



What Works For Children ?

Meeting the needs of families with disabled children:
What Works & What's promising?

December 2003

This Evidence Briefing is primarily based on the report "What Works in Services for Families with a Disabled Child"¹ and includes some updating and the addition of key publications recommended by experts in the field. Unless stated, all references can be found in the above. The editor of the overview, Greg Khine, takes responsibility for the interpretation. Date warning: this work was completed in December 2003, and findings change with the passage of time.



WHAT WORKS FOR CHILDREN?

An ESRC funded project as part of the Evidence-based policy and practice initiative

This project is a collaboration between Barnardo's, City University and the University of York.

The 'What Works for Children?' initiative works predominantly at the implementation end of the evidence-based spectrum. It is important that our work and project outputs are meaningful to those whose task it is to plan and deliver services. In particular, we are looking at:

- How to make research available to those who provide or manage services.
- How to make the available research meaningful.
- How to get meaningful research into practice.

The project works with 6 Children's Fund Programmes in the Yorkshire area to look at levers and barriers to implementing research evidence into service planning and practice.

Our implementation officer, Sarah Frost, is based in Leeds and works with practitioners to identify their support needs and on issues related to implementing research.

As part of this work, we have developed some resources to assist practitioners and service planners. These are available on the website at www.whatworksforchildren.org.uk

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I. Introduction

This Evidence Briefing is based on an extensive review undertaken by Bryony Beresford, Patricia Sloper, Sally Baldwin, and Tony Newman for Barnardo's. The report was published in 1996 as "What Works in Services for Families with a Disabled Child?".¹

Parents with a disabled child are at pains to tell us that they see their child first, the disability second. It is important to underline that, whilst a child may experience a disability, they will also have important abilities. Sometimes the presence of a disability can prevent us from seeing the individual. Yet, if we are to meet their needs, we must strive to do exactly that.

It is intended to offer a concise overview of the issues faced by families with a disabled child, and how services may better meet their needs. For more detailed information on particular interventions or issues, we ask the reader to refer to the above report, as well as the suggested further reading.

It draws on two main bodies of research: Firstly, those studies that seek to identify factors which either help or hinder families to cope with the significant demands of caring for a disabled child. Secondly, work that describes the needs of disabled children and their families.

This briefing takes a needs based approach in looking at what works for families with disabled children, and is structured around six key areas of need that research repeatedly identifies:

- [information](#)
- [material resources](#)
- [break from care and domestic help](#)
- [coping skills and strategies](#)
- [social support](#)
- [service co-ordination](#)
- [needs of disabled children from black minority ethnic groups](#)

For each of these key areas this briefing identifies the **key messages** from research, as well as '**What Works**' and **What's promising**, where the evidence warrants this.

Our view of disability acknowledges both the social and the medical models of disability. Whereas the social model advocates an approach focussing on disabling environmental and social factors the medical model based interventions seek to treat, or sometimes prevent disability. It is questionable whether either model can be applied consistently to all forms or type of impairment.

II. Information Needs:

Key Messages

- The need to know about their child's disability, available services, benefit entitlements, and how they can support their child's development is common to all families of disabled children.
- Information has been shown to be one of the most valued aspects of families' contact with services, and yet is frequently not met.
- Knowledge and information are key to enabling individuals to cope with difficulties, and the lack of these can lead to feelings of helplessness, distress and depression.
- Meeting information needs is of ongoing importance, but particularly crucial at the time of diagnosis when parents are faced with a new and unknown situation.

... at diagnosis:

Issues around disclosure of diagnosis are relevant to medical, nursing and midwifery staff. Support from services concerned with families' social and emotional welfare is crucial at this time.

Many studies have found high-rates of dissatisfaction; both with the information and the way disclosure was handled.

While it is often suggested that a parent's anger at the diagnosis inevitably results in dissatisfaction, the evidence finds that midwives' opinions support parents' views, and there seems to be no relation between a parent's satisfaction with disclosure and

satisfaction with community services in the long-term.

Many professionals lack training in communication skills that could help them deal with disclosure more sensitively and effectively.

Parents' views of what is important are remarkably similar across studies. Research has produced blueprints for service development that appear to be effective in increasing satisfaction rates.

... continued provision:

Family needs change as the child develops, and mechanisms providing families with up to date information are needed throughout the family life cycle.

As the child gets older, information regarding preschool and school provision, the statementing process, services and opportunities after leaving school, and sexual development, have all been highlighted as areas of unmet need.

Disabled children themselves and their siblings also need information. Disabled children want information about their condition and treatment, living with the condition and tackling disabling barriers. They want professionals to talk to them directly in a way that they can understand, and not only to talk to them through their parents.²

Attractive information booklets can be produced and updated at relatively low cost, but attention needs to be given to their presentation and readability. Many leaflets are written in less than accessible language.

Further exploration of effective ways of providing information is needed. These need to encompass individual preferences as well as the information needs of different communities. Particular attention is needed to consider information needs of families from ethnic minority communities.

Families need personal support, and a facilitator or key worker who can help families access and co-ordinate information and appropriate services, remains crucial.

What Works and what's promising?: meeting information needs

- Parents receiving supportive services and counselling in the early period after diagnosis have lower levels of distress than those who don't.
- Written information in the form of a "Helping Booklet" can provide an initial resource, assisting parents to find out more.
- Some practices that seem promising include the use of the Parent Held Record to help improve information to families, and improve communication between parents and professionals, use of individualised letters to parents following appointments with paediatric consultants, and audio-taping of consultations.

III. Material Resource Needs:

Key messages:

- The demands of caring for a disabled child affects a family's access to and expenditure of money and material resources. Meeting the child's needs impedes parents' capacity to earn, while additional needs come at a cost.
- Employment and earnings patterns are affected, and both mothers and fathers are less likely to be in full-time employment, and on average earn significantly less than the general population.

Disability in a child creates significant extra costs, altering the way that families spend their money. The costs of bringing up a disabled child have been found to be three times as much as for a non-disabled child.³

A large proportion of families incur regular additional expenses directly related to the disability, as well as ordinary items such as water and electricity. Families can also face substantial capital outlay, often related to suitable housing, appropriate equipment and convenient transport.

Worries about money, housing, lack of vital assets such as cars and telephones, and employment are associated with high levels of parental distress.

What Works and what's promising?: meeting material resource needs

- There is no systematic evaluation of the effects of providing material help to families with disabled children, however the evidence offers clear and comprehensive accounts of what families' needs and preferences are likely to be.
- Studies on the impact of Family Fund grants evidence how parents value this kind of material help and its capacity to reduce day to day stresses and improve the quality of family life.
- Research gives an exceptionally clear idea of how parents want social workers and other professionals to respond to their needs for material resources. Such an approach suggests that we:
 - need to fully appreciate the pressures on living standards and build our professional practice with families around this.
 - need to develop an understanding of how and when particular conditions are likely to be causing extra costs and affect employment, as well as being alert to trigger events, such hospitalisation.
 - require a thorough and up to date understanding of the available financial help provided by the state or voluntary sector.
 - use this knowledge, to anticipate families' needs, alert them to sources of help, and assist them in asserting their entitlements.
 - must build an awareness of local capacity, so as to allow for referral of families to local agencies where needed, for example for financial advice.

IV. Needs for Breaks from Care & Domestic Help:

Key messages:

- Taking a break is one of the most frequently reported needs among parents caring for a disabled child and has been identified as a key support service to families. However, in the majority of cases this need remains unmet.
- Research suggests that parents satisfied with short-term care facilities believe that it plays a significant role in enabling them to continue to care for their child at home.
- Short-term care is associated, at least in the short-term, with reductions in parental stress for the majority of parents who use it.⁴
- Around a third of parents choose not to use a short term care scheme, and some studies indicate that some parents view using such a service as a sign of failure or “not coping”, and many have concerns about the child’s ability to cope with the separation.
- Parents’ need for domestic help is evident. In a survey of parents with severely disabled children, around 40% expressed a need for help with housework and the day-to-day care of their child.

The need for short-term care increases with time. Parents find the long term demands of meeting their children’s needs wearing, while managing behaviour problems can be more difficult as the child grows older, and assistance from extended family and friends tends to dwindle.

Though many parents do not use short-term care when their child is young, some recognise their future need for a break from care and like to set in place such support well in advance. Knowing that support will be there when needed is in itself reassuring and supportive.

Mothers with a disabled child are less likely to work outside the home compared to mothers of non-disabled children. Among mothers with a disabled child, those that do work outside the home experience less distress than those who don’t. For some, it is their lack of access to day care that prevents their return to work.

The degree to which disability creates extra work in the home is positively associated with mothers’ reported levels of stress. Receiving help in the form of a grant or household equipment has been shown to result in greater sense of well being and lower levels of stress.

The exact type of home based support preferred, will in part depend on the help a family is receiving. Services should be able to respond to needs during crisis times, and aim to be as unobtrusive and flexible as possible so as not to disturb normal family life.

What Works and what's promising?: family based short term care

- Family based short term care can offer wider social experiences and increased independence for the child. Parents often report a positive and supportive relationship with the host family.
- National surveys have found that family based care schemes provide the highest levels of satisfaction in terms of both the standard of care received and meeting the child's needs. Areas of dissatisfaction are the lack of overall supply, and problems with availability at times when parents need it most, such as weekends and during school holidays.
- Comparative studies suggest that mothers particularly benefit, reporting lower levels of stress and greater engagement in social activities.
- Research characterises a good short term care scheme as one that is local, available on demand, provides age-appropriate and good quality care including emergency support, and access to adequate specialist support facilities. As well as information and choice, there should be careful preparation for the first placement and the programme should offer a positive experience for the child.
- While research suggests that family-based schemes are the preferred short term care option for parents, practitioners report that recruiting sufficient families can be difficult, particularly in areas of high deprivation where potential host families either have support needs of their own or do not have the space to accommodate another child.
- Though there has been little evaluation of short term care schemes from the perspective of the child, research suggests that the majority of children enjoy using short term care services.
- Elements valued by both children and parents were recognition of the importance of friends and play in children's lives; recognition of the child's need for close and lasting relationships with adults and children; and the confidence that the child is enjoying new experiences and relationships with people who cherish them and are competent to deal with their special care needs. Research also shows that these criteria are not always met, and in these instances children's experiences with short term care are far from positive.

V. Need for Coping Skills and Strategies:

Key messages:

- Coping skills are important in mediating the relationship between the difficulty experienced and levels of distress or well-being. While parents clearly express a need to acquire these additional skills, this is largely unmet.
- Feeling competent to make a positive contribution to the child's development and being able to deal with difficult behaviour can counter the feelings of helplessness and lack of control that parents with a disabled child commonly report.
- "Professionalising parents" and expecting them to learn skills and undertake treatments with their child is not the aim. However services need to respond to parents' consistently expressed need for skills in a way that will be sensitive to existing abilities, needs and motivations, together with support from professionals.
- Disabled children are also likely to experience sleep and/or behavioural difficulties, both of which are key sources of stress as well as one of the reasons for admission to long term care.

... managing behaviour problems:

While the majority of children with a disability do not have behaviour problems, studies have shown that disabled children, particularly those with learning difficulties, are significantly more likely than non-disabled children to experience behavioural and emotional difficulties.

Behaviour problems encroach on normal family life, and threaten parent-child relations, significantly increasing parents' reported levels of stress.

Difficult behaviour is a frequent reason for excluding children from school and short-term care.

Reports from intervention programmes suggest that training parents in behaviour management skills considerably benefits both parent and child, reducing the child's behaviour problems and enhancing parents' sense of competence.

Physiological causes of problem behaviour may also need to be investigated. For example, children with and without disabilities are more likely to experience behaviour problems where the child suffers recurrent minor infections.

Over time, behaviour attributable to such events can become habitual and behaviour problems can develop. This underlines the importance of monitoring health problems and ensuring support for parents in adjusting parenting strategies when children are ill, as well as in re-establishing norms after periods of illness.

Although behaviour problems tend to emerge and increase in severity as children grow older, this is one area where it is possible and important to provide preventative services as well as interventions.

... managing sleep problems:

Children with severe learning disabilities often have persistent sleep problems. One study found that, half the parents of children with severe learning disabilities had trouble settling their child at night, and two thirds reported night waking problems.⁵

However, recognition of sleep problems as a challenging behaviour requiring attention is lacking. The problem occurs at night, and is therefore invisible to professionals, while many parents assume it as an inherent part of the child's learning difficulty and do not seek help.⁶

Sleep problems can be helped through behaviour modification and parents can be trained in the use of these techniques to overcome or substantially reduce their child's sleep problem. In the absence of harm arising from behavioural intervention, their potential benefits may merit exploration before considering physical intervention.⁷

... strategies for dealing with stress:

Coping strategies are what parents actually do (or think) in response to the stresses they encounter. Research clearly indicates that the strategies parents use (as well as the availability of coping resources) have a greater influence on their well being than other factors such as the severity of disability.

People have different preferences for dealing with stress, regardless of the cause of the stress. Some ways of coping seem to be more effective than others.

Without adequate resources, parents may adopt coping strategies, which do not successfully deal with the stress. This increases their likelihood of experiencing health problems.

What Works and what's promising?: meeting the need for coping skills and strategies

- Early intervention programmes, such as the Portage schemes, seem effective in the short run, however long-term effects on the child's intellectual development is less certain. Despite this uncertainty, it has been argued that certain services, including early intervention schemes, should be available as a basic right.
- However, there are concerns that parents may risk becoming over-burdened and feeling pressurised to adhere to such intervention programmes, and that parents of children with profound multiple disabilities risk becoming disheartened if programmes are not carefully tailored to their children's development.
- Pharmacological interventions remain the most widely used method of managing sleep problems, yet parents seem to find behavioural interventions more useful⁸.
- A recent review looking at five behavioural strategies to alleviate sleep problems (sleep scheduling, bedtime routine and gradual distancing of parents, extinction, bedtime fading with or without response cost, and chronotherapy) reported sleep improvement in 83% of participants.⁹
- Such intervention strategies seem to have different effects on mothers and fathers, with particular benefits for the mother¹⁰. This highlights the need to assess all family members' needs.

- Research findings suggest that parents can benefit from coping skills training. For example, one study of mothers with disabled children reports lower depression scores, improvements in coping skills, and greater satisfaction with the relationship between mother and child following skills training.
- Coping skills training is probably in its best developed form in the USA. It involves training parents in the use of coping strategies such as positive self-statements, relaxation, and developing social and problem solving skills.

VI. Social support:

Key messages:

- Research with families of disabled children indicates that the aspects of support most strongly related to parental distress are parents' perceptions of the quality of internal family relationships and support from their informal network.
- Social support can have both negative and positive consequences, particularly where a relationship is not reciprocal over the long term. In highly unequal relationships the parents may experience feelings of guilt and indebtedness, whereas the provider may develop resentment. Families with disabled children can be particularly prone to feeling unable to reciprocate and may cease to seek support.
- Social support via formal services is complex, and research has shown that parents' dealings with services can exacerbate stress, particularly where they experience difficulty in obtaining information and help. Where families have many appointments with services, this can lessen their contact with social networks, as well making their working lives more difficult.

Evidence from general studies of stress and social support suggests that the most important type of support is confiding relationships or strong ties, most often found within the family.

While such relationships provide support, families with very dense support networks (closely linked with many people knowing each other), may remain at risk, as members of such networks are more prone to burn out and parents may feel that they are placing too many demands on too few people.

What Works and what's promising?: meeting needs for social support

- Substantial research on the role of services in providing family support in the USA suggests that effective help-giving is characterised by relationship building; communication, honesty and clarity; an understanding of the family's own concerns, help in translating concerns into needs and then into the use of resources to meet them; and responsiveness to family values and goals.
- Parents can gain considerable support from meeting others in similar situations. Both self-help groups and befriending schemes can facilitate this. Whilst not all parents want to be involved in or will benefit from such initiatives, there is evidence that many who take part, find considerable support.

... Self-help, befriending, and link schemes:

Parents from black and minority ethnic groups and those on very low incomes are less likely to know about the existence of support groups.

One study found self help/befriending groups to have been particularly valuable to socially isolated Bangladeshi mothers in enabling them to meet and support each other.

Professional involvement in self-help groups is variable, and there is no one model of best practice. However the training and support of parents who organise and facilitate such schemes is an important issue, often overlooked.

Special groups, such as those for black and minority ethnic families, have an important role in the provision of family services, but for groups to be accessible for many families, practical considerations of child-care and transport need to be addressed.

There is a role for groups in fulfilling parents' support needs, but better ways of informing parents about groups and targeting hard to reach populations are needed

Link family schemes are another way to offer support and respite to parents. In such schemes, families with disabled children are linked to volunteer families with non-disabled children who share some of the care of the disabled child.

An evaluation of a Link Family Scheme suggests the service was effective, with users of the service reporting less maternal stress, greater perceived social support, and fewer sibling behaviour problems.

... Supporting fathers:

The usual patterns of service delivery can marginalise fathers with both home visits and appointments for the child tending to happen during working hours.

Fathers in one study reported that when the family returned home after the birth of their child with Down's syndrome, no help was offered specifically to them, all help was focused on the mother and child.

They felt frustrated at not being able to get information first-hand, and the mothers' imposed role as an envoy could create tension, disempower the father, and cause the mother to feel inadequate if the information she was able to give was seen as insufficient by the father.

The effectiveness of interventions may be compromised where they focus exclusively on one family member, as they tend to ignore other family members' ways of coping. Programmes that teach skills to only one parent can disrupt established patterns of family interaction and reduce cohesion within the family.

Where fathers receive less support in understanding their child's disability, differences between the parents in patterns of interaction with the child may be accentuated. An observational study of mothers and fathers teaching their children with learning disabilities found that fathers were less flexibly attuned to their children's responses and less successful in their interactions. With less support enabling them to gain confidence with their child, fathers may become more negative.

What Works and what's promising?: meeting fathers' support needs

- To better meet fathers' needs, flexibility in timing of appointments is needed.
- Examples from the USA include setting up specific activities for fathers to undertake with their children at weekends, evening discussion groups for fathers to share ideas and problems and gain support from each other, and family meetings.
- An evaluation of the above using pre- and post-test measures, found that both mothers and fathers showed decreases in stress and depression, as well as increases in satisfaction with social support.
- Although these results suggest promise, we need further robust evidence, in order to ascertain whether such changes occur as a result of the intervention.

... Supporting siblings:

As with fathers, the needs of siblings of disabled children have received relatively little attention in research and services. A study comparing service staff predictions of parents' concerns with actual parent responses showed that staff clearly underestimated the extent of concerns about siblings.

Research reviews suggest that while siblings are at increased risk of developing behavioural and emotional problems, there is considerable variability in their response.

Such, sibling adjustment is most clearly linked to variables relating to family functioning, particularly family relationships and maternal depression.

The consideration of the needs of siblings in a whole family approach is necessary. Many studies have relied on parents' accounts of sibling reactions to a disabled child or retrospective accounts from adult siblings. Research which consults brothers and sisters directly can provide a complementary viewpoint.

The following aspects of service support for siblings have been identified based on research with parents, practitioners, and siblings:

- information and discussion about their brother or sister's disability.
- advice about how to help as well as deal with difficult behaviour.
- advice about how to deal with others' attitudes towards disability.
- a life of their own – opportunities to develop their own friendships and activities independently of their brother or sister. These needs can be met through a combination of advice and information to parents and inclusion of siblings in contact with professionals.

As with any sibling relationship, both negative and positive feelings and perceived inequity in parental treatment, are commonly expressed. However, the added factor of disability in one sibling may increase feelings of guilt about negative feelings in brothers and sisters.

For example, one study describes a sibling's feelings of embarrassment about unusual behaviour, jealousy at the amount of attention paid to the disabled sibling, isolation and difference from peers, anger at restrictions on family activities, and experiences of bullying and teasing at school.

Such issues may be difficult to express at home and sibling groups have been seen as a way of providing support for and meeting the needs of siblings. However, evaluations have tended to lack detail about the structure and content of such group work, making it difficult to assess its overall effectiveness.

What Works and what's promising?: meeting siblings' support needs

- One evaluation describes a workshop for child siblings of children with autism and related disorders, aimed at improving their competence in managing situations related to their disabled sibling and helping children express both positive and negative feelings. Two leaders ran the workshops, which included a variety of activities; opportunities for discussion in groups and in pairs; role play; and social activities.
- The evaluation showed positive results. After the workshops the majority of participants were spending more time with their sibling, felt they had better relationships, and had more ideas for activities to share. Almost half found it easier to bring friends home and talk to friends about feelings. In addition to an increased confidence in explaining the disability to others, there was a substantial increase in the number of siblings who felt able to ask their parents questions about their brothers and sisters, and the majority felt more able to talk to their parents.
- Parents felt that siblings were more willing to be with the disabled sibling, more tolerant and patient, as well as more knowledgeable about the disability. Moreover, three quarters of parents thought the effects of the workshops were not confined to the sibling; the family as a whole had benefited.

... Supporting disabled children themselves:

Only recently have the needs of disabled children themselves been recognised in policy and research, earlier work has overwhelmingly concentrated on parental needs. The movement towards involving children themselves in decisions that affect their lives contributes to a holistic approach to fulfilling a family's support needs.

Balancing the needs of family members and supporting parents whilst encouraging opportunities and development for the child, requires new approaches and knowledge.

Much attention has focused on the cognitive and motor development of disabled children, but far less attention has been given to their social life and the factors that may affect it. This is despite the fact that interaction with peers is well recognised as an important influence on children's development and well being.

Disabled children need opportunities for social interaction with peers as much as any child, yet evidence suggests that for many, social contacts are limited.

Environmental obstacles include unsuitable housing and a lack of play opportunities in the children's home neighbourhood and school, unsuitability of local facilities, lack of transport, attitudes of staff and public, cost and lack of money, as well as lack of personal support.¹⁰

School-aged children's social contacts are most often with children who attend the same school. Disabled children who attend special schools at some distance from their homes are more likely to be restricted in forming social contacts in their home neighbourhood.

One study found that children with Down's syndrome attending special schools were less likely than those in mainstream schooling to play with schoolmates outside school times. Although most (87%) had some informal play contacts with other children, the majority of these contacts were only once a week or less.

Childrens' and professionals' views of the benefits of inclusive services can vary significantly. For example, a recent consultation¹¹ reports that in the area of inclusive play, professionals emphasise learning life skills, increasing independence, and self-esteem, whilst children focused on friendships and fun.

The increasing developmental gap between children with learning disabilities and their same-age peers may contribute to the reduction of social contacts, as children get older. Schemes that actively encourage and facilitate contacts between disabled children and their non-disabled peers are needed.

What Works and what's promising?: meeting disabled childrens' support needs

- Relatively few studies have consulted directly with disabled children, though the number and quality of such studies is growing. One such study, although acknowledging the challenges involved in researching disabled children, confirms the importance of social relationships. Young people saw relationships as major contributors to their satisfaction with daily life, and relationships figured prominently among their future aspirations.
- However this study also gives cause for concern, as it reported that disabled children's lives were often quiet, fairly solitary and suggestive of limited personal relationships.
 - most of their social contacts revolved around their daily placements, which were largely segregated from non-disabled peers this was particularly the case for young women and those with multiple service needs
 - many were dependent on their parents for assistance in getting out
 - they were more likely to rely on parents as confidants than non-disabled children

VII. Co-ordinating Services:

Key messages:

- Many agencies are involved in meeting the needs of families with disabled children. Lack of coordination can place a burden on parents.
- One study found that families with severely disabled children had been in contact with an average of 10 different professionals over 12 months. Half of the parents felt they had done most of the work in contacting services and getting help for the family and child. Those parents who did not take an active approach to obtaining help were likely to have the highest levels of unmet need.
- Up to 80% of families report poorly co-ordinated services¹² and inspection report continue to echo this¹³.
- One major and longstanding recommendation of research on family support is the need for families to have a single point of contact with different agencies via a key or link worker. Research continues to find that only a minority (33%-50%) have access to a key worker.
- Where a key worker system is in place, the overall quality of life in families with disabled children is improved.¹⁴
- The need for a coordinated approach to services for disabled children is emphasised in the guidance to the Children Act 1989 and in Quality Protects.

Parent's views support the belief that key workers are effective in improving parent-professional relationships. Parents who had a key worker were more likely than those without to report a positive relationship with professionals, based on mutual respect, equality and recognition of each other's contribution.

A detailed evaluation of a project involving the provision of specialist resource workers to families of severely disabled children suggests promising outcomes. Comparing families with and without resource workers, the study showed that:

- parents' opinion of the service were positive, almost all felt it had made a difference to their lives, with over half reporting a very great difference
- families with a resource worker were more likely to have obtained practical help, such as aids and alterations to property and were less likely to feel that the care of their child was onerous
- they also showed a decrease in feelings of restriction, were more satisfied with respite facilities, and had generally received more information

Parent-professionals partnerships have received considerable attention, particularly on what the characteristics of positive relationships should be and how they can be achieved.

Fundamental characteristics of partnership approaches recognize:

- parents' expertise regarding their child and family
- the individuality of each family
- the importance of parental choice in decision-making

Partnership approaches to supporting families of disabled children have a number of implications for service delivery. Such services will emphasise:

- a needs led approach which is flexible, family centred and individualised

- assessment of the family's own concerns and respond to family identified needs
- recognition that needs form a hierarchy. If basic needs are not met parents are less likely to see higher level interventions as important. Professional demands which do not fit the family's hierarchy of needs can produce negative effects, increase stress and cast the family as non-compliant
- support that is empowering rather than taking control
- acknowledgement of parents' own expertise with regard to the child and family

... Multi-Agency and Multi-Disciplinary Team Working:

Co-ordinating services has organisational implications, requiring a team approach within which information and skills can be shared.

Multi-disciplinary teams have a long history particularly in learning disability services, with Community Learning Disability Teams (CLDTs) and for children with special needs, in Child Development Centres.

Not all families benefit from contact with such teams and lack of co-ordination remains an issue.

Although the challenges of inter-professional and inter-agency working cannot be ignored, evaluation of multi-disciplinary and multi-agency approaches, from the point of view of parents and staff, suggests that they have significant advantages for the provision of effective family support services.

What Works and what's promising?: Multi-Agency and Multi-Disciplinary Team Working

- Research within the NHS indicates that team working can be effective, resulting in better patient outcomes and lower staff stress levels.¹⁵
- According to staff involved in multi-agency initiatives, the following impacts were identified:¹⁶
 - For children and their families: improved access to services, addressing needs more appropriately, and better prevention
 - For agencies: broader understanding within agencies, better interactions, increased joint working in other areas, and helped individual agencies to attain targets
 - For professionals: greater understanding of how other agencies work, interaction with other professionals, rewarding but also increased work pressure
- Whilst there is a lack of good evidence on the effectiveness of collaborative working in relation to effects on patient care¹⁷, there is good agreement on factors that facilitate or inhibit collaboration:¹⁸
 - Facilitative factors are: clearly defined roles and responsibilities; senior level commitment; explicit goals and shared vision; clarity in lines of accountability; inter-agency training; timetable for implementation; effective systems of two-way communication at all levels; service mapping and evaluation shared information; shared resources; and flexibility.
 - Inhibitive factors are: structural, organisational and cultural differences;

organisational change; professional differences; change in personnel; lack of commitment at agency or individual level; lack of trust between individuals and agencies; a reluctance or inability to share information; lack of leadership and/or key personnel; differences in accountability; loss of power and autonomy; time pressures; and limited resources.

- Although more research is needed to evaluate different team approaches from a service user perspective, the strong consistency across different reviews is striking. This suggests that the above elements are important in creating efficient team structures and that such strategies have the capacity to promote effective outcomes for families.
- One potential way of improving multi-disciplinary and multi-agency working is interprofessional education, and research suggests that this is most effective at improving patient care and/or the organisation of care where it is of longer duration, delivered in the workplace (as part of continuing professional education rather than as part of undergraduate or postgraduate education), and in the acute sector.¹⁹

VIII. Meeting the Needs of Disabled Children from Black and Minority Ethnic Groups

Key messages:

- Ethnicity presents a dilemma to those carrying out studies reviewing aspects of child welfare services. To present the needs of black and minority ethnic groups separately can de-emphasise the common experiences and needs of all families with disabled children. To fail to present them risks ignoring important needs.
- Nonetheless, despite the need for caution, the evidence for significantly different – and mostly undesirable – outcomes for many black and minority ethnic children and families who encounter social welfare services is beyond dispute. However, care must be taken not to apply this general observation indiscriminately to all groups in all circumstances.
- In relation to disabled children, the observation that black and minority ethnic children tend to be over-represented in services characterised by social control and under-represented in preventative and supportive services remains, sadly accurate.
- While attention should not be detracted from the shared experience and needs of all disabled children (and universal principles of good practice), the circumstances of black children and their families in the UK are sufficiently distinctive to warrant some separate and additional attention.
- Explanations for the distinctive experiences and the weight attributed to them are the subject of considerable debate. Institutionalised racism, failure of welfare services to consult with and respond to black and minority ethnic communities, inaccurate and stereotypical beliefs about black and minority ethnic families and barriers to access are familiar structural deficits.
- On the other hand, the disproportionate presence of black and minority ethnic communities in inner city areas, poverty, migration patterns and poor housing are factors also associated with social class and are therefore likely to affect any family.

Black and minority ethnic communities are often impeded from accessing welfare services and the prevention of initial and equal access and the inappropriateness of service provision were noted by a joint ADSS/CREE report as early as 1978. A more recent review of services to black communities suggests this is still the case.

One cross-cultural study of support services for families with a disabled member considers that a family's cultural background is important in planning a response to need.

Consequently, much of the research, both in relation to general welfare services to black and minority ethnic groups and specific services to disabled children, stresses the need for responses which change the context within which services are designed and delivered.

One such study, relating to the needs of disabled Asian children proposes that:

- all staff should have regular anti-racist training
- ethnic monitoring of supply and demand should be standard
- more bilingual minority ethnic staff should be recruited

- key information should be available in appropriate languages
- more account should be taken of minority ethnic needs when assessing community care needs
- local authorities should fulfil their responsibilities to provide appropriate services to minority ethnic groups under the Race Relations Act 1976

... Information Needs

Consultation with black and minority ethnic families and communities is widely seen as a means of rectifying both the information and attitude based deficiencies of primarily white led and staffed welfare organisations.

These deficiencies, as they affect disabled children, include:

- inadequate information and support for families with pre-school children
- poor home-school liason
- limited use of short-term breaks and inadequate residential care

... Short-term breaks:

Black and minority ethnic families have unmet needs for short term-breaks. One study notes how parents of black and minority group children with learning disabilities make disproportionate use of hospitals rather than families for short-term breaks.

There is conflicting evidence as to whether Asian family members and neighbours contribute more to the care of disabled children than white families. However the belief held by some service providers that 'they prefer to look after their own' is contested.

One study suggests that, rather than take-up rates being low due to client preference for intra-community and family-support, low take-up rates were associated with service rather than family characteristics. In other words services were not seen to be appropriate rather than families being content with their situation.

Parents express concern about whether their child's culture, religion and language will be respected and whether ethnic matching with short break carers and sitters is possible. Misconceptions about the role of social services and social work can also play a role in limiting uptake.²⁰

Measures to increase the take up of families based short-term breaks may include recruiting from local black communities, making available appropriate oral and written means of communication to all users, and understanding and respecting the cultural and religious customs of individuals and communities.

In the context of such a lack of needs fulfilment, delaying the introduction of a service until evidence of their effectiveness is available would be irresponsible. Nonetheless, there is only a small amount of firm evidence that certain approaches are as powerful in their contribution to programme effectiveness as claimed.

For example, cultural and ethnic congruence between client and staff is often proposed to boost uptake, yet studies bear mixed results. One study of take up rates of day services for young disabled Asian women, suggests that gender may be a more powerful determinant than cultural and ethnic variables.

We need to find out, not just whether such interventions or service characteristics are broadly effective, but what particular factors contribute to effectiveness.

IX. Conclusion:

It is clear from the above that there is no one blueprint for an effective service. Different families have different needs and their response to services is affected by their differing characteristics. It is important that we recognise the individuality of families, fathers and mothers, as well as siblings and circumstance. Although services must consider the family as a whole, account also needs to be taken of individual needs and preferences.

As the views of disabled children and their siblings are given greater importance, we need to further develop ways of accessing their views. Similarly, further attention is needed in developing ways of consulting with parents, particularly those from families whose circumstances make it hard for them to participate in existing groups and networks.

Parents' views relating to family needs and coping strategies has enriched research in those fields, and research on the effectiveness of interventions would greatly benefit from more evidence from parents.

This will require new methods of working with parents and children as individual and collective consumers, participating via mechanisms such as consultation workshops, and ongoing arrangements for contributions to the development and review of services.

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Useful Resources:

Be Evidence Based

www.be-evidence-based.com

Based at the University of Exeter Centre for Evidence Based Social Services (CEBSS), the site aims to provide a one-stop resource of key research findings from critically appraised social care research. The material covered spans the broad range of functions that Social Services now perform and is designed to be of use to both users and providers of services. Separate sections include online web training and information about accessing social care material. There is a skills section allowing you to develop your skills for evidence-based practice and decision-making.

Centre for Evidence Based Social Services (CEBSS)

www.ex.ac.uk/cebss

Based at the University of Exeter. Provides access to various useful databases: CAREDATA, Pubmed and the NHS Centre for Reviews and Dissemination (CRD) Systematic Reviews from the Cochrane and Campbell databases. It also provides very good training tools and information on using the internet to locate research, such as the Internet Social Worker tutorial.

Electronic Library for Social Care (eLSC)

www.elsc.org.uk

As well as linking to Caredata (a database of article abstracts and research summaries) the eLSC has access to the Practice, Guidance and Standards Database; SCIE best practice guides, currently under development; and other social care resources.

International Center for Disability Resources on the Internet (ICDRI)

www.icdri.org

ICDRI is a US based gateway to information regarding disability and includes a knowledge base of quality disability resources and best practices.

Making Research Count

www.uea.ac.uk/menu/acad_depts/swk/research/mrc/welcome.htm

A partnership between seven English Universities and local authorities, and promotes evidence based practice through workshops, the development of training materials and the preparation of Quality Protects guidelines.

International Center for Disability Resources on the Internet (ICDRI)

www.icdri.org

ICDRI is a US based gateway to information regarding disability and includes a knowledge base of quality disability resources and best practices.

Joseph Rowntree Foundation

www.jrf.org.uk

Provides summaries of all their funded studies. The JRF Findings (summaries of JRF funded research) can be found at: www.jrf.org.uk/knowledge/findings and include a vast array of studies on all aspects of disability.

Research in Practice

www.rip.org.uk

An initiative of the Association of Directors of Social Services organisation set up to promote evidence based practice in social care and currently working with a network of over 65 childcare agencies. Searchable evidence bank open to all including summaries (brief appraisals) of key reviews and published research in practice research reviews available on-line.

Social Policy Research Unit, Department of Social Policy and Social Work, University of York

www.york.ac.uk/inst/spru

The SPRU carries out research in relation to social security, health and community care. In addition to a range of publications available online, the 'Research Works' series offers concise briefings on research findings that will particularly appeal to practitioners. These cover a wide range of issues and can be found at: <http://www.york.ac.uk/inst/spru/pubs/researchwks.htm> 'Research Works' is available in Braille.

What Works for Children?

<http://www.whatworksforchildren.org.uk/>

What Works for Children is part of the ESRC funded EvidenceNetwork and is a joint initiative between Barnardo's, the University of York and City University. This is a three year project looking at the levers and barriers for implementing research evidence in health and social care practice.

Our team produces resources for practitioners wanting to use evidence in their work. Have a look at our website, and particularly the resources section for access to our evidence guide, Evidence Briefings and EvidenceNuggets, as well as other tools and summaries of research evidence.

For news about this initiative, you can read our latest project newsletter online or, to be added to our mailing list, send an email to Kristin Liabo at k.liabo@city.ac.uk .

