

## What works in services for families with a disabled child? - Summary

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### ***The 'What Works?' series***

Some ways of dealing with problems work better than others. Every child has the right to expect that professionals intervening in their lives will do so on the basis of the best available knowledge. But the majority of interventions in social care are not evaluated before they are introduced. In that sense, much of the work done with children is an uncontrolled experiment.

Barnardo's has a special interest in evidence-based practice, that is, finding out what works, and ensuring that the interventions we and others make in children's lives are as good as they possibly can be.

As Roy Parker and his colleagues have pointed out:

*'A hundred years ago, the benefits of providing separate care for deprived and disadvantaged children were thought to be self evident. It has since become increasingly apparent that unless outcomes in childcare can be adequately measured, we have no means of justifying the actions of social workers, which may have far reaching and permanent consequences for individuals.'*

Qualitative work, and user studies, for which the UK has a good record, are important in understanding the processes which enable interventions to work well, and understand what service users most value. They do not, however, help us to know what interventions work best, or why.

In order to understand cause and effect - the relationship between a particular intervention and an outcome - randomised controlled trials are important. RCTs in the UK and North America include studies of day care, home visits, accident prevention, and other early childhood interventions.

The cohort studies, such as the National Child Development Study (NCDS) enable us to see who does well after a poor start in life, and understand what factors may lead to resilience.

Barnardo's What Works reports draw on a range of research designs and evaluations which suggest that particular interventions are worthwhile.

## ***This report in brief***

This report discusses effective practice with families who have disabled children up to the age of sixteen. The evidence reviewed comes from research, examples of good practice and parents' views. The authors acknowledge that the report is deficient in not directly addressing the views of children themselves. The intended audience are those responsible for the social welfare of children and their families. Notions central to the report's approach are that the child should be seen first and the disability second, and that parental support should concentrate more on the 'parenting' than on the 'caring'.

The report situates itself in the field of 'disability' by examining and defining what is meant by disability and how this will affect notions and judgements about interventions. Medical and social models of disability are contrasted and the importance of taking a social model approach is emphasised. The report also emphasises the importance of understanding the role that families, as opposed to services, play in managing their particular situation. The policy and practice context is covered by a review of the evolution of children and disability legislation and their associated implications for service provision.

Two main bodies of research have been drawn on within the report: i) studies that have sought to identify which factors help / hinder families in their efforts to cope ii) studies that describe the needs of disabled children and their families. The report takes a needs-based approach, identifying seven key areas of need. These are looked at in turn, and for each need the following is considered:

- research which demonstrates its existence
- services that meet it
- where no evaluative work is available, suggestions as to what would constitute good practice are made

There is a dedicated section on 'assessing effectiveness' with regard to service provision. It looks to an evidence-based approach, while acknowledging reservations held by others. The authors summarise various methods of evaluation, where the prime difficulty lies in identifying clear causation. The overriding message is that professional welfare activities should be justified, wherever possible, by proof of effectiveness. Researchers need to produce this information for decision making.

## ***Meeting Family Needs***

### **Information**

Shown to be one of the most valued aspects of families' contacts with services and particularly crucial at the time of diagnosis. Family members need to understand their own position and construct their own interpretation and ways of dealing with the demands they face. The importance of respecting parents and trusting them as experts on their own child is re-emphasised throughout the report. Information is needed not only by parents, but also by disabled children and their siblings. Good practice examples are cited. However, even with better information families still need personal support. A contact in the form of a keyworker / facilitator is recommended to enable families to define needs and access further information/ services.

The report addresses good practice at diagnosis through Cunningham's (1994) framework, which incorporates structural procedures, manner of delivery of diagnosis and information imparted, and organisational aspects. The main areas of need for information for parents are with regard to:

- child's disability
- services available
- how they can support their child's development
- financial benefits entitled to

There needs to be continual provision of information as the child develops and as services and entitlements change. The different life stages are identified within the report and their corresponding information needs. Further exploration of different modes of information giving is recommended, as is consideration of the needs of different communities.

## **Material resources**

Meeting the child's needs for care and support impedes parents' capacity to earn; at the same time it creates different, and additional, needs which call for more money. This section aims to:

- identify different ways in which disability in a child is known to affect families financially
- point to some key sources of help
- suggest good professional practice

There are extra costs in the form of spending on items such as laundry equipment, transport costs, bedding and clothing; the poorest families have particular problems in absorbing these. There are also capital outlays in the pursuit of suitable housing, appropriate equipment etc. Financial help is available through the benefits system is insufficient. These additional costs vary according to families' circumstances, preferences and needs created by different conditions.

The report addresses linkages between employment and earnings and looks to specific trends. For example, compared to mothers with non-disabled children, mothers are less likely to be in paid employment. Lower living standards and financial problems are also covered as is their relationship with high levels of parental distress. Ensuring that families obtain, as easily as possible and without embarrassment, all the financial help possible, should be a fundamental aim of all those charged with supporting them.

## **Breaks from care**

Provision of short term breaks is identified as a key support service, among a range that should be available to families. It has a role in enabling parents to continue to care for their child at home. Overall, families prefer to use family-based short term care services as opposed to residential units. Whatever the service, families will choose not to use short term care if they feel it will be a negative experience for their child. However, there have been improvements in the quality of short term care services over recent years with a greater emphasis on providing the child with a positive and inclusive experience as opposed to being conceived merely as a break for parents.

The need for short term breaks tends to increase as the child gets older because support from extended family / friends may dwindle and/or managing behavioural problems becomes more difficult. School holiday schemes are also needed, as these can be crisis periods for the family. Difficulties with accessing childcare is one of the key reasons why parents are unable to work outside the home. The preferable characteristics of a short term breaks service are identified, based on 1992 guidelines produced by NCH and the Council for Disabled Children.

## **Domestic Help**

Having a disabled child substantially increases care and housework tasks. The provision of support which reduces the burden of housework has been shown to significantly reduce mothers' levels of stress. It also allows parents to spend more time with their child as their parent as opposed to their carer. Parents differ in the type of home-based support they would like to receive. But it does need to 'fit in' with a family's normal routine and activities.

## **Skills and strategies**

It has been found that the degree of difficulty a parent experiences (as measured by indicators such as the severity of the disability) does not directly relate to levels of distress or well-being. It is more to do with the resources and strategies a parent brings to their situation. This is known as the coping process. Coping resources consist of socio-environmental (money, information, breaks from care, emotional and other forms of social support etc.) and personal (parents beliefs, physical and mental health etc.) resources. Coping strategies are what parents actually do (or think) in response to the practical and emotional stresses they encounter. Not all stresses can be solved, some have to be 'lived with', and therefore strategies can have the function of either i) managing or ii) mastering a stressor. Interventions which seek to strengthen families' coping processes is one of the few areas where there is robust evidence of their effectiveness, and their long-term positive impact.

Parents may need to acquire skills which go beyond typical parenting, for example, those which will aid the child's development or enable the parent to manage sleep and behavioural problems more effectively. There is a distinction drawn between acquiring new skills and professionalising parents. The aims of programmes should be constant with family's own priorities and sensitive to other demands upon them.

Disabled children, particularly those with learning difficulties, are significantly more likely than non-disabled children to experience behavioural and emotional difficulties. Difficult behaviour is a frequent reason for excluding children from services such as school and short-term care. It is therefore important that sufficient preventative and early intervention programmes are in place. Good practice examples are used to substantiate recommendations made.

## **Social Support**

The concept of social support includes the number of people in a person's social network, frequency of social contacts and an individual's own perception of the supportiveness of others. Support can be emotional and practical and come from formal and informal sources. Research has shown that support and relationships within the family have most influence on parents' well-being. Negative consequences of social support networks can also be seen, for example, if relationships are unequal. Different types of support are examined, including the characteristics of effective support from services, counselling, self-help groups, befriending schemes and link family schemes. Benefits of support vary from the intangible 'knowing that someone is there', through the talking things through with others and exchange of information, to accessing local services.

Parents from some minority ethnic groups and those on very low incomes have been found to be the least likely to know about support groups, and yet these are the very groups that studies suggest have most to gain from group membership. Most services concentrate on interventions to support mothers of disabled children. Fathers, siblings and the children themselves may also have substantial and different support needs. For example, the usual pattern of service delivery may marginalise fathers and ways of overcoming this, such as flexibility in timing of appointments, are investigated. Sibling needs are identified and the report advocates consideration of these in a 'whole family' approach. Until recently research literature has overwhelmingly concentrated on parents' needs, this report puts a case forward for listening to and heeding the voice of the child in research, policy and practice.

## **Co-ordinating Services**

Many different agencies are involved in meeting the needs of families of disabled children. A co-ordinated approach pays attention to:

- family's own point of contact with services
- arrangement for assessment of need and care management
- quality of relationships between parents and professionals and between different professionals and agencies involved

Research consistently shows that families want a single point of contact with services through a 'key' or 'link' worker. Parents' views support the belief that keyworkers are effective in improving parent-professional relationships and research indicates that families who have a key worker fewer unmet needs. At present, between one-third and one half of families with a disabled child have access to a keyworker. For effective partnership with parents there needs to be recognition of parent's expertise, the individuality of the family and the importance of parental choice in decision making. The professional view of the interests of the child may not be consistent with that of the parent. The implications this has for service delivery are expanded upon. For example, a key worker should take a needs-led approach which is flexible, family centred and individualised, and provide support that is empowering.

Multi-disciplinary team working is also addressed, emphasising the sharing of information and skills. The difficulties inherent in such working should be further evaluated and improved. The qualities behind an effective team are identified and encompass shared philosophy and aims, clear policies and procedures, mutual support between team members and open lines of communication / negotiation.

### **Disabled children from minority ethnic groups**

There is evidence to suggest that outcomes are different, and mostly less desirable for disabled children from some minority ethnic groups. These children tend to be over represented in services characterised by social control and under represented in preventative and supportive services. Race and / or culture, and people's perception of it, can have an influence on accessing services, information consultation and service provision. Disabled children from minority ethnic families, particularly where discrimination is compounded by poverty and poor environmental circumstances, are failing to gain access to supportive services.

## **Conclusion**

A number of themes are identified by the report:

- there is abundant evidence on needs reported by mothers of disabled children, but investigation of the differing needs of fathers, siblings and other family members, e.g. grandparents is lacking
- reports of innovative services to meet needs can be cited, but less common are detailed descriptions of services and evaluation of their effects on recipients
- more involvement of parents and children is needed at an early stage of a service's aim and objectives formulation, thereby ensuring that outcomes are based on their priorities and relevant to their lives
- there is no one blue print for an effective service
- family needs and responses are affected by socio-economic circumstances, culture, family values and coping styles, age and type of disability of child
- evaluation needs to address 'what works?' and 'for whom?', even if good practice is established, there will always be families for whom such services are not appropriate
- research on family needs and coping strategies has produced a considerable amount of useful information, research on the effectiveness of interventions now needs to follow suit
- lack of resources are among the barriers to service development. Not every need can be met and choices in resource allocation have to be made – these must involve those at the receiving end of the services. This requires services to work openly and creatively with family members to identify and address issues of needs, priorities, and access to services
- parents and children should be involved in both the planning of services at a local level and in planning their own individual care.

The report concludes with the message that there has been a lack of implementation of research findings in practice. More emphasis on the value of rigorous social welfare research and the promotion of evidence based practice will hopefully increase the likelihood of research findings being translated into effective practice for families who have disabled children.



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