
**Outcomes for parents with disabled children
and carers of disabled or older adults:
Similarities, differences and the implications
for assessment practice**

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Summary

This paper draws on data collected in the course of two studies that were carried out as part of SPRU's Outcomes of Social Care research programme and compares the outcomes desired by parents with disabled children and by carers of disabled and older adults. It finds that there are striking similarities in the range of outcomes that each group of carers desires to achieve from social care services. For example, both groups of carers desire:

- A life/identity of their own, over and above their role as parents/carers
- Having control over their life
- Spending 'quality' time with the person receiving support, over and above care-giving activities
- Maintaining physical and emotional well-being
- Having adequate resources
- Feeling skilled and informed
- Maintaining family life
- Service process outcomes relating to positive relationships with professionals and working in partnership with services

Some differences in desired outcomes were identified, but these could largely be explained by the different stages in the life course between the two groups of carers.

These findings were contrasted with the guidance that currently underpins policy and practice relating to the assessment of parents' and carers' needs. Guidance on assessments for parents with disabled children recommends the use of the generic Children in Need Framework. This gives priority to meeting needs relating to the child's safety and well-being and largely overlooks the substantial additional care-related needs of disabled children or the threats to parents' and family well-being arising from the presence of childhood disability. In contrast, successive legislation and guidance on assessments of people caring for a disabled adult or older person have increasingly focused on the quality of life of carers themselves as well as the care recipient; and on identifying outcomes for carers which take account of their life beyond caring.

The paper argues that these differences in legislation and practice guidance are not justified by the empirical evidence on parents' and carers' desired outcomes. In particular, the Children in Need Framework risks overlooking significant areas in which parents of disabled children identify desired outcomes. Rather, the assessment frameworks that have been developed for carers of disabled adults and older people need to be extended, so that the carer-related outcomes identified by parents with disabled children are accorded equal recognition with those of their children.

Introduction

Between 1996 and 2005 the Social Policy Research Unit (SPRU) undertook a programme of research and development funded by the Department of Health on the outcomes that service users desire from social care services. The programme had two main objectives:

- To identify the outcomes of services that are valued and desired by different groups of social care;
- Through development work with service managers, front-line staff and service users, to devise outcomes-focused approaches and processes that could be integrated into local contexts and routine practices.

The programme yielded a wealth of information on the outcomes valued by different groups of service users, including older people; working age adults with physical and sensory impairments; carers of disabled adults and older people; and parents with disabled children (for example, Bamford *et al.*, 1999; Nicholas, 2001; Qureshi 2001; Beresford *et al.*, forthcoming).

When the SPRU programme began in 1996, the concept of outcomes was relatively unfamiliar in social care policy and practice. However, the development and delivery of outcomes-focused services have since become central features in the modernisation of public sector services. A wide range of policies in social care have emphasised the importance of focusing on ‘the quality of services experienced by, and the outcomes achieved for, individuals and their carers and families’ (Department of Health, 1998: para. 1.7). For example:

- The Green Paper on Adult Social Care (DH 2005a) and the subsequent White Paper on Health and Social Care (DH 2006) both place heavy emphasis on outcomes-focused services;
- There have been major outcomes-focused developments in children’s services following the publication of Every Child Matters (ECM) (DfES 2003) and the National Service Framework for Children, Young People and Maternity Services (DH/DfES 2004);
- Developments in self-directed support such as direct payments (Leece and Bornat, 2006), individual budgets and In Control have extended new opportunities for older people, disabled adults, carers and families with disabled children to establish support arrangements that meet individual desired outcomes;
- During 2006, the Commission for Social Care Improvement (CSCI) proposed the introduction of outcomes-focused performance assessment measures for English adult social care services (www.csci.org.uk/pdf/paf_consultation); similar proposals are undergoing consultation in Scotland.

Despite the increasing prominence of an outcomes focus in policies and services for disabled adults and children alike and their families, policy and practice relating to

adults and older people and to children have tended to develop separately. In particular, separate guidance has been produced relating to assessments of the social care and other needs of people caring for disabled adults and older people, and to the needs of parents with disabled children. How far do these different approaches reflect the service outcomes that are actually desired by these respective groups of carers? Does the divergence in respective policy contexts and practice guidance reflect real differences in the outcomes that are desired by the parents with disabled children and carers of disabled adults and older people respectively? Or are there in fact significant areas of similarity and overlap in the outcomes desired by these different groups of carers?

This paper examines these questions by reanalysing some of the data collected in the course of two projects undertaken as part of the SPRU Outcomes programme, in order to compare the outcomes desired by parents with disabled children and by carers of disabled adults and older people. The paper first describes the development over the past decade of the frameworks and formal guidelines that now underpin assessments of need amongst each of these two groups of carers. It then describes the desired outcomes identified by parents with disabled children and by the carers of disabled adults and older people respectively and highlights both the similarities and the differences between these. Finally, the appropriateness of the different assessment frameworks in identifying and responding to the desired outcomes of these two groups of carers is discussed.

Policy and practice relating to outcomes and assessment for parents with disabled children

The five outcomes of 'be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being' have become central to all policy for children (DfES, 2003; DfES, 2004a). The role of parents in achieving these outcomes is acknowledged; for example *Every Child Matters: Next Steps* (DfES, 2004b, p26) asserts that 'parenting is the most important influence on children and young people's outcomes'. However, the focus in these policy documents is mainly on the support needed *from* parents to achieve the desired outcomes for children, rather than the support needed *for* parents in carrying out their roles as parents.

The need for parents and other people caring for children to have more and better information, advice and support has nevertheless been recognised (DfES, 2004b). A Parenting Fund of £25 million was set up to support the voluntary and community sector in developing a range of support services for parents; and in October 2006, DfES issued guidance for local authorities on the provision of parenting support (DfES, 2006). However, the predominant discourse around support for parents is on services such as childcare, helplines, parenting groups and parenting interventions,

and how these may improve outcomes for children, rather than on the help that parents themselves might require in order to support their parenting role.

For parents with disabled children, consideration of the outcomes services should aim to achieve is especially important as research has shown that these parents provide extra care, over and above that of 'the reasonable parent' and it is with this extra care that they need support (Roberts and Lawton, 2001). Parents with disabled children are also particularly vulnerable to stress, which can result from trying to meet the extra demands of caring for the child without appropriate resources and support (Knussen and Sloper, 1992; Beresford, 1994). Parental stress in turn impinges upon children's development (Wallander and Varni, 1998) and has also been identified as a reason for residential placements of disabled children (Morris *et al.*, 2002).

The closest policy to an outcomes-focused approach for parents with disabled children is the National Service Framework (NSF) for Children (DH/DfES, 2004). Standard 8 of the NSF defines the standard to be achieved by services for disabled children and their families as follows: 'Children and young people who are disabled or who have complex health needs [should] receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them *and their families* (our italics) to live ordinary lives.' Attaining social inclusion and an 'ordinary life' are broad outcomes that many parents of disabled children would wish to achieve and it is significant that this standard was informed by wide-ranging consultation with parents. Detail on how the standard could be achieved also highlights the need for services that can help parents achieve these outcomes: a range of family support services that are 'flexible and responsive to children and families' needs' (including those of fathers and siblings); training for parents in managing sleep and behaviour problems; breaks from care; home care and child care; appropriate and accessible information about treatment and care services; involvement in decisions about services; key workers to help parents obtain the services they and their children need; and the option to use direct payments (DH/DfES 2004).

Beyond this, however, policies rarely articulate in more detail the outcomes that parents with disabled children want to achieve for themselves from service provision. This is not surprising, as most research has focused on the needs of such families and the services they receive, rather than the outcomes that parents hope to achieve in their own lives from services (Beresford *et al.*, forthcoming).

Parents typically report that their needs and desired outcomes are not included in assessments (Beresford *et al.*, forthcoming). Assessments of the needs of parents with disabled children are contained within the Children in Need (CIN) assessment framework (Department of Health, 2001a) and this framework is very limited in the way it explores parents' needs as carers. The CIN assessment framework includes the child's developmental needs; family and environment factors; and parenting

capacity. 'Family and environment factors' include family functioning, the wider family and social networks, community resources, housing, employment and income. However, these are essentially regarded as either resources or risk factors in relation to the child's (and, to a lesser extent, the family's) well-being more generally. No explicit mention is made of the impact that family and environment factors may have on parents' own needs as carers. For example, with regard to housing, the assessment framework asks whether the accommodation is suitable for the disabled child; there is no reference to housing needs associated with caring responsibilities. Similarly, 'parenting capacity' refers to parents' ability to carry out parenting tasks including basic care, ensuring safety and providing emotional warmth, stimulation and guidance, with the emphasis clearly on the child's, as opposed to the parents', well-being.

There are historical reasons for this emphasis on parenting capacity, rather than a wider definition of parenting which might more easily incorporate disability-related caring tasks and responsibilities. The CIN assessment framework is a generic framework and therefore covers all aspects of family support and child protection. It aims to identify and meet those needs which will protect the child's safety and well-being and ensure the child can remain living at home. The importance of supporting parents is highlighted, but only in terms of the role that any such support can play in enhancing a child's well-being, as opposed to maximising the well-being of parents and families and families *per se*. Moreover, neither the additional care-related needs of disabled children nor the well-documented threats to the well-being of parents and other family members caused by the presence of childhood disability are covered by this framework. Its efficacy in identifying the support needs of, or outcomes desired by, parents caring for a disabled child is, therefore, questionable. This shortcoming is reflected in the fact that most of these parents report that their needs as parents/carers are unmet (Beresford, 1995; Chamba *et al.*, 1999).

These shortcomings reflect an apparent discrepancy between the policy and practice frameworks for assessing the needs of, or outcomes desired by, parents with disabled children and those for other groups of carers. Indeed, policy guidance on the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004 (DH, 2005b) recommends that, despite its inadequacies, the CIN Framework should remain the primary mechanism for assessing the support needs of parents of disabled children. As well as creating a different route for accessing an assessment, the tenor of the assessment processes are also different. The CIN assessment is needs-based and a parent's life, aspirations and responsibilities beyond that of being a parent are ignored. This contrasts with assessments for other groups of carers which, as described below, should be carer-centred and 'looking to achieve outcomes which, while helping the carer to care, also take account of the carer's life beyond their caring' (DH 2005b, p.12).

Policy relating to outcomes and assessment for carers of disabled adults and older people

Over the last decade there have also been a number of policy initiatives aimed specifically at the carers of disabled, sick or older adults. These initiatives include the Carers (Recognition and Services) Act 1995; the National Strategy for Carers (DH, 1999a); the Carers and Disabled Children Act 2000; and the Carers (Equal Opportunities) Act 2004. Issues relating to carers are also included in other policy measures, including several National Service Frameworks (DH, 1999b; DH, 2001b; DH 2005); the Green Paper *Independence, Well-being and Choice* (DH, 2005a); and the subsequent White Paper *Our Health, Our Care, Our Say* (DH, 2006).

The Carers (Recognition and Services) Act 1995 was a landmark in social policy legislation. It gave certain groups of carers the right to ask for an assessment of their circumstances and capacity to care at the same time as the local authority was conducting an assessment of the disabled or older person. The Act required local authorities to take the results of the carer's assessment into account, but only in connection with decisions about the services which were to be provided to the care recipient. Whilst the accompanying guidance detailed what a carer's assessment might cover, there was no suggestion that practitioners should give any special attention to the outcomes desired by carers, over and above those relating to their capacity to continue providing care (DH, 1996). In this respect, this piece of legislation was arguably similar in scope to the frameworks underpinning consideration of the needs of parents; any identified needs and the provision of support were justified primarily in terms of their contribution to the outcomes of the adult or child who is receiving care.

However, subsequent legislation has considerably extended the extent to which the assessments of people caring for disabled adults and older people are required to consider a range of other issues. The Carers and Disabled Children Act 2000 strengthened carers' rights to an assessment of their own. Under the terms of the legislation, local authorities were empowered to provide services directly to carers, even if the care recipient had refused an assessment or services. The practice guidance to the 2000 Act stated that a carer's assessment should focus on what the carer identified as the best possible outcome for her/him, which would in turn reflect the impact of caring on the particular carer (DH, 2001c, p10). At the same time, practitioners were advised to adopt a holistic approach to outcomes which took into account outcomes that the disabled person would want to see for themselves and for their carer, and *vice versa*. Significantly, practice guidance to support the implementation of the Act adopted a framework of outcomes for carers that had been developed in the course of SPRU's Outcomes Programme (Nicholas, 2001); this was intended to assist practitioners in developing outcomes-focused approaches to carer assessments. The carers' outcomes framework included:

- *Quality of life for the care recipient*: desired outcomes in this domain concerned carers' wishes to maintain the safety, comfort, dignity and independence of the person supported, as well as to enhance the latter's social contact and meaningful activity.
- *Quality of life for the carer*: the guidance noted that carers value attention to their own quality of life, over and above their caring role. This involves the provision of support to achieve outcomes related to maintaining (or improving) carers' own physical and emotional health; peace of mind; financial security; opportunities to take part in employment and social activities.
- *Managing the caring role*: carers want to feel supported in their caring role. This requires information, practical assistance, emotional support and training to be available and accessible.
- *Service process outcomes*: the way in which services are organised and delivered can also help carers achieve desired outcomes. Carers value services that recognise their expertise as carers; that are accessible; and that fit with their existing routines and patterns of care. Positive relationships with staff are important, as is value for money (DH 2001c, Appendix A).

Most recently, the Carers (Equal Opportunities) Act 2004 came into force in April 2005. It is intended to help ensure that carers have access to opportunities that individuals without care-giving responsibilities take for granted. The accompanying policy guidance (DH 2005b) urges practitioners to adopt carer-centred approaches to assessment, 'by ... looking to achieve outcomes which, while helping the carer to care, take account of the carer's life beyond their caring' ... The assessment of the person's willingness and ability to care must also now take into consideration, for example, whether the carer works or wishes to work or undertake education, training or any leisure activity' (DH 2005b, pp20-1).

To highlight the differences in the extent to which the outcomes desired by the two groups of carers are recognised in policy and practice guidance, Table 1 summarises the types and range of outcomes that are recognised in the relevant policy measures and associated guidance relating to assessments for parents with disabled children and carers of disabled adults and older people respectively.

Table 1. Outcomes for parents with disabled children and for carers of disabled adults and older people identified in relevant assessment guidance

Outcomes for parents with disabled children	Outcomes for carers of disabled adults and older people
<ul style="list-style-type: none"> • enabling parents to achieve <i>Every Child Matters</i> outcomes for the disabled child • achieving social inclusion and an 'ordinary life' for the whole family 	<ul style="list-style-type: none"> • quality of life for care recipient • quality of life for carer, including equal opportunities with non-carer adults • managing the caring role • service process outcomes

The next section of this paper draws on a reanalysis of research evidence to examine how far these differences in policy and practice guidance reflect actual differences in the outcomes desired by the two groups of carers.

Parents and carers' desired outcomes – evidence from research

This section of the paper draws on two studies conducted within SPRU to identify the outcomes that parents and carers desire from services. Both studies included focus groups and interviews with parents and carers about the outcomes they desired from social care and other services.

- Study 1: outcomes for family carers of disabled people and older people (Qureshi *et al.*, 1998; Bamford *et al.* 1999). This study included nine carers of disabled adults and 22 carers of older people; the latter group included six carers of older people with dementia and seven non-resident carers.
- Study 2: outcomes for parents of disabled children and young people (Beresford *et al.*, forthcoming). This study focused on families of children with complex health needs, children who do not use speech to communicate, and children with autistic spectrum disorders. Sixty-nine mothers and 16 fathers took part; their disabled children were between two and 18 years old.

First, the published results of these studies (Qureshi *et al.*, 1998; Bamford *et al.*, 1999; Beresford *et al.*, forthcoming) were examined. These findings suggested that there were considerable similarities, but also some differences, between the outcomes desired by parents with disabled children and the carers of disabled adults and older people. Both projects reported that parents and carers identified desired outcomes associated with service processes - the way services are delivered; and a number of common impacts, or end results, of service support. Common themes were:

- *Having a life of one's own apart from caring and having control over one's life*: all groups of carers identified these as key desired outcomes. Carers and parents both wanted support to ensure that they had time to themselves to pursue other interests and to spend with family and friends.
- *Achieving a balance between caring and parenting/having a choice over the nature and extent of caring*: again, both the parents with disabled children and the carers of disabled adults and older people wanted opportunities to spend 'quality time' with the person they were supporting outside of the care-giving role. Such opportunities were particularly important for those caring for a very close relative such as a partner or child. Carers of disabled adults spoke about the importance of having a degree of choice over exactly which caring tasks they did or did not undertake, while carers of older people and parents with disabled children placed more emphasis on controlling the time spent on care-giving tasks rather than on limiting the range of tasks.

- *Maintaining physical and emotional well-being*: all groups of carers identified maintaining their own well-being as a key desired outcome and gave equal priority to support for their emotional well-being and support for their physical well-being.
- *Having adequate practical and financial resources*: all groups of carers spoke about problems with financial resources, for instance because of having given up paid work to look after their relative and having to pay for services and equipment. All wanted to feel that they had adequate financial resources to care properly for their relative. In addition, parents emphasised the importance of practical resources, particularly suitable housing, aids and equipment, in enhancing both the care of their disabled child and their own quality of life as carers.
- *Working in partnership with services*: all groups wanted to feel that they were working together with professionals and formal services to achieve the best outcomes for the child or adult they were caring for, and that responsibility for achieving these outcomes was shared between themselves and the relevant services. All wanted to be valued and treated with respect by services; have their expertise as carers recognised and respected; be treated as an individual; be involved in making decisions with services; and be able to influence service delivery.
- *Having a positive relationship with staff and having confidence in services*: all groups wanted to feel confident that their child or adult relative was looked after well by all the services s/he used and that services understood and responded to his/her needs. They wanted services to be reliable and to have a relationship of trust with staff. This reduced anxiety for parents and carers and contributed to their own peace of mind.

However, a few desired outcomes appeared to be confined to one group of carers only. For parents with disabled children, feeling skilled and informed, maintaining family life and the positive adjustment of non-disabled siblings, and sustaining personal identity were additional key themes. For the carers of disabled adults and older people, being able to adjust to and manage change, and obtaining value for money from services were additional desired outcomes.

In order to check that these differences were real and did not simply reflect differences of emphasis in reporting, the original transcripts of the interviews and focus group discussions in both studies were re-examined. First, the desired outcomes that appeared from the published study reports to be unique to parents with disabled children (feeling skilled and informed; maintaining family life and the positive adjustment of siblings; and sustaining personal identity) were mapped. The transcripts of the interviews and focus groups with the carers of disabled adults and older people were then examined to identify whether these outcomes were in fact also desired by the other groups of carers. This process of reanalysis had some limitations: in particular, the two studies had been conducted some five years apart; the samples were of different sizes and had been selected according to different criteria; and the topic guides used in the respective interviews and focus groups with

each group of carers were not identical. Nevertheless, the reanalysis identified some clear similarities in the outcomes identified by the two groups of carers, albeit with differences of emphasis that reflected differences in stages of the life course, family situations and the types of care-giving relationships involved.

First, *feeling skilled and informed*, a desired outcome identified by parents with disabled children, was also referred to by many carers of older people and disabled adults. Many of the latter felt that they were not very skilled or informed and some carers spoke specifically about needing more information, both about the condition of the person they were looking after and about the services which might be available to the family. Two carers who had received some training from professionals, specifically with regard to lifting and physiotherapy, valued this because it had helped them to feel more skilled and informed.

Parents with disabled children also reported needs for information about the child's condition and about services. However, the skills they reported that they needed were more wide-ranging. They included skills in managing sleep and behaviour problems; communicating with their child; supporting their child's physical, social, communication and cognitive development; supporting the child's growing independence; and managing their child's nursing, comfort and care.

Maintaining family life was also important for both groups of carers, although the emphasis given to this outcome and the particular issues involved were different, reflecting the different stages in the family life cycle of the two groups of carers. Parents with disabled children were particularly concerned about maintaining a sense of the family as a whole through being able to share experiences and activities, such as outings that involved all the family members. However, this was difficult for many families because of a lack of accessible venues; the unhelpful attitudes of staff (for example, in leisure and recreation facilities) towards their disabled child; and a lack of additional people to help them manage their disabled child's extra care needs outside the home. Families commonly found that one parent did something with the non-disabled child(ren) while the other did something else with the disabled child. Another aspect of maintaining family life for parents centred around keeping the mother-father relationship intact. For some of the carers who were looking after a parent or an adult son or daughter, maintaining family life tended to focus around being able to do things with their spouse, such as going on holiday. Carers looking after a spouse, in contrast, were more likely to identify going on holiday with their spouse, or going shopping with another family member, as indicators of being able to maintain a normal family life. However, on the whole this theme appeared to receive less emphasis from family carers.

A related theme identified in the published reports of the outcomes valued by parents with disabled children concerned their aspirations for *siblings to be able to make a positive adjustment* to having a disabled brother or sister. Parents wanted their other

children to lead ordinary lives and to enjoy everyday childhood experiences. They also wanted to see a positive relationship between the disabled child and his/her siblings. Not surprisingly, this outcome was not mentioned by the carers of disabled adults and older people. Moreover, even when the analysis was extended to include any aspirations relating to the needs of family members other than partners, this still did not appear as a theme among the carers of disabled adults and older people.

The carers of disabled adults and older people – particularly the former – identified *being able to adjust to and manage change* as a desired outcome of the support they received from services. Relevant changes included giving up paid work; disruptions to home life, friendships and leisure activities; changes in their roles and responsibilities; and changes in relationships, particularly marital relationships. Data from the study of parents with disabled children were therefore reviewed and it became clear that many aspects of managing these changes were contained within parents' discourses on the importance of retaining their own *personal identity* and having a life apart from caring. It was clear that many parents felt they had 'lost' some aspects of their identity, with the roles of carer and parent dominating how they and others saw themselves. Some parents reported that they had lost friends and interests, or the benefits to their identity and social participation of being able to work outside the home. Finding appropriate care arrangements for their child which would enable them to regain these aspects of their identity was therefore important.

Finally, there appeared to be a difference between the two groups of carers in the importance placed on *value for money* in services, with the carers of disabled adults, but not the parents with disabled children, identifying this as a desired process outcome. Further analysis revealed that this outcome appeared to relate particularly to charges for adult social care services and a concern that, following the commissioning of these services from independent providers, quality standards and value for money were not always appropriately monitored. However, it must be noted that this group was small (only nine carers of disabled adults took part in Study 1) and this outcome was not raised by carers of older people nor by parents.

Discussion

As noted above, the research evidence on which this paper draws is neither very extensive nor detailed. The findings of two studies on the outcomes valued by different groups of carers have been compared. However, the two studies were carried out some years apart; involved different strategies to sample their participants; and employed differently worded interview schedules and topic guides.

Despite these limitations, the comparison has identified some important similarities in the outcomes that parents with disabled children and carers of disabled adults and older people aspire to achieve from services. Table 2 below summarises the domains in which there were significant overlaps in outcomes of services that each group of carers identified as important to them.

Table 2. Desired outcomes identified by parents with disabled children and carers of disabled adults and older people

Parents with disabled children	Carers of disabled adults and older people
<p><i>Outcomes for parents</i></p> <p>Having a life/identity of one's own over and above being a parent of a disabled child</p> <p>Having control over one's life</p> <p>Spending 'quality time' with the disabled child</p> <p>Achieving a balance between the time spent caring with the time spent parenting/enjoying quality time with the child</p> <p>Maintaining one's own physical and emotional wellbeing</p> <p>Having adequate financial resources</p> <ul style="list-style-type: none"> • Having other material/practical resources <p>Feeling skilled and informed:</p> <ul style="list-style-type: none"> • About their child's condition • About services • About managing the child's behaviour problems and supporting the child's development <p><i>Outcomes for families</i></p> <p>Maintaining family life:</p> <ul style="list-style-type: none"> • Helping siblings adjust to having a disabled brother/sister • Undertaking activities with all family members • Maintaining mother-father relationship <p><i>Service process outcomes</i></p> <p>Working in partnership with services</p> <p>Having positive relationships with professionals</p> <p>Having confidence in services</p>	<p><i>Outcomes for carers</i></p> <p>Maintaining interests/identity of one's own over and above being a carer, in the context of changing circumstances that threaten this</p> <p>Having control over one's life</p> <p>Spending 'quality time' with the cared for person</p> <p>Limiting the time spent on caring tasks (carers of older people)</p> <p>Limiting the range of caring tasks (carers of disabled adults)</p> <p>Maintaining one's own physical and emotional wellbeing</p> <p>Having adequate financial resources</p> <p>Feeling skilled and informed:</p> <ul style="list-style-type: none"> • About their relative's condition • About services <p>Adjusting to change</p> <p><i>Outcomes for families</i></p> <p>Maintaining family life:</p> <ul style="list-style-type: none"> • Undertaking activities with spouse or other family members <p><i>Service process outcomes</i></p> <p>Working in partnership with services</p> <p>Having positive relationships with professionals</p> <p>Having confidence in services</p> <p>Value for money</p>

The priorities of the two groups of carers are strikingly similar. Where differences occur, these may partly reflect substantive differences in the demographic and life course circumstances of the two groups of carers.

The differences in desired outcomes around maintaining family life are clearly related to stages of the family life cycle, with parents with disabled children having to balance the needs of the disabled child and those of non-disabled siblings, all of whom, in many families, are still dependent on parents. Their desired outcomes strongly reflected the NSF standard that families with disabled children should be supported to lead an ordinary life, yet their comments revealed that as yet such support was lacking. In contrast, most carers of adults and older people did not have dependent children. In addition, parents with disabled children appeared to place more emphasis on maintaining spouse relationships. This again may reflect a reaction to the many demands on parents of caring for a disabled child and other siblings, and possibly the greater vulnerability of spouse relationships in the child rearing years.

There were also differences between parents with disabled children and the carers of adults and older people on outcomes relating to feeling skilled and informed. While both groups wanted information about the cared for person's condition and services, parents placed a lot of emphasis on wanting the skills to support the various aspects of their disabled child's development and manage difficulties that are common in some groups of disabled children, such as sleep and behaviour problems. These differences reflect the developmental nature of childhood; and the characteristics of the groups of children involved in Study 2; and the realisation amongst parents that with the right skills they can make a difference to their child's development and wellbeing. In addition, while both groups flagged up the desire to feel informed about services, it is important to note that families with disabled children will typically need to know about a far more complex and diverse set of services because of their child's needs and the ways in which some services (for example, housing services) are more adult focussed in terms of the way their service is publicised and delivered (Beresford and Oldman, 2000).

Other differences between the two groups may reflect the different types of services that each uses; adults and older people may be more likely to use social care services for which charges are levied, while disabled children and their families typically have greater levels of contact with education and health services, both of which are free at the point of use. This helps to explain why carers of adults and older people identify 'value for money' as a service process outcome, while parents with disabled children do not.

However, overall it is arguable that the similarities in the desired outcomes identified by the two groups of carers significantly outweigh any such differences. The significant areas of similarity in the outcomes identified by the two groups of carers also call into question the appropriateness of current policy and practice relating to assessments of their needs. In particular, current policy advice that the needs of parents with disabled children should be assessed through the generic Children in Need (CIN) framework may risk overlooking significant areas in which such parents express needs for support and look to services to help them achieve desired outcomes. As noted above, the CIN framework prioritises 'parenting capacity' rather than the extra help parents with disabled children may need with specific tasks, over and above 'parenting'. At present there appears to be some mismatch between the CIN framework and the aspirations of the NSF that families with disabled children should be enabled, as far as possible, to 'live ordinary lives'. The outcomes that parents identified for themselves in the study reported here, such as being able to go out as a whole family and having time to spend with family and friends, can be seen as part and parcel of ordinary family life for most families with non-disabled children. Yet the current framework for assessing the needs of parents with disabled children fails to acknowledge the extra help they may require in order to enjoy the same levels of opportunity as parents whose children do not have disabilities – a right explicitly conferred on carers through the 2004 Carers (Equal Opportunities) Act.

In addition, the CIN assessment framework for disabled children and their parents fails to acknowledge the *additional* outcome domains identified by parents and which are explicitly included in the outcomes that practitioners are required to address in conducting assessments of carers of disabled adults and older people. Thus, Section 2 of the practice guide accompanying the 2004 Carers (Equal Opportunities) Act includes a section on 'Outcome focused assessments'. This includes the carers' outcomes framework developed by SPRU that covers the quality of life of the person being cared for; the quality of life of the carer; managing the caring role; and service process outcomes (Cass, 2005).

Table 1 above summarised the outcome domains, identified from assessment guidance, that practitioners conducting carers' assessments are required to consider. Table 3 below shows how many of these broad domains are also relevant to the service outcomes identified by the parents with disabled children. These outcome domains are over and above the CIN outcomes relating to the disabled child.

Table 3. Additional outcome domains identified by SPRU research with the parents with disabled children

<p><i>Quality of life for the carer or parent</i></p> <ul style="list-style-type: none"> • Having a life/identity of one's own • Having control over one's life • Maintaining physical and emotional well-being
<p><i>Managing the caring role</i></p> <ul style="list-style-type: none"> • Achieving a balance between the time spent caring with the time spent parenting/enjoying quality time with the child • Having adequate financial and appropriate material support • Feeling skilled and informed about supporting the child's development and managing the child's behaviour • Maintaining family life, including the adjustment of siblings and spouse relationship, and equal opportunities for family activities as families with non – disabled children
<p><i>Service Process Outcomes</i></p> <ul style="list-style-type: none"> • Working in partnership with services • Having confidence in services

Current guidance that the CIN framework should also govern assessments of the needs of disabled children and their families therefore risks overlooking significant areas, illustrated in Table 3, in which the parents of disabled children identify additional desired outcomes. Ignoring these additional outcomes effectively treats parents with disabled children less favourably than the carers of disabled adults and older people. Moreover, it is arguable that any shortcomings in recognising and addressing these additional outcomes, that parents with disabled children share with other groups of carers, might even jeopardise the achievement of key outcomes for the disabled children themselves.

The major gains that carers have achieved over the past decade in securing access to outcomes-focused assessments of their own needs of course apply to all groups of carers, including parents with disabled children. There is no legislative reason why the outcomes-focused assessment frameworks that have been developed for carers of disabled adults and older people should not also be extended to parents with disabled children. While acknowledging the limited evidence base on which this paper draws, it appears that the similarities in the outcomes of services identified by the two groups of carers significantly outweigh any differences. There is therefore a strong argument for reviewing current policy and practice guidance on the appropriate assessment frameworks for carers, particularly for carers of disabled

children, so that their carer-related outcomes are accorded equal recognition with the outcomes of their children.

References

- Bamford, C., Qureshi, H., Nicholas, E. and Vernon, A. (1999) *Outcomes of Social Care for Disabled People and Carers*, Outcomes in Community Care Practice, Number Six, Social Policy Research Unit, University of York, York.
- Beresford, B. (1994) Resources and strategies: how parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry*, 35: 171-209.
- Beresford, B. (1995) *Expert Opinions: A national survey of parents caring for a severely disabled child*, Bristol: Policy Press.
- Beresford, B. and Oldman, C (2000) *Making homes fit for children: Working together to promote change in the lives of disabled children*, Bristol: policy Press.
- Beresford, B., Rabiee, P. and Sloper, P. (forthcoming) Families with a disabled child: developing a framework of parents' desired outcomes, *Child and Family Social Work*.
- Cass, E (2005) Practice Guide 5: *Implementing the Carers (Equal Opportunities) Act 2004*, London: Social Care Institute for Excellence. Accessed 13.12.2006
<http://www.scie.org.uk/publications /practice guides/carersguidance/index.asp>
- Chamba, R., Ahmad, W., Hirst, M., Lawton, D. and Beresford, B. (1999) *On the Edge: minority ethnic families caring for a severely disabled child*, Policy Press, Bristol.
- Department for Education and Skills (2003) *Every Child Matters*, Nottingham: DfES Publications.
- Department for Education and Skills (2004a) *Every Child Matters: Change for Children*, Nottingham: DfES Publications.
- Department for Education and Skills (2004b) *Every Child Matters: Next Steps*, Nottingham: DfES Publications.
- Department for Education and Skills (2006) *Parenting Support: Guidance for Local Authorities*, www.everychildmatters.gov.uk
- Department of Health (1996) *Carers (Recognition and Services) Act 1995: Practice Guide*, London: Department of Health.
- Department of Health (1998) *Modernising Social Services*, London: Department of Health.

Department of Health (1999a) *Caring about Carers: A National Strategy for Carers*, London: Department of Health.

Department of Health (1999b) *National Service Framework for Mental Health*, London: Department of Health.

Department of Health (2001a) *Framework for the Assessment of Children in Need and their Families*, London: Department of Health.

Department of Health (2001b) *A National Service Framework for Older People*, London: Department of Health.

Department of Health (2001c) *A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000*, London: Department of Health.

Department of Health (2005a) *Independence, Well-being and Choice*, Cm 6499, London: Department of Health.

Department of Health (2005b) *Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004: Combined Policy Guidance*, London: Department of Health.

Department of Health (2005c) *The National Service Framework for Long-term Conditions*, London: Department of Health.

Department of Health (2006) *Our Health, Our Care, Our Say: A New Direction for Community Services*, Cm 6737, London: Department of Health.

Department of Health/Department for Education and Skills (2004) *National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and those with Complex Health Needs*, London: Department of Health.

Knussen, C. and Sloper, P. (1992) Stress in families of children with disability: A review of risk and resistance factors, *Journal of Mental Health*, 1: 241-256.

Leece, J. and Bornat, J. (2006) *Developments in Direct Payments*, Bristol: Policy Press.

Morris, J., Abbott, D. and Ward, L. (2002) At Home or Away? An Exploration of Policy and Practice in the Placement of Disabled Children at Residential Schools, *Children and Society* 16: 3-16.

Nicholas, E. (2001) 'Implementing an outcomes approach in carer assessment and review', in H. Qureshi (ed) *Outcomes in Social Care Practice*, Outcomes in Community Care Practice, Number Seven, York: Social Policy Research Unit, University of York, pp. 65-117.

Qureshi, H. (ed) (2001) *Outcomes in Social Care Practice*, Outcomes in Community Care Practice, Number Seven, York: Social Policy Research Unit, University of York.

Qureshi, H., Patmore, C., Nicholas, E. and Bamford, C. (1998) *Overview: Outcomes of Social Care for Older People and Carers*, Outcomes in Community Care Practice, Number Five, Social Policy Research Unit, University of York, York.

Roberts, K. and Lawton, D. (2001) Acknowledging the extra care parents give their disabled children, *Child: care, health and development*, 27: 307-19.

Wallander, J.L. and Varni, J.W. (1998) Effects of pediatric chronic physical disorders on child and family adjustment, *Journal of Child Psychology and Psychiatry* **39**, 29-46.