Outcomes for Parents with Disabled Children

Bryony Beresford, Parvaneh Rabiee, Patricia Sloper

RESEARCH works

Parent and family support is central to government policy on ensuring the well-being of children. Whilst much is known about the difficulties and challenges parents with a disabled child face, and what parents want for their children, very little is known about how parents want their own lives to be. We report here the findings from research with parents of disabled children about the outcomes they desire for themselves, and their views on the role services can play in helping them achieve those outcomes.

▼ Parents' desired outcomes focused on maintaining or enhancing their personal identity, their physical and emotional well-being, and their skill and knowledge base. They also expressed a desire for a better balance between their caring and parenting roles.

▼ In addition to individual outcomes, parents described family-level outcomes including maintaining family life and ensuring the positive adjustment of siblings.

▼ Parents wanted sufficient practical and financial resources to meet the needs of their disabled child and the rest of their family.

▼ Parents also wanted to feel confident about the services they were using and to know that professionals were working in partnership with them.

Background

Outcomes now take centre stage in children's policy. The Every Child Matters framework identifies five areas of child outcomes that are to be used to inform service provision and against which services will be inspected. Recent policy changes also mean that other groups of carers should be assessed in terms of the outcomes they want to achieve in their lives. However, assessments of parents of disabled children remain within the Framework of Assessment of Children in Need which focuses on parenting capacity and child well-being, possibly to the neglect of parent-centred needs and desired outcomes.

We already know that parenting a disabled child goes beyond 'ordinary' parenting. It is not surprising, therefore, that parents of disabled children are more likely to require support than parents of non-disabled children. What is not known, however, is what outcomes parents themselves desire from such support.

The purpose of the research reported here was to work with parents to identify the outcomes they wanted for their lives, in their role as parent/carer of a disabled child and also in other aspects or roles within their lives.

Findings

The outcomes parents described were grouped into eight areas, see Box 1.

Box 1

Parents' desired outcomes

- Personal identity
- Physical and emotional well-being
- Feeling skilled and informed
- The balance between caring and parenting
- Maintaining family life
- Positive adjustment of siblings
- Practical and financial resources
- Experiences as a service user

Personal identity

Many parents felt they had 'lost' aspects of their personal identity, with the role of parent/carer dominating how they felt about themselves and how other people viewed them. There were differences between parents in the aspects of their identity they wished to regain, maintain or obtain. Work, interests, and personal relationships were the three areas that parents said played a key role in their sense of identity and which they wanted to have time or support to allow them to pursue. Help with domestic work and care tasks, synchronised appointments and improvements in the way services were accessed and coordinated, were seen as ways to free up parents' time. The sorts of substitute care that would support parents varied according to what parents wanted to achieve and covered sitting services, pre-school day care, short-term care services and after school care.

Physical and emotional well-being

Parents emphasized the need to be physically and emotionally healthy in order to properly look after their child. Lifting, sleep problems, and the chronic care and supervision needs of the child were some of the factors that threatened parents' physical and emotional well-being . Accepting and adjusting to the child's diagnosis was an on-going emotional task, with changes in the child's condition and times of transition bringing such issues back to the surface. Watching the child suffer from ill-health or pain was emotionally distressing. Accessing and dealing with services was identified by many parents as stressful *and* distressing. Having to use a service that was inadequate or inappropriate was a source of anxiety and even despair.

To maintain physical well-being, appropriate equipment, suitable housing, short-term care, and skills in dealing with their child's sleep problems were seen as important. To promote their emotional well-being, parents wanted to feel that responsibility for their child was being shared with formal support services. More specifically, professional counselling support and contact with other parents were identified as important. Here the need to address fathers' emotional needs was raised by a number of parents.

Feeling skilled and informed

Feeling skilled and informed was seen by parents to be critical to their sense of competence, their ability to make the right decisions, and their ability to support their child's well-being and development.

Parents identified needs for a wide range of skills including: managing sleep and behaviour problems; communicating with their child; supporting their child's physical, social, communication and cognitive development; supporting independence; and managing their child's nursing, comfort and care needs. However, parents did not want to acquire these skills in order to 'take over' the roles of professionals, but wanted professional support as they implemented these skills. Parents' information needs were equally diverse and were generated by predictable (diagnosis, transitions) and unpredictable (unexpected changes in condition, crises) events.

The balance between caring and parenting

Most parents felt they spent too much time doing caring tasks and not enough 'quality' time with their disabled child or their non-disabled children. They were concerned about the impact of this lack of fun, relaxed time on the children themselves and their relationships with their children. Given that the disabled child was getting parental attention as caring tasks were carried out, lack of time with their non-disabled children caused parents most concern.

The support parents said they needed to allow more parenting time included: substitute care, help with care and domestic tasks, a laundry service, delivery service for medications, nappies and other equipment, and synchronised appointments.

Maintaining family life

Here two distinct issues arose: maintaining a sense of family through shared experiences, and ensuring the mother-father relationship remained 'intact'.

Maintaining a sense of family Families commonly found that one parent did something with the non-disabled child(ren) while the other looked after the disabled child. While family trips were not something parents necessarily wanted on a frequent basis, they were seen as an important aspect of family life. The support parents said they needed to spend time together as a family included: information about venues, helpful and disability-aware staff, and having an 'extra pair of hands' on the day.

Preserving the mother-father relationship Some parents were concerned about the strain imposed on their relationship with their partner. Doing something to support or preserve the relationship was often a high priority for these parents. Ways to support the mother-father relationship included: meeting fathers' emotional needs, greater involvement of fathers in consultations with professionals, short-term care and domiciliary support to release parents from the caring role and domestic tasks, and help with the disabled child's sleep problems.

Positive adjustment of siblings

The desire for siblings to make a positive adjustment to having a disabled brother or sister was commonly raised by parents. Parents also wanted the relationship between the disabled child and his/her sibling(s) to be positive. Access to emotional support (for example, peer support, professional counselling), accessible and appropriate information about their sibling's condition, time-out from the disabled child, quality time with parents without the disabled child, and positive whole family experiences were all seen as ways to support sibling adjustment and sibling relationships.

Practical and financial resources

Some of the families participating in this study had access to practical (for example, suitable housing, equipment, domestic support) and financial resources that helped them cope with the 'extra-ordinary' demands associated with caring for their disabled child. Families without such resources wanted the practical and financial resources to properly care for and bring up their child and the rest of the family. As well as lack of resources being a source of stress in itself, their absence was also seen as a barrier to achieving other outcomes for themselves and their family.

Experiences as a service user

Parents identified two key outcomes in relation to being service users and how that makes them feel:

- a sense of working in partnership with services;
- having confidence in the services being used by the child.

Concrete evidence of working in partnership was greater communication between parents and professionals, improved access to services, and continuity in interventions between home and school to support the child's learning and behaviour. All parents said they wanted to know that their child was looked after well in all the service settings he/she used. Features of a quality service included skilled and knowledgeable staff, the service providing a positive experience for the child, staff continuity and the service being reliable.

Implications

The wide-ranging nature of outcomes described by parents highlights the impact that caring for a disabled child can have on the lives of parents and families. The findings also draw attention to inadequacies in current systems of identifying support needs of parents, where the focus lies on parenting capacity, and most parent support services are actually provided to the child (for example, short-term care). Whilst these expensive, specialist services might meet some of parents' desired outcomes, either intentionally or unintentionally, they may not help parents achieve what they regard as their most important desired outcomes. A key reason for this is the lack of a parent-centred, outcomes-focussed assessment.

In addition, greater creativity is needed in thinking about what parent support services constitute. Parents identified different forms of support that would help them achieve their desired outcomes (for example, domestic help, home delivery of medication, information). Many of these are not high cost services. There needs to be recognition that funding services for parents can be an effective and legitimate way of supporting a disabled child's development and well-being.

Methods

Parents of children (aged between 2 and 18 years) with complex health needs, degenerative conditions, autistic spectrum disorders, or whose children did not use speech to communicate, were invited to participate in the project via invitations distributed by social services, health and voluntary sector professionals. Ninety mothers and eighteen fathers across three local authorities participated. All parents were interviewed: these interviews covered desired outcomes for their child and themselves. In addition, thirty-two of the parents attended focus groups with other parents of children with the same condition and of a similar age. These groups were facilitated using various exercises to help parents think about their lives now and what changes they would want to make to their lives. The discussions also explored barriers to achieving those desired outcomes and the role of services in achieving them. All interviews and group discussions were tape-recorded and transcribed. The data were then analysed using the well-established 'framework' approach.

We can send an email notification to you when each new issue of **Research Works** is posted on the website.

To register for this service please email us at spruinfo@york.ac.uk with the following information:

Name (Mr/Ms/Mrs/Dr etc.); Job Title; Organisation; Address (including Postcode); Tel/Fax/Email

The Social Policy Research Unit is an independent research organisation at the University of York. Established in 1973, SPRU has an international reputation for excellence in key areas of social policy, especially health and social care, poverty, social security and employment. Its Director is Professor Gillian Parker. For further information about SPRU contact the Director or the Information Office, or visit our website at **http://www.york.ac.uk/spru/**

Social Policy Research Unit,
The University of York, Heslington,
York Y010 5DD, United Kingdom.
Telephone +44 (0)1904 321950
Fax +44 (0)1904 321953
Text +44 (0)1904 321951
E-mail SPRU@york.ac.uk