999), Monteith and Sneddon (1999) and Monteith *et al.* (2002) found that professionals were aware of the need to consult disabled children

and young people but highlighted difficulties such as dealing with conflicting views of parents and children. Likewise, Kelly (2002a) discovered that social workers felt they did not possess the necessary skills or experience to communicate effectively with disabled children. Policy makers and service providers need to actively involve parents and children in the planning process and listen to their views so that public services can develop to more effectively meet their needs. The absence of consultations with disabled children and young people means that service providers are reliant on adult interpretations of their needs. Aside from the denial of the child's right to contribute their views and be involved in decisions affecting their lives, this is also inappropriate since studies have shown that the views of parents and children are often very different and parents are not always their child's best advocate (McConkey and Smyth 2000; Monteith and Sneddon 1999). Hence, it is important that service providers consider how to ask questions, what methods of communication should be employed and how much time is available to consult disabled children in an ethical and appropriate manner without the presence of other adults. Several researchers have employed creative methods that practitioners could use to involve disabled children and young people in decision-making (Educable 2000; Monteith 2002; Kelly 2002a; Kernohan 2003). Indeed, Kelly (2000b) discussed methods one

Health and Social Services Board used to involve young disabled people in a steering and reference group for Children's Services Planning. Monteith *et al.* (2002) and Kelly (2002a) explored the views of disabled children and parents and found that parents and professionals often did not appreciate the extent of their children's awareness of feeling different from others. Most families rarely discussed disability with their disabled child and children's awareness of disability was often founded on negative experiences such as sibling rivalry or bullying. These authors suggested that parents should have access to information and support on how to guide their child through the experience of growing up with a disability, especially how to overcome disabling barriers they are likely to encounter.

Conclusion

Research has provided valuable information on how support services in Northern Ireland can be targeted to meet the needs of disabled children and their families, some of which is based on the views of these children and their parents who are most able to identify the types of services they require. It is imperative that this knowledge is incorporated into the delivery and development of support services in Northern Ireland. Likewise, future research initiatives should further develop understanding of the lives of disabled children and young people in Northern Ireland and seek to address gaps in current knowledge such as disabled children's identity, personal and sexual relationships and educational

provision for young people who have learning disabilities.

Two crucial gaps in service provision for disabled children and young people emerging from the literature are access to social networks and opportunities to have a say in decisions about their lives and the support services provided to meet their needs. Indeed, Monteith *et al.* (2002) recommended that the Equality Commission and the Assembly in Northern Ireland should urgently lead holistic disability awareness and equality programmes targeted at all staff in the public sector. New developments in Northern Ireland, such as the current review of services for disabled children and the introduction of the Carers and Direct Payments Act (NI), should advance service provision for disabled children and their families. If the necessary resources are forthcoming, these developments should impact positively on services for disabled children and their families in Northern Ireland.

References

- Contact a Family (2002) *Everybody Here? Contact a Family* Department of Education (NI) Research Report II (1998) *Practice in Mainstream Schools for Children with Special Educational Needs*. DENI
- Department of Health and Social Services (1996) *Review of Policy for People with Learning Disabilities*. HMSO 2/95, Dd 8400949, C10, 14575
- Educable (2000) *No Choice: No Chance. The Education Experiences of Young People with Disabilities*. Save the Children
- Family Information Group and Contact a Family (2001) *Parents Stories*. Guildhall Press
- Geraghty, T (1999) *Getting it Right? The State of Children's Rights in Northern Ireland at the End of the Twentieth Century*. Children's Law Centre
- Higgins, K, Pinkerton, J and Devine, P (1998) *Family Support in Northern Ireland. Part II Perspectives from Practice: An Overview of the Five Process Evaluation Reports*. Centre for Child Care Research, Queen's University Belfast
- Kelly, B (2002a) *The Provision of Family Support Services for Children who have Learning Disabilities and their Families in the Context of Current Social Policy and Legislation*. Unpublished Thesis, University of Ulster at Magee
- Kelly, B (2002b) Disabled Children as Active Citizens, *Child Care in Practice*, 8, 3, 220–222
- Kelly, B, McColgan, M and Scally, M (2000) A Chance to Say: Involving Children who have Learning Disabilities in a Pilot Study on Family Support Services, *Journal of Learning Disabilities*, 4, 2, 115–127
- Kernohan, G (2003) *Methods of Involving Disabled Children and Young People in Children's Services Planning*. Southern Area Children's Services Planning and University of Ulster
- McConkey, R and Adams, L (2000) Matching Short Break Services for Children with Learning Disabilities to Family Needs and Preferences *Child: Care, Health and Development*, 26, 5, 429–443
- McConkey, R (2003 forthcoming) Information Needs of Parents about Learning Disabilities, *Journal of Learning Disabilities*
- McConkey, R and Bhurgri, S (2003 forthcoming) Children with Autism Attending Preschool Facilities: The Experiences and Perceptions of Staff, *Journal of Early Childhood Education*
- McConkey, R and McAteer, D (1999) The Contacts which Families and Children with Learning Disabilities have with Health and Social Services *Child Care in Practice*, 5, 2, 112–121
- McConkey, R and Smyth, M (2000) *Not So Different? The Experiences and Views of Parents and School-Leavers with Severe Learning Difficulties* University of Ulster and Eastern Health and Social Services Board
- McConkey, R *et al.* (2003 forthcoming) The Characteristics of Children with a Disability Looked After Away from Home and their Future Service Needs, *British Journal of Social Work*
- McCrystal, P (2000) *Children in Need: Implementing Article 18 of the Children (NI) Order 1995* The First Two Years, Centre for Child Care Research, Queen's University Belfast
- McKeever, B (2000a) *Bridging the Gap? Professionals Together: Parents, Voluntary and Statutory Workers in Partnership – Can it Work?* Family Information Group
- McKeever, B (2000b) *More Than Just Time Out*. Guildhall Press
- McKeever, B (2000c) *Listening to Parents: Parents as Professionals*. Guildhall Press
- McKeever, B and Griffiths, H (2001) *In the Telling: Research into the Experiences of Parents, Recalling How their Children were Diagnosed with Disabling Conditions*. Guildhall Press
- Mencap (2003) *Breaking Point. A report on caring without a break for children and adults with severe or profound learning disabilities*. MENCAP
- Monteith, M and Cousins, W (1999) *Children and Young People with Disabilities in Northern Ireland Part Three: Social Services Developments and the Impact of the Children (NI) Order 1995*. Centre for Child Care Research, Queen's University of Belfast
- Monteith, M, McCrystal, P and Iwaniec, D (1997) *Children and Young People with Disabilities in Northern Ireland Part One: An Overview of Needs and Services*. Centre for Child Care Research, Queen's University of Belfast
- Monteith, M and Sneddon, H (1999) *Children and Young People with Disabilities in Northern Ireland Part Two: The Circumstances, Experiences and Aspirations of Young People with Disabilities Making the Transition to Adulthood*. Centre for Child Care Research, Queen's University of Belfast
- Monteith, M. *et al.* (2002) *Is Anyone Listening? Childhood Disability and Public Services in Northern Ireland*. Barnardo's
- Policy Planning and Research Unit Statistics and Social Division (1992) *The Prevalence of Disability Among Children in Northern Ireland*. Policy Planning and Research Unit
- Policy Planning and Research Unit (1994) *Disabled Children in Northern Ireland: Services, Transport and Education*. PPRU
- Policy Planning and Research Unit (1995) *Northern Ireland Annual Abstract of Statistics*. PPRU
- Prewett, B (1999) *Short-Term Break Long-Term Benefit: Family-Based Short-Term Care for Disabled*

Children and Adults. Joint Unit for Social Services Research	Do We Need To Know? <i>Child: Care, Health and Development</i> , 25, 2, 85–99	<i>Child Protection: Practice Guide</i> . HMSO.
Sloper, P (1999) Models of Service Support for Parents of Disabled Children: What Do We Know? What	Social Services Inspectorate (1995) <i>The Challenge of Partnership in</i>	

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The Foundation has recently completed an 8 year programme of research and development work on disabled children and young people, mostly based in England. Summaries of the main policy

and practice messages and research findings from this work are available free of charge from the Joseph Rowntree Foundation: Louise Ross, Research Department, JRF, 40 Water End, YORK YO30 6WP (Tel: 01904 615942; Email: Louise.Ross@jrf.org.uk) or downloaded from the JRF website: www.jrf.org.uk

Other relevant research summaries include: "*Supporting disabled children and their families*" (JRF Foundations November 1999 Ref N79) and "*Moving into adulthood: Young disabled people moving into adulthood*" (JRF Foundations June 2002 Ref 512).

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Section 2: Children and families with a learning disability in Northern Ireland

This section of the reports expands on certain themes from Section 1 with particular reference to children and families with learning disabilities.

Numbers of children and families

Children with a learning disability in Northern Ireland are recorded on the Child Health System – Module V. In addition, if the child and family receive social services from a HSS Trust, they should be recorded on Soscare. A study had been undertaken of the administrative prevalence of learning disability based on data from these two systems in 2002 (McConkey, Spollen and Jamison, 2003).

A total of 8,231 children and young people who had a learning disability and who were aged 19 years and under were recorded. This gives an overall prevalence rate of 16.42 per 1,000 of the child population. Of these 79% were recorded as having a moderate learning disability and 21% as severe/profound disability. This is a considerably higher than the rate noted in the Irish Republic (Health Research Board, 2003) which in 2001 had 7.75 per 1,000 recorded on their intellectual disability database. It is likely that the Northern Irish system records children whom community paediatricians consider *may have* a learning disability whereas in the Irish Republic the systems records children with a confirmed diagnosis in receipt of services.

However in both countries the rates vary according to the age bands as Table 1 shows

Table 1: The number of children with a learning disability by age bands

Age Bands	NI Number	Rate per 1,000	RoI Number	Rate per 1,000
0-4 years	364	3.17	1021	4.08
5-9 years	1721	14.03	1955	6.91
10-14 years	2968	22.21	2885	8.85
15-19 years	3178	24.42	3361	9.90
Total	8231	16.42	9222	7.75

This data suggests that in Northern Ireland considerable numbers of children are not identified until school age.

Moreover in Northern Ireland around 30% of the children were also included in the Soscare systems which gives an indication – albeit possibly an incomplete one – of those in receipt of social services. (However this varied significantly across HSS Board with 49% of children recorded in the WHSSB and 15% in NHSSB.). This would give a rate of 4.88 per 1,000 which is much lower than the rate in contact with services in the Irish Republic.

However the Irish data also includes school attendance. In Northern Ireland, 7,222 children had statements of special educational needs for the period 1997 to 2002 (O'Connor, Hartrop and McConkey, 2003). Of these, around 60% are for learning difficulties. This suggests that some 4,300 children had a 'diagnosis' of moderate or severe learning disabilities: a rate of 8.6 per 1,000. It is possible that most of these children are included in the Soscare records. This suggests that Northern Ireland may have a higher proportion of children with a learning disability than the Irish Republic. Moreover the figures are probably higher than in Great Britain although comparable

data is not available nationally. However these comparisons are fraught with difficulties if common assessment criteria are not employed.

Looked after children

Data is not available for all of Northern Ireland on the numbers of children with a learning disability who are looked after away from their natural families. A survey in the largest HSS Board, found that 53 children were living in some form of residential accommodation (N=31) or with foster carers (N=22) (McConkey et al, 2004). This represents 0.28 per 1,000 child population or 3.3% of children with recorded learning disability in the Board area (using the corrected figure of 8.6 per 1,000 – see above). If these figures were projected to Northern Ireland as a whole, this suggests that around 140 children live away from their natural families. Most of the children in residential accommodation were 14 years and over.

In the Republic of Ireland, twice as many children (7%) live in some form of residential accommodation with an unknown number in foster care arrangements (Health Research Board, 2003).

However the Northern Irish study suggested that in the Eastern HSS Board area an additional 16 places were required to met the needs of those young people presently living with families but a further 14 places are also needed for those inappropriately residing in hospital or adult residential accommodation. (If an extra 16 places were to become available, the proportion of places would still be significantly lower at 4.3% than for the Irish Republic.)

If the figures for increased needs were projected to Northern Ireland as a whole, an additional 75 places are required for young people who need to live away from the family home. Many of these young people have severely challenging behaviours and autistic spectrum disorders. They are difficult to foster because of their complex behavioural problems or health needs and they can be difficult to accommodate in mainstream children's homes.

However, increasing residential places for young people necessitates planning for their adult years in order to ensure continuity of their care and this needs to be factored into projections of future accommodation and support needs (see Chapter 3).

Database of unmet needs

Planning for service improvements is hampered by a lack of data about the needs of families. None of the existing databases in use in Northern Ireland are set up to provide information about family circumstances or their needs for services. The proposed Register of children with disabilities to be set up under the Children (NI) Order is also unlikely to do this. This means that the evidence required to argue for increased funding is not readily to hand.

The Intellectual Disability Database in the Irish Republic does record unmet needs although the published data does not give information broken down by age. The most common need was for more respite breaks.

Short breaks – out of the family home

The demand for increased respite breaks has also been documented in Northern Ireland (Sines, 1999). Families preferred the option of after-school or leisure activities at evenings and weekends or having a 'flexicare worker' come to the family home (McConkey and Adams, 2000). More homely services, serving small numbers of

compatible children, were preferable to other forms of residential provision. The features that parents identified as distinguishing 'better services' are noted in the box (McConkey, Truesdale and Conliffe, 2004).

Box : Features of preferred short break service

- Small numbers of children at a time
- Homely environment
- Located in pleasant surroundings
- Low risk of abuse
- Child looks forward to going
- Child orientated service
- High standard of care provided
- Children are shown love and affection
- Stimulation and activities for the children
- Gives me someone to talk to
- I meet other parents
- I'm told about other services

Accessing play and leisure activities

Children and teenagers with disabilities are often unable to access mainstream play and leisure activities. A study in the Greater Belfast area involved a postal survey of over 130 summer schemes and play and leisure facilities (Thompson, Taylor and McConkey, 2000). Around one-third of schemes had experience of taking a child with some form of disabling condition. However the biggest obstacles to the inclusion of these children were the lack of training for leaders, insufficient staff and resources.

A linked study involved the evaluation of a model service aimed at supporting five mainstream summer schemes which enrol children with severe learning disabilities and complex needs, such as autism and multiple disabilities. This showed that such schemes are feasible with most children attending regularly and taking part in a range of activities. Family reactions were also positive as were those of the volunteer helpers and other people involved in the schemes. Few problems were reported but many benefits were cited especially for the other children attending the scheme. The study confirmed the importance of training, the use of dedicated volunteer helpers and the need for a co-ordinator to liaise with families and to support and advise summer scheme and centre staff.

A survey of 56 staff working in 38 preschools of various types in the Greater Belfast area found that a sizeable number had the experience of taking children with autistic spectrum disorders and staff receive some advice and support from a range of professionals (McConkey and Burghri, 2003). Nearly all were committed to enrolling such children in the future but they felt that a lack of staffing could preclude this. A majority of staff felt they have had inadequate or no training to equip them to meet the

children's particular needs and they report a lack of knowledge and skills to help these children.

Subsequently a 10-hour training course on autism was devised and evaluated with a self-selected group of 62 preschool personnel from a range of facilities (Crawford et al, 2004). It aimed to enhance participant's knowledge about autism and of the intervention strategies that are effective in assisting young children with this condition to communicate and interact with others as well as structuring their learning through play and more formal tasks.

The course was well received by the participants who three months later had implemented much of the advice given on the course. Course participants appeared more willing to enrol children with autistic spectrum disorders in their groups although a minority did express some reservations. A resource pack for tutors has been prepared so that similar courses can be delivered elsewhere in the future.

In summary, there appears to be a willingness among community personnel to include children with a learning disability in mainstream play and leisure schemes. Training inputs are welcome and appear successful in boosting the confidence and competence of staff.

Information needs of parents

A common complaint from parents is the lack of information available to them. A survey of over 400 parents and carers of children and adults with severe learning disabilities in N. Ireland found that the most commonly mentioned informants were social workers and staff in schools and centres (McConkey, 2003). In addition, GPs were named by nearly one-third respondents but little use had been made of voluntary services such as Mencap and Citizen Advice Bureau. A similar pattern was found regarding the informants they would approach in the future.

The most commonly reported topics on which parents would seek information were the availability of services, leisure and holidays and benefits. However other topics varied according to the age of the child, with parents of children under 10 more likely to want information on education and therapies.

The preferred means of getting information was through face-to-face contacts in the home and this was particularly marked with parents or carers of adult persons. It was concluded that any specialised information service must be promoted among professional staff and should work in close partnership with them if the information needs and preferences of parents are to be effectively addressed.

Maternal stress and well-being

The presence of a disabled child is known to increase family stress and parental ill-health (see Section 3). However it unclear the extent to which support services can alleviate this.

Families using two, short-break services – both residential and domiciliary - formed the study population (N=68) (Truesdale and McConkey, 2001). Significant proportions of these mothers were stressed and had high levels of psychiatric morbidity. The sole predictor of stress was parental ill-health which in turn was linked with children who had higher scores on motor skills and the presence of other disabled dependents in the family. Families who were most stressed or in poorer health received no greater amounts of support.

A wider ranging study nearing completion by Truesdale (2004) involving over 100 mothers and fathers from over 70 families, has again confirmed that support from professionals has little impact on the levels of stress and well-being of mothers or the coping strategies employed by families. In the main professional support is more closely linked to the characteristics of the child rather than on the needs of families. However there was some evidence that a new style of service, based around person-centred approaches and creating opportunities for young people to be involved in community-based leisure activities, did result in improved scores on a measure of family functioning. The main reasons appear to be that families have more time for themselves and for their other children.

These findings reinforced the complexity of disentangling the relationships between family needs and service supports. The findings also suggest that existing presumptions about more services reducing family stress are too simplistic. The meaning of support for families needs to be critically reviewed along with an examination of the coping strategies used by families. This should result in better matching of support services to individual family needs.

Standards and Outcomes

The emphasis on evidence-based practice and the need to evaluate service outcomes against 'best value' criteria have yet to be felt in family services. Supporting families – mothers in particular – rarely features explicitly in the job description of many members of the multi-disciplinary team. It is to be hoped that the Inspection of Children's services will identify the importance of defining the standards that will form the hallmark of quality family support services (see Section 3). The recently produced 'Manifesto' for Wraparound Projects in the SHSSB area (2003) is a further example of explicit service standards.

References

- Crawford, H., Doherty, K. Crozier, B., Bhurgri, S. and McConkey, R. (2004) An evaluation of a short training course on autism for preschool personnel. *Good Autism Practice Journal (in press)*
- Health Research Board (2003) *National Intellectual Disability Database: Annual report 2001*. Dublin, Health Research Board.
- McConkey, R. (2003) Information needs of parents about learning disabilities. *Journal of Learning Disabilities*, 7, 211-219.
- McConkey, R. and Bhurgri, S. (2003) Children with autism attending preschool facilities: The experiences and perceptions of staff. *Early Child Development and Care*, 173, 443-452
- McConkey, R., Nixon, T. Donaghy, E. and Mulhearn, D. (2003) The Characteristics of Children with a Disability Looked After Away from Home and their Future Service Needs. *British Journal of Social Work (in press)* .
- McConkey, R., Spollen, M. and Jamison, J. (2003) *Administrative prevalence of learning disability in Northern Ireland*. Belfast: DHSS&PS
- McConkey, R., Truesdale, M. and Conliffe, C. (2004) The features of short-break residential services valued by families who have children with multiple disabilities. *Journal of Social Work (in press)*
- O'Connor, U., Hartrop, B. and McConkey, R. (2003) Parental attitudes to the statutory assessment and statementing on special educational needs. Belfast, DENI.
- SHSSB (2003) An interim evaluation of the Wraparound Project. Armagh: SHSSB.

Sines, D. (1999) Identifying the need for respite care for people with learning disabilities in Northern Ireland. *Journal of Learning Disabilities*, 3, 81-91.

Truesdale, M. (2004) An investigation of the impact of support services on families caring for a child with a learning disability. PhD Thesis, University of Ulster.

Truesdale, M. and McConkey (2001) Maternal health and stress in families with a child who has multiple disabilities. *Child Care in Practice*, 7, 143-152

Thompson, B., Taylor, H. & McConkey, R. (2000) Promoting inclusive play and leisure opportunities for children with disabilities. *Child Care in Practice*. 6, 108-123

Section 3: International literature

An extensive literature exists on children and families, although mostly from American and British researchers. For the purposes of this paper, the focus is on four main themes:

- What's different about families who have a child with disabilities?
- What problems do parents encounter with services?
- What supports are effective for families?
- Priority Issues in Service Development

At the outset though, the common shortcomings in this research have to be acknowledged.

□ Little regard has been paid to the possible cultural and societal differences among families who have a child with a learning disability. There has been relatively little cross-cultural research; hence findings from one culture may not apply to others. There are indications for example, that Northern Irish families differ in some respects from those in other parts of these islands although few formal comparative studies have been undertaken.

□ Much of the research has been cross-sectional with few longitudinal studies hence we have an incomplete picture as to the ongoing impact on families of having a child with a learning disability.

□ In recent years there have been major changes in family life within these islands with more single parenting; fewer children in families; more working mothers and a lessening dependence on the extended family. The ramifications of these changes have yet to be fully explored in the literature but their impact may already be felt within services.

□ The focus of much research has been on mothers with comparatively little research on fathers and siblings, and still less on documenting the experiences and feelings of the child with disabilities.

□ The thrust of much research has been on describing the common experiences and impacts on families and on discovering why certain families cope better than others. But given the great variation in terms of the children's characteristics, parents' background and attitudes, family compositions and local societal influences, these common influences may be of little practical significance with service responses needing to be designed for each individual family.

In sum, although a great deal has been learnt about the impact on families of having a child with disabilities, much remains to be discovered.

Finally there is a small but growing body of research into the needs of parents who themselves have learning disabilities although their offspring may or may not be similarly affected. This issue is not considered specifically in this review except to state that much of the insights into best practice equally to this client group and it is the augmentation of these supports that offers the best hope of sustaining these families and ensuring the well-being of all its members (Department of Health, 2001a).

What's different about these families?

A great deal of research has been carried out contrasting families who have children with various disabilities and those who have non-disabled children. There are conflicting results often due to differences in the samples and measures used. Even so, a number of consistent findings have been reported. However the impact on mothers has been studied more thoroughly than the impact on fathers.

Latterly the conceptual models underpinning this research have expanded beyond examination of 'atypical' individuals towards an investigation of the social and environmental factors that impact of the lives of families. The inter-relationships among all these variables should be noted. The presence of a child with disabilities may not be the main cause of the family's distress or of the need for service supports.

- Mothers – and to a lesser extent fathers – report higher levels of stress. It appears that it may be the child's behaviour or sleeping problems, rather than type or severity of disability, that is associated with greater stress (Stores, 1992).
- Mothers are more likely to report symptoms of ill-health; particularly depression (Andersson, 1993).
- Families of disabled children have lower incomes than other families and are more likely to experience social deprivation. They face extra costs that are not always covered by disability benefits (Glendinning, 1992).
- Mothers are less likely to be in employment – either part-time or full-time (Booth & Kelly, 1999). Single parents then face extra challenges (Beckman, 1983).
- Families may receive less informal support from family and friends especially if the child has more complex care needs. They have fewer opportunities for leisure pursuits and breaks (Twigg & Atkin, 1994).
- Families experience more problems with poor housing and lack of transport (Twigg & Atkin, 1994).
- Families may have other dependents to care for, including a second child with a disability; an ageing carer or a sick or disabled spouse (Department of Health, 2001b).
- The care of a child with a disability often extends into adulthood. Many continue to live with their parents until middle age and when the parents are no longer able or available to provide a home (Harrison, 2000).

Families who face particular challenges - and those more likely to find that their needs are not met - include families with:

- Children who have very severe impairments (including those who are technologically dependent) who require high levels of nursing and personal care (Redmond and Richardson, 2003).
- children and adults with challenging behaviours and mental health problems (Maes et al, 2003)
- More than one disabled child.
- Families from ethnic communities (Hatton et al, 2003).

What problems do parents encounter with services?

Over the past 20 years there appears to have been little improvement in meeting the substantial unmet needs in parents with disabled children. Why should this be?

- The focus of professional attention is on the child with disabilities. No one professional has the responsibility to ensure that the needs of carers are met. Indeed parents often ignore their own needs and those of other family members as they 'battle' for the help they feel that will benefit their child.
- Disabled children and their families require interventions from many different services, such as education, hospitals, primary healthcare, therapists, social services, housing and benefits agencies. They have numerous contacts with different workers (McConkey and McAteer, 1999). Although these bring benefits, the problem is often the lack of co-ordination of the work of these different agencies which may result in confusion and conflicting advice and demands on parents (Sloper, 1999).
- Although an assessment of carer needs is now enshrined in legislation in the United Kingdom; fewer than 50% are thought to have had an assessment made and of those assessed as requiring respite breaks, over a third will not have had this service (Carers National Association, 2000; Williams and Robinson, 2000).
- A common complaint from families is the lack of information available to them in accessible formats about the services available to them and their entitlements to services .. about the roles of different agencies and workers ... and to know who to go to for help.
- Services are not equally available across all geographical areas. A so-called 'post-code lottery' exists.
- Children and teenagers with disabilities experience high levels of social exclusion in leisure activities and friendships with non-disabled and disabled peers. This places a greater onus on parents and can lead to a greater dependency among the young people and fewer opportunities for controlled risk-taking.
- Transitions seem to pose particular difficulties for parents' notably from school to adult services; from 'children's teams' to 'adult teams'. Familiar personnel and routines are replaced by uncertainty and people who are new to the family (Ward et al, 2003).
- Changes in society has placed new demands on parents; for example the breakdown of extended families and people moving to new neighbourhoods. Also the expectations of parents are higher. They expect services as a right not as an act of charity.
- The relationship between parents and professionals is often combative. For example: "*In many services a culture has developed that sees families as a problem and difficult to work with ... services need to find constructive and positive ways to work with families in the best interests of people with learning disabilities. (DHSS, 2001b)* Many professionals receive little or no training in working with families.
- Professionals can inadvertently over-emphasise the negative effects of having a child with disabilities. They overlook the positive impact that the child can have on family life (Hasting et al, 2002). These attitudes spill over to the wider community

with consequent hurt to the parents and the young people with disabilities as they encounter stereotypical reactions of pity and rejection (Dale, 1996).

- The changing nature of families – single parenting; remarriages; working mothers – is not always reflected in the expectations professionals hold about parents primarily as carers of the disabled child and failing to appreciate the many other roles they play (Carpenter, 2000). Moreover meeting times that suit professionals are not always convenient to parents.

What supports are effective for families?

Although the needs of parents are well documented, there is less empirical evidence as to the professional supports and systems that demonstrably make a difference.

Indeed it has been found that more engagement with professional services can increase the stress and demands on parents to the inadequacy of provision, protracted negotiations and disagreements with service providers (Smith et al., 2001). Others have noted that it is the satisfaction with each source of support that is a better predictor of the quality of a support networks quality rather than the number of sources (Dunst, Trivette & Cross, 1986). Another emphasis has been on the need to build trusted relationships between the parents and the 'supporters' rather than the type of service provided (Cotterill, Hayes, Flynn and Sloper, 1997).

Moreover families will differ greatly in their needs for services and preferences as to the form they take. This means that there is unlikely to be a main effect across all parents but rather the focus should be on understanding which services benefit which parents at which points in time. This research has barely begun to happen, particularly as there has been a scarcity of longitudinal studies.

However, experience of service personnel and the outcomes of service evaluations has started to identify some of the supports that appear to help most families, most of the time.

Key-worker or link person

S/he maintains regular contact as needed with the family, and has responsibility for collaborating with professionals from a range of services, and of co-ordinating support for the family (see Section 1 of this chapter). Particularly important are the key-workers' knowledge and ability to access information and services from a range of agencies. This extends across social services, health, education and community services (both formal and informal). Research suggests that fewer than one third of families in Great Britain have a named worker they can call on (Sloper, 1999). However there is no legal requirement on UK services to provide a named worker unlike other countries (e.g USA).

Partnership styles of working

Effective support for families is largely based around interpersonal aspects of the relationship between families and service personnel. Features of effective help-giving have been identified as relationship building; clear and open communication, honesty and clarity, understanding of families' own concerns and responsiveness to family values and goals. Mothers often rate the helpfulness of professionals on these criteria rather than their technical competence. Parents also appreciate the regular, long-term contact they have with professional workers (Barr, 1999).

Individual Family Plans

In the United States, a legal requirement of early intervention programs with families of disabled children is for a written family plan to be drawn up that integrates the diverse inputs that families will receive as well as documenting the 'informal' contribution of parents, siblings and the extended family to the child's growth and development. Such plans encourage inter-professional sharing and joint working in assessing and planning for the family as a whole.

Breaks from caring

Many carers testify to the value of having planned breaks from caring. These have mainly taken the form of the child being cared for in a residential setting away from the family home. However to date there is little empirical evidence that such breaks have consistent or enduring beneficial effect on carers' well-being (McNally et al, 1999). A possible explanation is the failure of such schemes to forge supportive relationships with the carers. Families in N. Ireland have reported a preference for more leisure activities in the form of evening and weekend activities that would provide their child with positive experiences while also giving the parents a break from caring (McConkey and Adams, 2000.)

Parent Counselling

Various studies have demonstrated the value of offering group or individual based counselling to parents/families who have children with disabilities (Singhi et al., 1990). This can be done informally through parent self-help groups or parent associations, or as a planned series of meetings facilitated by trained counsellors. This approach has been used most often with parents whose child has been newly diagnosed. However not all families wish to meet other parents.

Parent Training

Reports on interventions that focus on training parents to acquire or develop certain coping skills are more common in the USA than in UK (Baker, 1988). The training may focus on particular child problems such as behaviour management or sleep difficulties, or else the emphasis is on more general parenting skills such as training in problem-solving and decision-making, communication, and accessing and utilizing social networks.

Informal supports

The impact of informal supports (e.g. from family, friends and neighbours) has been found to have greater impact on families than professional supports. Some commentators promote the need for professionals to mobilise locally-based informal supports for families, e.g. through parent-to-parent schemes; enrolment in Mother and Toddler Groups and playgroups. Also the important role that these supporters play in the lives of the families should be recognised by inviting them to be present at key events, e.g. appointments, training courses (Carpenter, 2000).

Practical Assistance

Housing adaptations, the provision of suitable aids and equipment, and assistance with transport are all practical ways of reducing strain and stress in families. Yet many families describe having to 'battle' for these and other supports; the bureaucratic and

complex procedures involved, as well as the prolonged waiting times before they are made available (Bevan, 2002).

Summary

The Box summarises the features of a quality family support service. These can form the basis of standards that have been proposed for evaluating family support services.

Features of a Quality Family Support Service

(Adapted from Sloper 1999)

- The service takes a holistic approach to assessing and meeting the family needs;
- The importance of relationship building between parents and professionals is recognised. Home visits feature as part of their work and first names are used.
- They provide a consistent, single point of contact for the family, such as a link or key-worker. They should be contactable at evenings and weekends to facilitate working mothers.
- They have a flexible, individualised, needs-led approach to their work with families and children. A menu of services needs to be provided rather than prescriptive programmes.
- The parents' own expertise with regard to their child and family is recognised, and actively sought when professionals undertake assessments of the child and when service plans are drawn up.
- They focus on parents' own concerns and recognise the importance of understanding parents' own perceptions of their priority needs;
- The support provided to parents empowers them rather than taking control away from them.
- Siblings and other close relatives such as grandparents are included.

Priority Issues in Service Development

Various commentators have identified a number of common issues that services need to address. Their importance will vary from area-to-area and across services. Hence an audit in each locality (e.g. local government of Trust area) would identify particular shortfalls. This would also help to reduce inequalities in service availability.

Moreover families of children with severe learning disabilities/difficulties tend to be better served than those whose children have physical or sensorial disabilities and chronic illnesses.

Information

A report for DHSS expressed it thus: "A requirement on authorities to offer, and to publicise a range of services to people with (learning) disabilities that need to be on offer if people are to have a real choice in the sort of provision they have access to.

(This models requirements under section 17 of the Children Act)". Research in N. Ireland has confirmed this need (McKeown et al, 2001).

Parental Advocacy

Arguably some, perhaps many parents of children with disabilities have been reluctant to advocate for their needs. Although this is changing – notably in education and the choice of schooling - but even here parents benefit from the opportunity to have someone who can advocate alongside them or on their behalf. This pressure can bring extra resources into the system as it has done in the field of education. However there is presently limited scope for parents to enlist the help of advocates.

Consultation with children and young people

Recent legislation and guidance across education, health, leisure and social services strengthens the expectation that professionals will consult with children and young people about the decisions that affect them. This can prove harder when the child has a disability but various studies have investigated this issue and provided guidance on ways of overcoming communication difficulties (e.g. Kelly et al, 2000). However much remains to be done especially of those children and young people with multiple disabilities.

Entitlement to health and social services

Demand for family support services often exceeds supply but the procedures for allocating services to families and children are often not transparent. Moreover when services are spread too thinly it is questionable the amount of benefit that families actually receive. There has been a dearth of research and even auditing of family support services. Nor can access to these services be determined solely on the characteristics of the child with the disability; parental and family needs must also be taken into account.

Direct Payments

For older teenagers the extension of Direct payments to families opens up new possibilities for families to obtain the services they feel are best suited to the needs of their families. (This is proposed to happen in Scotland). The development of voucher schemes and service brokerage have also been proposed as ways of giving more power to parents over the services they access. The English White Paper – Valuing People – gave considerable support for Direct Payments.

Inclusion

Increasingly parents expect services to be available in ordinary settings; notably mainstream preschool and school settings or in mainstream leisure settings (Thompson, Taylor & McConkey, 2000: O'Connor, Hartrop & McConkey, 2003). This has implications for health services in particular, in that more of the therapies and specialist nursing services will need to be provided in mainstream settings rather than in special schools which tends to be the predominant model at present in Northern Ireland, although this appears to be less so in other parts of these islands.

Short Breaks - Leisure Activities

Many parents seek breaks from the caring role but prefer those that offer their children a perceived benefit. After-school clubs, evening and weekend activities need to be

more widely available. Family-based, short break schemes are also seen to offer benefits to the child (Prewett, 2000) as can domiciliary support workers when they facilitate the child participation in community activities or outings. If provision is provided in a residential settings, families prefer these to be in small, homely and local accommodation (McConkey, Truesdale and Conliffe, 2003: see Part 2).

Transitions

The period from 14 to 25 years has been characterised as a particularly difficult time for family carers and the young person (Ward et al, 2003). Among the proposals for improvements is the development of a multi-agency transition plan; the provision of a named worker to co-ordinate the service changes and greater choice of post-school options (see Chapter 4).

Autistic Spectrum Disorders, ADHD and mental health needs

Increasing numbers of children are being diagnosed with these two conditions. This places increased demands on already under-developed health and social services for families. The emphasis is currently on the need for early identification and intervention services but this has yet to be realised in many localities (Moore et al, 1999). The debate is whether services need to be designated specifically for these syndromes or whether the needs of the children and their families can be met by existing generic Child & Family Services. This is thought unlikely in the immediate future given the dearth of expertise within these services and the pressures they are under although this could well be a longer term goal. The conclusion reached in a recently completed UK Review by the Foundation for People with Learning Disabilities (2002) was that an augmented Child and Adolescent Psychiatry service would best provide the specialist help required by children and young people with additional mental health needs. They also recommended closer working between Child and Adolescent Psychiatry and learning disability services.

High quality staff training

Opportunities for staff in health and social services to be trained in family-centred approaches has been limited. This needs attention in both pre-service and in-service training. Supervised practice should form a core element of such training alongside the participation of parents and young people with disabilities as trainers.

Involvement of parents in service planning

Mechanisms need to be found so that the voice of parents is heard in planning forums at local, regional and national levels (Department of Health, 2001).

Circles Network (2004) have recently developed a leadership and empowerment programme aimed at training and supporting parents to become Partners in Policymaking. This has built on experiences in the USA and UK and a course has recently been completed in Northern Ireland. The aim is to develop "community leaders who will work with others to build a fairer and more just society for all by ... working with others to change things locally and nationally". Although it is early days to assess the impact of this initiative it does attempt to redress the imbalance of information that is available to parents and opposed to professionals.

Re-organisation of services

Some have proposed a radical overall of existing services if multi-professional, family-centred services for children with disabilities in particular is to be attained. Within Britain, some local authorities have merged their social services, housing and education departments and forged partnerships with primary healthcare with a view to providing one-stop, local services for families (Russell, 2003) and Government is considering the establishment of 'Children's Trusts' with a remit for service delivery. These arrangements would provide for the joint funding of services as well enabling professionals to work in partnership under common management structures. Voluntary agencies are also well placed to provide integrated services particularly in the preschool years.

Conclusions

Family-centred services for children with disabilities are slowly becoming more of a reality in our education, health and social services. This has been triggered by parental lobbying allied with increasing recognition by professionals of the complexity of creating an ordinary family life for children with disabilities. Present services are bound by bureaucratic and rigid operating procedures as much as by a lack of monies and suitably trained personnel which are required to create a new paradigm in responding to the needs of families – and not just to the disabilities of the child.

References

- Andersson. (1993). Depression and Anxiety in families with a mentally handicapped child. *International Journal of Rehabilitation Research*, 16 (3), 165-169.
- Baker B. (1988) Evaluating parents training. *Irish Journal of Psychology*, 9, 324-345
- Barr, O. (1999) Supporting families : reflecting on tacit messages. *Journal of learning disabilities for nursing, health and social care*, 3, 121-122
- Bevan, M. (2002) *Housing and disabled children: The art of the possible*. Joseph Rowntree Foundation: Findings November 2002.
- Booth, C.L. & Kelly, J.F. (1999). Child care and employment in relation to infants' disabilities and risk factors. *American Journal on Mental Retardation*, 104, 117-130.
- Carer's National Association, 2000.
- Carpenter, B. (2000). Sustaining the family: meeting the needs of families of children with disabilities. *British Journal of Special Education*, 27, 3, 135-143.
- Circles Network (2004). Partners in Policymaking. www.circlesnetwork.org.uk
- Cotterill, L., Hayes, L., Flynn, M. and Sloper, P. (1997). Reviewing respite services: some lessons from the literature. *Disability and Society*, 12, 5, 775-788.
- Department of Health (2001a) *Valuing People*. London. HMSO.
- Department of Health (2001b) *Family Matters: Counting Families In*. London: DoH.
- Dunst, C.J., Trivette, C.M., & Cross, A.H. (1986). Mediating influences of social support: Personal, family, and childhood outcomes. *American Journal of Mental Deficiency*, 90, 403-417.
- Foundation for People with Learning Disabilities (2002) *Count us in- report of an inquiry into the needs of young people with learning difficulties who have mental health needs*. London: Foundation for People with Learning Disabilities

- Glendinning, C. (1992). *The costs of informal care: Looking inside the household*, London, HMSO.
- Harrison, N. (2000). Respite care services for adults with learning disabilities: Carer stress and satisfaction with services. *Masters Dissertation in Applied Psychology*. University of Ulster.
- Hastings, R.P., Allen, R., McDermott, K. and Still, D. (2002) Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 269-276
- Hatton, C., Akram, J., Robertson, J., Shah, R. and Emerson, E. (2003) The disclosure process and its impact on South Asian Families with a child with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16, 177-188
- Kelly, B. & Monteith, M. (2003) Supporting Disabled Children and their Families in Northern Ireland. National Children's Bureau Report
- Kelly, B., McColgan and Scally, M. (2000) Chance to say: Involving children who have learning disabilities in a pilot study on family support services. *Journal of Learning Disabilities*, 4, 115-127.
- McConkey, R. and Adams, L. (2000) Do short breaks services for children with learning disabilities match family needs and preferences? *Child: care, health and development*, 26, 429-444
- McConkey, R. and McAteer, D. (1999) The contacts which families and children with learning disabilities have with health and social services. *Child Care in Practice*, 5 (2), 67-73.
- McNally, S., Ben-Shlomo, Y. and Newman, S. (1999) The effects of respite care on informal carers' well-being: a systematic review. *Journal of Disability and Rehabilitation*, 21, 1-14.
- Maes, B., Broekman, T.G., Dosen, A., and Nauts, J. (2003) Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability Research*, 47, 447-455
- McKeown, P., Piggot, M., Burghri, S. and McConkey, R. (2001) An evaluation of the Mencap Family Adviser Service in Northern Ireland. *Child Care in Practice*, 7, 273-287
- Moore, K., McConkey, R., Sines, D. and Cassidy, A. (1999) Improving diagnostic and assessment services for autistic spectrum disorders. *Early Child Development and Care*, 154, 1-11.
- O'Connor, U., Hartrop, B. and McConkey, R. (2003) *Parental attitudes to the statutory assessment and statementing procedures on special educational needs*. Belfast, DENI
- Prewett, B. (2000) *Committed to caring: The views of short break carers for children who are 'hard-to-place'*. York: York Publishing Services.
- Russell, P. (2003) Effective family support: message from research and practice in UK. Paper given at 4th European Congress on Mental Health and Mental Retardation: A lifespan multidisciplinary approach. Rome.
- Redmond, B., and Richardson, V. (2003) Just getting on with it: Exploring the service Needs of mothers who care for young children with severe profound and life-threatening intellectual disability, *Journal of Applied Research in Intellectual Disability*, 16, 205-218
- Singhi, P.D., Goyal, L., Pershad, D., Singhi, S. & Walia, B.N.S. (1990). Psychosocial problems in families of disabled children. *British Journal of Medical Psychology*, 63, 173-182.
- Sloper, P. (1999) Models of service support for parents of disabled children. What do we know? What do we need to know? *Child: Care, Health and Development*, 25 (2), 85-99
- Stores, G. (1992). Annotation: Sleep studies in children with a mental handicap. *Journal of Child Psychology and Psychiatry*, 33, 8, 1303-1317.

Thompson, B., Taylor, H. and McConkey, R. (2000) Promoting inclusive play and leisure opportunities for children with disabilities. *Child Care in Practice*. 6, 108-123

Twigg, J. & Atkin, K. (1994). *Carers perceived: policy and practice in informal care*. Buckingham: Open University Press.

Ward, L., Heslop, P., Mallett, R., and Simons, K. (2003) Transition: The experiences of young people with learning disabilities and their families in England. *Tizard Learning Disability Review*, 8, 19-28.

Williams V and Robinson C (2000) *In their own right*. Bristol: The Policy Press.