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**Priorities and Perceptions of Disabled  
Children and Young People and Their  
Parents Regarding Outcomes from  
Support Services**

**DH 2147**

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# Executive Summary

## Background

There is a now growing recognition of the need to promote the well-being of children through the adoption of outcomes-focused practices and assessment by social care and other support services. Initially, the Looked after Children (LAC) framework defined seven dimensions on which the progress of children looked after by the local authority should be assessed: health, education, identity, family and social relationships, social presentation, emotional and behavioural development, and self care skills. More recently, the government's Every Child Matters outcomes framework for all children and young people - focusing on the five outcomes of be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being - has become central to all policy for children. Similarly, the National Service Framework for Children, Young People and Maternity Services sets standards of good practice for services in promoting the health and well-being of all children, and emphasises the need for services to work together to achieve positive outcomes for children and young people.

Such policies provide a context within which agencies are expected to deliver services which achieve the best possible outcomes, aiming to ensure that the children and families most at risk of social exclusion have every opportunity to build successful and independent lives. These developments point to the need to look more closely at the situation of disabled children. Clearly, both the LAC and ECM outcomes are valuable and relevant for disabled children. However, interpreting what these outcomes might mean can be difficult when the presence of an impairment or a complex health condition may compromise the achievement of developmental milestones or impact on physical health and functioning. For instance, how do we view 'achievement' for a child with a degenerative condition, or 'being healthy' for a child with a life limiting illness? How can we assess what is appropriate progress for child with an autistic spectrum disorder on 'making a positive contribution'?

In addition, these frameworks focus only on outcomes for children, rather than the outcomes that parents themselves might require from service provision 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 they provide extra care, over and above that of 'the reasonable parent', and it is with this extra care that they need support. In addition, they are particularly vulnerable to stress, which can be produced by trying to meet the extra demands of caring for the child without the necessary resources and support. Parental stress in

turn impinges upon children's development, and has also been identified as a reason for residential placements of disabled children.

## **Research aims**

This project built on both the above frameworks and earlier SPRU work on outcomes for disabled adults and older people and aimed to:

- identify desired outcomes of support services from the perspectives of disabled children, young people and their parents;
- explore managers' and practitioners' perspectives on outcomes;
- work with local authority staff, children and parents, to develop ways of collecting outcome information that can be used in practice;
- pilot and evaluate the use of outcome assessment in practice.

## **Design and methods**

The project consisted of four stages:

1. Qualitative research, including individual interviews, focus groups and observation, with children and parents about desired outcomes of support services.
2. Participatory workshops with managers and practitioners to identify professionals' perspectives on outcomes for disabled children.
3. Development of systems for collecting data on outcomes within the research sites.
4. Pilot implementation of collection of outcomes data and evaluation of that process within the research sites.

The project took place within three local authorities, selected to cover different organisational and geographic structures and to ensure inclusion of diverse socio-demographic groups, including ethnic minorities. In consultation with policy makers at DH, it was recognised that outcomes for disabled children are best viewed as a multi-agency collaborative responsibility and a focus on social care alone could restrict the data. Therefore, a further criterion for selection of authorities was existence of multi-agency planning groups willing to collaborate with the research.

### *Sample for Stage 1*

Disabled children are not a homogeneous group. The needs and priorities of children with different conditions and impairments are likely to differ. The groups included in this project were diverse and also represent groups identified as causing concerns for service providers. They were:

- children with complex health care needs (CHN)
- children who do not communicate using speech (NS)

- children with autistic spectrum disorders (ASD)
- children with degenerative conditions (DC).

Within each group there were approximately equal numbers of children in three age bands (0-6yrs; 7-11yrs; 12-19yrs). Ninety-five families took part in the project representing a total of 100 children. Bereaved families were also included in the DC group. Ninety mothers and 18 fathers participated. Twenty-seven 'other informants' were interviewed. Twenty-nine children participated directly, and a further 12 teenagers with autistic spectrum disorders were observed in a therapeutic group setting discussing friendships and transition.

### *Methods*

Individual interviews and observation were used for obtaining children's views of their desired outcomes and parents' desired outcomes for their children. Methods were developed to include as many children as possible in 'interviews'. Where we were not able to engage children in 'interviews', we used observation of children, observation of a therapeutic group for teenagers with ASD, and interviews with 'other informants' (for example, teachers and care staff) to collect information from perspectives other than those of parents.

Data collection on parents' views of desired outcomes for themselves was carried out in focus groups and during the individual interviews with parents about outcomes for their child. Qualitative analysis using the 'framework method' was applied to all data to identify themes regarding outcomes.

Participatory workshops with managers and staff were held where results of the research with parents and children were presented, participants' perspectives on outcomes were gathered and initial plans for developing an outcomes focus in that area were drawn up.

### *Sample for evaluation of outcomes assessment tools*

Two different tools to collect information on desired outcomes for children and parents were developed. One site developed a tool to support outcomes-focussed assessment for both children and parents. The other site developed an outcomes-focussed tool looking at parental well-being. These were then piloted by staff with families and evaluated by researchers through interviews with parents (n = 25) and staff (n = 15).

## **Key findings**

### *Outcomes for children*

Desired outcomes for the disabled children included in this research encompass the dimensions identified by ECM. Like other children, many of the disabled children we interviewed wanted to be healthy, to have friends and interests, to be part of the local

community, to acquire social and self-care skills and future independence, to feel confident and respected by others, and to experience success and achievement. Parents and other informants also wanted this for the children. However, there are certain important caveats. First, we identified a significant omission from the framework and that concerned communication. Second, what an outcome meant for a disabled child could sometimes be very different to what that outcome would mean for a non-disabled child. Third, some outcomes were seen as fundamental because they needed to be achieved before other 'higher level' outcomes could be achieved. These fundamental outcomes were being healthy, being able to communicate and staying safe. Higher level outcomes were those which fell into the categories of enjoying and achieving, making a positive contribution, and economic well-being.

### *Fundamental outcomes*

- *Being healthy* was fundamental for all groups, but the emphasis on the dimensions of health differed. For many children with CHD and DC, being comfortable and not in pain was central to achievement of any other outcomes, and for some children, having a good span of life was an important issue. For other children, including those with NS or ASD, maintaining health and functioning was important and was seen by parents to be threatened by difficulties experienced in using health services (ASD) and problems with supply and availability in different settings of equipment (CHN and NS). For the children with DC there was a tension between maintaining physical health and abilities against quality of life.
- Emotional well-being was a key concern for parents of children with ASD, amongst whom many found it difficult to assess their child's emotional state. Making a positive adjustment to having a disability or health condition was something that parents across all condition groups highlighted. Meeting the emotional needs of children with DC, including during the end stages of life, was stressed by parents of these children.
- *Communication*: being able to communicate was seen as fundamental to well-being and achieving progress in other areas of life by all groups. Both children and parents highlighted the importance of other people who had regular contact with the child (including parents and siblings, teachers, carers and peers) having the knowledge and skills to understand the child's means of communication.
- *Staying safe*: keeping children safe from exploitation and abusive relationships or physical danger, and the difficulties this poses when children receive care from a number of people, cannot communicate well or lack any sense of danger, was emphasised by parents in all groups. Staying safe was also talked about in terms of preventing the child having accidents. There were different reasons

why a child might be vulnerable to accidents including using inappropriate or unsafe equipment, living in unsuitable housing and/or requiring high levels of supervision.

The level of achievement expected or desired in all outcomes differed from normative developmental progress and between different children with the same condition, depending upon the severity of the condition or the way the condition manifested itself. Interviews indicated that the achievement of many or all outcomes required both specialist support or interventions and progress towards a more inclusive society so that disabled children are not denied opportunities available to non-disabled children.

#### *Outcomes for families: parents and siblings*

Key outcomes parents desired for themselves included:

- *Personal identity:* parents wanted to maintain or regain an identity beyond being the parent of a disabled child. To do this they wanted to be able to take up or maintain employment, interests and social activities.
- *Parenting:* most parents felt they spent too much time doing caring tasks and did not have enough 'quality' time with their disabled child or their non-disabled children. They wanted to be supported to parent the child, not just to be the child's 'carer' or nurse.
- *Feeling skilled and informed:* to have the necessary skills to support their child's development and deal with problems, and to know about the child's condition and sources of support. The skills encompassed many aspects of a child's life 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.
- *Physical and emotional well-being:* to be healthy and not stressed. Parents highlighted needs for support with maintaining both physical and emotional health, and some parents emphasised the need for support to minimise the emotional impact on themselves of the diagnosis and ongoing crises.
- *Maintaining family life:* here two issues arose - first, maintaining a sense of family through shared experiences and activities, with opportunities to spend time together and do things as a whole family; and second, ensuring the mother-father relationship remained intact. A number of different ways of supporting the mother-father relationship were identified by parents. These included meeting fathers' emotional needs and supporting their adjustment to the diagnosis, greater involvement of fathers in consultations with professionals,

short term care and/or domiciliary support to release parents from the caring role and domestic tasks, and help with addressing settling and other sleep problems.

- *Practical and financial resources:* Some of the families participating in this study had access to practical and/or financial resources which helped them as they coped with the 'extra-ordinary' demands associated with caring for their child. Families without such resources wanted to feel they had the practical and financial resources needed to properly care for and bring up their child and the rest of the family. As well as the lack of resources being a source of stress in itself, their absence was also seen as a barrier to achieving other outcomes.
- *A sense of partnership with services and having confidence in services used by the child:* parents wanted to have their expertise on their child recognised, to feel valued and respected by services, and to be involved in decision making. 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 staff who understood about the child's condition and were skilled in meeting their needs, the service being a positive experience for the child, the child being treated with respect, continuity of staff providing the service, and the service being reliable.

A strong emergent theme from interviews and focus groups with parents was their wishes in relation to outcomes for siblings. They wanted siblings to be able to make *a positive adjustment to having a disabled brother or sister*. This included not feeling left out or having restricted lives, having opportunities to take part in activities with their parents and with the whole family, having emotional support, understanding their disabled brother or sister's condition and forming a good relationship with them.

#### *Outcomes assessment*

Evaluation of the piloting of tools for outcomes assessment indicated that there were some problems in staff and parents' understanding of the concept of outcomes. Both had been more accustomed to a culture of service-led assessment rather than assessments which tried to ascertain what they aspired to achieve for the child or themselves from service provision. However, among those who did understand the outcomes approach, views were positive. It was felt to promote a more in-depth and holistic understanding of the family, and to empower staff and parents to 'think outside the box' in identifying what could be done to achieve desired outcomes.

Two different tools were developed in the project to explore outcomes. It is difficult to compare these as they were implemented in different areas and one covered both parent and child outcomes while the other focused solely on parents. There is some indication that the more structured tool used in Area A was slightly better received, and it was only in this area that changes were identified as a result of using the tool.

Some workers in both areas thought that the tools supported the identification of non-service solutions and welcomed the holistic approach, looking at all areas of children's and parents' lives, and working in partnership with parents to identify desired outcomes and ways of achieving these. However, this approach caused anxieties among staff if they felt they would be talking about areas that were not within their remit. Staff in both areas could see wider applications of the tool for other groups of children and families, but also had concerns about the time taken to complete the tools with families. They were concerned about raising expectations that could not be met, but recognised the role of the worker in helping parents to set realistic aims.

### **Implications for policy and practice**

Evidence from this research raises questions about the relevance of outcomes frameworks based on normative developmental models for assessing outcomes for disabled children. There is a need to widen the definitions and indicators of key concepts in these frameworks to take account of disabled children's views and capabilities. Three points are important in this context. First, while disabled children aspired to the same sort of outcomes as their non-disabled peers, the meaning of, and the level of achievement expected in, all outcomes differed from normative developmental indicators. Secondly, changes in the condition or impairment, and/or progress through developmental stages, affected both the outcomes being aspired to, and the priority given to outcomes in the different areas of the child's life. This indicates that regular reviews of desired outcomes and the support services being provided are needed. Thirdly, there needs to be greater recognition that for disabled children outcomes have a hierarchical structure and that achievement of 'higher level' outcomes is only truly possible when the fundamental outcomes (physical health and comfort, emotional well-being, being safe, having a means to communicate and being understood) have been achieved. Communication is a central outcome for many disabled children and its importance should be explicitly recognised within the ECM framework.

In addition, the achievement of these outcomes often requires specialist or extra support. The extent to which these needs for support map on to statutory agencies' views of their responsibilities for disabled children's well-being is debatable, and the interrelationships between outcomes in the different areas of a child's life highlight the need for multi-disciplinary assessments and multi-agency working.

The research underlines the importance of supporting parents to help their children to achieve their desired outcomes and provides evidence on what outcomes parents prioritise for themselves. It also points to the important role of professionals in helping parents to think about and discuss their own well-being, and identify actions that can be taken to improve this. Evidence from the development phase of the project suggests that collecting information about both children's and parents'

outcomes is possible, but requires a change in the organisational culture of services from a needs or service led approach to an outcomes-focused approach.

Finally, one of the challenges of this project was to develop methods to facilitate the direct participation of the children and young people. This continues to be a challenge in practice and the methods used in this project could be adapted to practice situations. However it should be noted that involving many of these children takes a considerable amount of time, particularly when exploring more abstract concepts such as aspirations.

# Chapter 1: Introduction

## 1.1 Policy background

For some years now, policy initiatives in social care have emphasised the importance of a focus on 'the quality of services experienced by, and the outcomes achieved for, individuals and their carers and families' (Modernising Social Services, 1998: para. 1.7). In children's services, Quality Protects (1998) placed a strong focus on identifying the needs of disabled children and ensuring that these 'are adequately met and reviewed' (Objective 6). In addition, the development of the Looking after Children (LAC) assessment and action records was designed to ensure a focus on assessing the quality of care provided to children looked after by the Local Authority and whether this care promoted the successful attainment of developmental progress. A central purpose of this assessment was to promote action to achieve progress in areas identified as problematic so that all children 'are offered the type of experiences necessary for success' (Parker *et al.*, 1991; Ward, 1995). The LAC framework defines seven dimensions on which children's progress should be assessed: health, education, identity, family and social relationships, social presentation, emotional and behavioural development, and self care skills. The Framework for the Assessment of Children in Need (Department of Health, 2001) built upon the LAC system to provide a systematic approach to assessment of all children in need, which offers more scope for identifying how a child's development interacts with family and environmental factors.

There is a now growing recognition of the need to promote the well-being of children through the adoption of outcomes-focused practices and assessment by social care and other support services. The government's Every Child Matters outcomes framework for children and young people - focusing on the five outcomes of be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being - has become central to all policy for children (Department for Education and Skills, 2003; 2004a). Building on the LAC materials and the Framework for the Assessment of Children in Need (Department of Health, 2001), the Integrated Children's System, which is currently being piloted by local authorities, marks an important stage in government policy to improve outcomes for children in need. It focuses on these five key outcomes for children's well-being and recognises the need for all agencies working with children to work together.

Similarly, the National Service Framework for Children, Young People and Maternity Services (NSF) (Department of Health/ Department for Education and Skills, 2004a) sets standards of good practice for services in promoting the health and well-being of all children, and emphasises the need for services to work together to achieve positive outcomes for children and young people.

Such policies provide a context within which agencies are expected to deliver services which achieve the best possible outcomes, aiming to ensure that the children and families most at risk of social exclusion have every opportunity to build successful and independent lives. These developments point to the need to look more closely at the situation of disabled children and to define what outcomes should be expected for this group. The NSF has a specific standard relating to disabled children (Standard 8) which states that 'Children and young people who are disabled or who have complex health needs receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives' (Department of Health/Department for Education and Skills, 2004b: p.5). Detailed recommendations are then set out to help services to achieve these broad outcomes of social inclusion and 'ordinary lives'. Similarly, the Strategy Unit report 'Improving the Life Chances of Disabled People' (Cabinet Office, 2005) sets out a long term programme of steps to be taken towards achieving improved outcomes for disabled people. Within this, two of the four key areas are support for families with young disabled children and transition to adulthood.

Clearly, both the LAC outcomes and the ECM outcomes framework are valuable and relevant for disabled children. However, interpreting what these outcomes might mean for disabled children can be difficult, as each of these dimensions can prove problematic when attempting to assess the progress of different groups of disabled children in relation to expected normative development. For instance, how do we view the assessment of self care skills under LAC or achievement under ECM for a child with a degenerative condition, or being healthy for a child with a life limiting illness? How can we assess what is appropriate progress for child with an autistic spectrum disorder on behavioural and emotional development or on making a positive contribution? Problems of the applicability of the LAC materials to disabled children arose in the early testing of the materials and supplementary questions were introduced to address some of these problems (Ward, 1995). However, these questions point to a more general concern about what the priorities for outcomes should be for children whose development is compromised in some or all these areas by their impairment, and how these children themselves, and their parents, might define these priorities.

A further issue is that these outcomes frameworks focus on outcomes for children but do not include outcomes for parents. Indeed the LAC system is primarily designed for children for whom the Local Authority has, or shares with the child's parents, parental responsibility. It therefore focuses on whether the quality of care provided for the child meets that of 'the reasonable parent' (Parker *et al.*, 1991). However, the majority of disabled children are cared for by their parents (Gordon *et al.*, 2000), with services being desired to support the family in that role. Within the strategy to achieve the ECM outcomes for children, the role of parents is recognised, for example Every Child Matters: Next Steps (Department for Education and Skills,

2004b) states that 'parenting is the most important influence on children and young people's outcomes' (p.26). However, the focus is mainly on the support needed *from* parents to achieve the desired outcomes for children, rather than the support needed *for* parents in their parenting role. The need for parents and carers to have more and better information, advice and support is highlighted (Department for Education and Skills, 2004a) and a Parenting Fund of £25 million has been set up to support the voluntary and community sector to develop a range of support services for parents. Yet in contrast to the focus on outcomes for children, the predominant discourse around support for parents is on service provision, such as childcare provision, helplines and parenting groups, rather than the outcomes that parents themselves might require from such provision in order to support their parenting role.

For parents with disabled children consideration of outcomes services should aim to achieve is especially important as research has shown that they 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). In addition, they are particularly vulnerable to stress, which can be produced by trying to meet the extra demands of caring for the child without the necessary 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).

Thus in looking at outcomes of services for disabled children it is necessary to consider outcomes for both parents and child, identifying where these concur and where they differ. To an extent this was recognised in Quality Protects, where the objectives concerning disabled children were the only ones in which parents and their needs were explicitly mentioned. Similarly, Standard 8 of the NSF specifically states that services should enable children *and their families* to live ordinary lives, and highlights the need for services that can help parents to achieve these outcomes, including a range of family support services and packages of care that are 'flexible and responsive to children and families' needs'. Despite this, policy rarely articulates 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 families with disabled children and the services they receive, rather than what parents hope to achieve in their own lives from service provision (Shearn and Todd, 2000). Consequently, the development of services has often been based on unproven assumptions about what parents need. For example, respite services may be focused on simply providing a break from care-giving, rather than looking in more depth at what parents want for their children and how they want to use time freed from care-giving in positive ways.

## 1.2 Outcomes focused approaches

Outcomes of services are defined as the impact, effects or consequences of a service on people's lives rather than the provision of a service (Nicholas *et al.*, 2003; Nocon and Qureshi, 1996). An outcomes-focused approach shifts the focus away from looking only at the levels and types of service provision to exploring differences services make to the lives of people using them, and the degree to which services help users' preferences and desired outcomes to be achieved (Qureshi, 2001a). The importance of paying attention to outcomes relates to assessment (What outcomes does the service user want to achieve?), care-planning (How can those outcomes be achieved?), service design and delivery (What services need to be in place to achieve those outcomes?) and monitoring and evaluating services (Has the service achieved the desired outcome?) (Nicholas *et al.*, 2003). To date most work on outcomes – both in terms of researching user views on outcomes and implementing an outcomes approach in practice - has focused on adult service users (for example, Patmore, 2001; Qureshi and Nicholas, 2001; Bamford and Bruce, 2000).

Distinctions have been made in the literature between service-based and user-based outcomes (Cheetham *et al.*, 1992) or 'intermediate' and 'final' outcomes (for example, Knapp, 1984). Service-based or intermediate outcomes focus on measures of service activity and performance, whilst user-based or final outcomes focus on the impact of services on the users, for example on their well-being. However a number of writers have noted the importance of distinguishing between service activity and the impact of this activity on users and suggested that the term 'output' should be used for the former and 'outcome' for the latter (for example, Shiell *et al.*, 1990; Axford and Berry, 2005). Work under the Outcomes Research Programme at the Social Policy Research Unit has focused on the identification of outcomes desired by users themselves (Qureshi, 2001a). The framework for understanding outcomes derived from the consultations with users, carers and staff in the first stages of this work comprised:

- **Maintenance outcomes** – for example, maintaining acceptable levels of personal comfort, social contact.
- **Change outcomes** – for example, improving confidence, improving accessibility of the environment and ability to get about, reducing risk of harm, regaining self-care skills.
- **Process outcomes** – the results of the way in which services are provided, for example whether people feel valued and respected, whether they feel they have a say over service provision, the 'fit' of the service with family and/or culture.

This framework adds new dimensions to the concept of outcomes. First, that for some service users, particularly older people, important impacts of services are not

about change but about maintaining quality of life, sometimes in the context of deterioration in abilities. Secondly, the importance of not just the delivery of a service but the *way* in which the service is delivered is highlighted in the concept of process outcomes and the effects of that process for service users. Similarly, user groups and disabled people have argued for a greater focus in service assessment on both what is to be achieved *and* how (for example, Morris, 1997; Turner, 2000). Users have argued that the impacts of the way in which services are delivered can be as important as outcomes of the service, and the way in which something is done can undermine or contribute to quality of life outcomes (Qureshi and Henwood, 2000).

It is clear that this framework has relevance for disabled children. For example, for children with progressive or degenerative conditions maintenance of comfort and social contact is important and improvement in functioning may not be a realistic aim (Wray and Wray, 2004). As Qureshi (2001b) notes, maintenance does not imply an unchanging level of support over time. Where a child's condition is deteriorating, increasing levels of input may be required to maintain the child's, and the family's, well-being. The salience of process outcomes is also demonstrated in Mitchell and Sloper's (2001; 2003) research with parents and disabled children and young people in defining their criteria for quality services. In drawing up essential criteria for different types of services, both parents and young people defined a core set of criteria which they felt applied to any type of service. Many of these criteria focused on the process of service delivery and, in particular, the way staff relate to and treat family members.

Core criteria proposed by parents were:

- meeting the child and whole families' needs
- listening to both the child and their family
- treating the child and all family members with respect
- staff knowledge and training
- welcoming and helpful staff
- service respects each family's culture.

Core criteria proposed by young people were:

- staff understand about my illness or disability
- staff know how to help me and look after me
- staff listen to me
- staff ask me for ideas and take notice of what I say
- I can ask staff questions and they explain things to me
- staff allow me to make choices.

As yet, there has been little investigation of disabled children and young people's or their parents' views on the outcomes they aspire to achieve from service provision,

or of the views of staff who work with disabled children on what outcomes they believe their services should try to achieve. A number of bodies of work - on outcomes for adult service users, on outcomes for children and young people in general, and on the needs of disabled children - can inform research on outcomes for disabled children and their families. However, in the absence of direct work with these children and their parents exploring what outcomes they aspire to achieve, none of these can provide the answers needed to inform the delivery of services, nor the assessment of their effectiveness in producing the outcomes desired by disabled children and their parents. The research reported here therefore proposed a programme of work that involved direct consultation with children and parents, followed by work with managers and practitioners, to place the information gained in the context of their own views on desired outcomes, and finally work in local authorities to develop and pilot systems of outcome assessment.

The aims were:

- To identify the desired outcomes of social care from the perspectives of disabled children and young people and their parents.
- To explore managers' and practitioners' perspectives on outcomes.
- Working with local authority staff, children and parents, to develop ways of collecting outcome information that can be used in practice.
- To pilot and evaluate the implementation of outcome assessment in practice.

The project therefore comprised both direct research with children and families and development work with local services. In the next section, we briefly consider some of the issues that informed the development stage of the project.

### **1.3 Implementing an outcomes approach in local services**

Evaluating progress in implementation of policy objectives and effectiveness of services clearly requires identification of outcomes for users of local services. However, the outcomes for disabled children highlighted in policy documents such as the NSF cannot usually be achieved through input from one service, nor should they be confined to one setting, such as school. As policy notes (for example, Department of Health/Department for Education and Skills, 2004; Cabinet Office, 2005), joined-up services are central to the achievement of positive outcomes for all children, especially disabled children. Thus any research exploring outcomes for disabled children and the implementation of outcomes approaches in practice must work across a range of services. At the outset of the project, it was agreed with policy customers that this work should take a multi-agency approach and not just focus on social services. However, the problems in developing multi-agency working have been highlighted in many studies (Sloper, 2004) and there is as yet little evidence of the outcomes for service users of partnership working (for example, Petch *et al.*, 2005; Cameron *et al.*, 2000). When this research started multi-agency

working in services for disabled children was not well developed in many areas. The process of pulling agencies together to implement change on a multi-agency basis requires considerable resources and time (Sloper *et al.*, 1999), and this was not available in this project. It was therefore important that the project worked with local areas in which multi-agency partnerships already existed in services for disabled children.

Lack of joint working has been identified as one of the barriers to implementing outcomes approaches in practice. However other barriers also exist in professional and organisational cultures, in the anxieties about performance that assessment of outcomes can engender amongst staff (Qureshi, 1999), and in what Marsh and Fisher (1992) describe as the DATA (we Do All This Already) response from workers. In working with services to implement approaches to the identification of the outcomes highlighted in our research, we needed to be aware of these barriers, and that the challenges of development work which attempts to implement research in practice, and therefore requires a process of change in practice, are considerable (for example, Smale, 1996; Effective Health Care, 1999; Sloper *et al.*, 1999; Nicholas, 2001). Linking research with change goes beyond conventional research, requiring different skills from those needed for conventional research and consideration of the researcher's role in how change is implemented (Robson, 1993). In this we were able to draw on the experience of two of the research team (BB and PS) in previous research and development work (Mukherjee *et al.*, 1999; Sloper *et al.*, 1999) and SPRU's work on implementing outcomes approaches in adult social care (Qureshi, 2001a). The plan for the development work was based on the concept of a cycle of innovation (West, 1997) consisting of initiation, planning, implementing and routinising, and, as recommended by Brown (1996) and Smale (1996), on analysing the nature of the change; understanding the context in which it would take place; identifying and engaging significant stakeholders; and identifying who would be affected by the change and their likely roles in relation to it.

It was clear that both managers and frontline staff would be involved in implementation of outcomes approaches, and may have different attitudes to the implementation (Le May *et al.*, 1998). Therefore it was important to involve both groups in planning the approaches to identifying outcomes.

One of the questions faced by the research team was how to define our role and where to draw the line between facilitation and intervention. Early on in the project, we decided that our role was to facilitate the services we worked with to take responsibility for developing ways of assessing outcomes, but not to intervene in a directive way in this. We were aware that as we had carried out the research on defining outcomes for children and parents, there was a danger that we would be tempted to take ownership of the processes of drawing up tools for identification of outcomes and we would need to guard against this.

In line with this approach, we also recognised that a key issue would be ‘adoptability’ of methods for identifying outcomes, including their compatibility with existing policies, values and ways of working and with existing forms of assessment; relative advantage in comparison with existing assessment and ways of working; adaptability to local circumstances; ease of understanding and use; low resource requirements; and the extent to which they could be tried out on a limited basis (Smale, 1996; Qureshi, 2001b). As Qureshi (2001c: p.12) notes, in relation to work on summarising intended outcomes for older people at assessment, identification of intended outcomes ‘is *not* another method of assessment and not intended to replace or supplant existing assessment documentation or procedures.... Rather it is an explicit recognition of an essential step between assessment and the construction and implementation of a care plan’. It was clearly important that staff in the services we worked with were not just given ‘tools’ to identify outcomes, but first of all understood the concept of outcomes and then had some ‘ownership’ of the ways in which identification these outcomes could be incorporated into their work.

## **1.4 Plan of the project**

As noted above, the project involved both primary research and development work. It consisted of four stages:

1. Qualitative research with children and parents about desired outcomes of social care provision.
2. Consultation with managers and practitioners to identify professionals’ perspectives on outcomes for disabled children and their ‘measurement’.
3. Development of systems of collecting data on outcomes within the research sites.
4. Implementation of collection of outcomes data and evaluation of that process within the research sites.

The project worked with three local authorities (research sites). The authorities recruited to the project represented different organisational, geographical and demographic structures: rural/urban; unitary/shire; and areas with high and low ethnic minority populations. All three authorities had existing multi-agency groups steering developments in services for disabled children.

## **1.5 Structure of the report**

In the next chapter, we summarise the methods for the research and pilot evaluation stages of the project. More detailed explanations of the methods used for the research with children are contained in the publications included in Appendix 4. The detailed results of the findings on desired outcomes for the four groups of children and for parents have been written up in papers for publication. These are in Appendix 7. In Chapter Three we summarise the results on desired outcomes for

children under the *Every Child Matters* outcomes framework. Chapter Four presents the results of the research on parents' desired outcomes. Chapter Five describes the development work on drawing up outcomes tools and using these in practice, and the results of the evaluation of this pilot study. In Chapter Six, we discuss how the findings on desired outcomes for the groups involved in this study relate to findings on outcomes within the wider programme of work carried out by the Social Policy Research Unit, and the implications for policy, practice and future research of the findings from this study. The appendices contain copies of research tools, published papers, and those in press and submitted for publication. Appendix 9 provides a list of all external dissemination activities so far.



## **Chapter 2: Methods**

This chapter summarises the methods used in the research phase and for the evaluation carried out in the development phase. Detailed accounts of the methodologies used in the research phase can be found in the papers located in Appendix 4.

### **2.1 Location of the research**

The study was carried out in three local authorities and ethical approval for the research was obtained from local NHS research ethics committees. The project included children from four 'condition' groups: autistic spectrum disorders, complex health needs, degenerative conditions and not able (for physical or neurological reasons) to use speech to communicate. The research involving children with autistic spectrum disorders and children with degenerative conditions and their parents took place in two neighbouring local authorities (referred to as Area A). Bereaved families of children with degenerative conditions were recruited through a children's hospice in a different region. The work with children with complex health care needs and children who did not use speech to communicate and their parents took place in one local authority (referred to as Area B).

### **2.2 The research phase**

Individual, semi-structured interviews were used to explore how disabled children and their parents defined their desired outcomes for their/their child's life and the role of services in helping them to achieve those outcomes. Parents were also invited to attend a focus group. Focus groups were used to explore parents' desired outcomes for themselves. Where the child did not want to or was not able to take part directly, permission was sought from the parent to speak to someone else who knew the child well in another context, referred to as 'other informants', such as a teacher or a non-parent carer. 'Other informants' were interviewed about their views with regard to the child's outcomes.

#### **2.2.1 Recruitment**

In accordance with data protection, all families were approached via social services, education, health or voluntary organisations. An invitation letter and information leaflet which described the research project was sent out by these organisations to potential participants (see Appendix 1). Children and young people were provided with an age appropriate written information leaflet, and wherever necessary leaflets containing symbols. This initial approach invited families to return a 'contact form' if they were willing to be contacted by the research team with a view to taking part in

the project. Families who responded were contacted by telephone when researchers answered any questions about participation in the research. If a parent wished to take part in the research, a suitable time and location for an interview was arranged. At that interview the involvement of the child was discussed further and parents were shown the sorts of methods that would be used in the interview with the child. Typically the child's involvement in the project was confirmed by a telephone call a few days after the interview with the parents to allow time for the parent to explain to the child more about what taking part would involve. (For children under five years, the researchers only sought to recruit parents to the project.)

'Other informants' were nominated by parents. A letter, project information sheet and contact form was sent to these individuals (see Appendix 1). All 'other informants' agreed to be interviewed.

### **2.2.2 The sample**

Across all three local authorities, 95 families took part in the project representing a total of 100 children, see Table 2.1. A further 12 teenagers with autistic spectrum disorders were observed in a therapeutic group setting discussing friendships and transition. This was undertaken in order to supplement the data collected directly from children and young people with autistic spectrum disorders.

Ninety mothers and 18 fathers participated. All were interviewed and 32 parents also attended one of seven focus groups where the discussion centred on their views about the outcomes they desired for themselves. Joint interviews (n=13) were carried out where both mother and father from one family wanted to participate. Twenty-seven 'other informants' were interviewed. Twenty-nine children participated directly. A range of socio-economic status and family composition was represented in the sample.

**Table 2.1: Families taking part in the research**

	<i>Autistic spectrum disorders</i>	<i>Complex health care needs</i>	<i>Do not use speech</i>	<i>Degenerative conditions</i>
Total number of families	25	26	24	20
Total no. of children represented	28	26	24	22
Parental involvement				
mother only	23	19	21	14
father only	0	3	2	0
mother and father	2	4	1	6
No. of children involved directly	5	11	7	6
No. of other informants	9	5	12	1
Age range of children	5 -19 yrs	2 -18 yrs	3 - 18 yrs	2 – 18 yrs (Bereaved families: 1- 23 yrs)
Boys	22	10	13	10
Girls	6	16	11	12
No. minority ethnic group families	2	11	9	5

*Note: This table excludes the teenagers attending the therapeutic group which was observed as part of the fieldwork.*

The children with complex health care needs had a number of different impairments (typically cognitive and physical) and/or significant health conditions. The children who did not use speech to communicate also typically had complex health care needs and, in addition, did not use speech to communicate for physical or neurological reasons. The degenerative conditions represented in the research included neuromuscular and metabolic conditions and severe neurological impairments with limited life expectancy. The range of autistic spectrum disorders was represented, including children with Asperger's syndrome. Care was taken to ensure the groups were as distinct as possible though there was, inevitably, some overlap.

### **2.2.3 The consent process**

Information sheets appropriate to potential participants' ages and abilities were provided. This was followed up by a telephone and then face-to-face conversation with the researcher.

Prior to interview, written consent to their own and their child's participation was gained from parents. Where possible, children's written consent was also obtained (see Appendix 1). There were situations where the researcher was not confident that the child could provide informed consent. Here the notion of assent was

adopted. That is, the child was assenting to be interviewed and was aware that they could terminate the interview at any time.

The notion of on-going consent was employed and, during all the interviews, the researchers continually checked (verbally and through observation of non-verbal behaviours) participants' ease and willingness to continue.

For the children with autistic spectrum disorders, a 'Social Story' (Gray, 1994) was prepared for each child providing written and visual information about the researcher's visit (see Appendix 4). Social Stories are used with children with ASD to prepare and reassure them about new situations. The Social Story was used by the parent a number of times before the researcher's visit

#### **2.2.4 Involving the children in the research**

A key issue was to develop methods to ensure the meaningful participation of children. As well as methodological issues *per se*, it was also important to consider the impact that impaired cognitive abilities and limited life experiences might have on children's abilities to reflect on their current lives and describe their desires and aspirations. In addition, a reluctance to participate, the potential for causing high levels of anxiety and the fact that features of autism include a lack of self-awareness and dislike of change, made the work with children with ASD particularly challenging.

The methods used to promote children's participation are reported in detail elsewhere (Beresford *et al.*, 2004; Rabiee *et al.*, 2005 – see Appendix 4). In essence, the strategy adopted was to start off with a concrete approach focusing on identifying the positive and negative aspects of their lives at the time of the study and where possible to explore desires and aspirations using visual techniques and different methods according to the child's abilities.

##### *Methods used with children with autistic spectrum disorders (ASD)*

A disposable camera was sent to the family prior to the interview and the child was encouraged to take photographs of the people, places and activities which were important to them. These were used as the focus of conversation during which the child and researcher made a poster about the child's life.

##### *Methods used with children with complex health care needs and children with degenerative conditions (CHN and DC)*

These interviews were facilitated by using a large board with a central circle representing the child and other labelled and illustrated circles representing different aspects of the child's life, including home, family, self-care, treatments, friends, school, equipment, people, moving about and things I do after school, together making a map of the child's life. The children could choose whether or not, and the order in which, they talked about the different areas of their life. Using the 'picture'

as the focus and prompt for discussion, the researcher then worked with the child to identify positive and negative aspects of these different areas of their lives. The researcher also explored children's views on how their lives could be made better by asking questions like 'if you had a magic wand, how would you change it?' At the end, children had a chance to add to the 'picture' any new experiences and opportunities they would want to see added to their lives by labelling and adding blank circles to the board. For children over 12, we explored what they aspired to in terms of adulthood, using a timeline.

#### *Methods used for children who do not use speech to communicate (NS)*

The data generated from the interviews with the children with complex health care needs, parents of children with no speech and existing research findings were used to inform the content of interviews with the children who did not use speech for communication. These formed the basis of a visual tool which enabled the children to show, in a simple, concrete way their desires and aspirations in terms of the different areas of their lives. Prior to these interviews, parents were asked to complete a questionnaire about their children's communication abilities (see Appendix 3).

### **2.2.5 Interviews with parents and other informants**

Interviews with parents were semi-structured and explored what they wanted for their child in all areas of their lives. A 'map' of the different areas of the child's life was used as a visual prompt and covered the following areas: health; activities and experiences; being at school; feelings and emotions; how the child feels about her/himself; relationships with family members, other children and other adults; the way the child is seen by other people; communicating and being able to make choices; and becoming independent. Parents were encouraged to talk about aspirations that had already been achieved, as well as hopes and desires for the future. The focus was very much on encouraging parents to think about desired outcomes as opposed to needs or difficulties. The interviews with the bereaved parents (who formed a sub-sample within the degenerative conditions sample) also asked about the nature and circumstances around their child's death.

The interviews with the 'Other Informants' were similar but limited to the areas of the child's life about which they felt able to comment. First language interviews were offered to all participants. Two parents requested interviews in another language.

While the individual interviews (or occasionally joint interviews) with parents focused on parental views on desired outcomes for the child, in the course of these interviews parents also spoke about outcomes they valued for themselves.

## **2.2.6 Focus groups with parents**

In addition to the individual interviews, data on parents' views about their desired outcomes were collected through focus group discussions. Focus groups were organised according to the type of impairment the child had and the child's age. The focus groups were facilitated using a number of exercises to help parents to think about their lives now and what changes they would want to make to their lives (see Appendix 2). Exercises included drawing pie charts to show actual and desired use of their time over a 24 hour period and identifying goals they would like to achieve in 12 months time. The discussion also explored barriers to achieving desired outcomes and the role of services in achieving those outcomes.

## **2.2.7 Data analysis**

The interviews and focus group discussions were tape-recorded and transcribed. The data were analysed by a process of data reduction and display, conclusion drawing and verification (Miles and Huberman, 1994). Three researchers each read a sub-sample of transcripts to identify a priori and emergent themes, and then agreed a framework for analysis, including categorisation of main and sub-themes. The data were then coded and drawn together using a computer assisted qualitative analysis package (Nvivo) and manual methods and analysed to identify over-arching themes and conclusions. Conclusions were verified by checking with transcripts and through on-going discussions within the research team.

## **2.3 Methods used to evaluate the pilot work**

In the development phase of the project, Areas A and B worked with the research team to devise tools by which information about children's and parents' desired outcomes could be collected by staff in practice settings. Area A chose to develop a tool to explore and record parental outcomes only, while Area B chose to devise a tool which collected information about the child's and parents' desired outcomes. These tools were piloted and evaluated. Here we report the methods used to evaluate the piloting of the tools, further details about the pilot phase can be found in Chapter 4.

The evaluation consisted of interviews with parents and staff who participated in piloting the tools, and an examination of completed tools. The aim of the interviews was to explore staff and parents' experiences of using the tools. These interviews were conducted by researchers who had not been involved in the research or development in the site concerned.

An information sheet describing the evaluation and a contact form were sent to all parents' and staff who were involved in the piloting phase (see Appendix 5). Parents

and staff who were interested in participating in the evaluation returned the contact form to the research team using a reply paid envelope. Interviews were then arranged. Written consent to interview and receive a copy of their completed tool was obtained.

### **2.3.1 Evaluation interviews with parents**

The evaluation interviews covered the way the tool had been used and administered, the appearance and 'user-friendliness' of the tool, expectations and actual experience of using the tool, views on outcomes-focussed assessment and practice, and suggestions as to how the tool and/or process by which it is used could be improved (see Appendix 6).

### **2.3.2 Evaluation interviews with staff**

The evaluation interviews with staff covered similar areas to the parents' interviews but also explored the assessment context(s) in which they had used the tool, views on the value of the information collected, barriers to the effectiveness of the tool, and training and supervision with regard to using the tool (see Appendix 6).

### **2.3.3 Data analysis**

Parents' and professionals' accounts were analysed separately. All interviews were tape-recorded and transcribed. Detailed summaries of each interview were made from the transcripts. These summaries were organised under a series of themes drawn from the topic guides and reading of a sub-set of the transcripts. The data for each theme were then collected together and examined and the findings contained within them written up.



# Chapter 3: Understanding the Findings of the Research within the *Every Child Matters* Framework

## 3.1 Introduction

The majority of first phase of the study, research on parents' and children's views of the outcomes they aspire to achieve, was completed in 2003 and results have been published in peer reviewed journals (Beresford *et al.*, forthcoming (a); Rabiee *et al.*, 2005 - see Appendix 7). The exception to this is the research with children with degenerative conditions and their parents. This was delayed due to two factors: transferring some of the project time allocated for two of the team (BB and TS) to collection and review of evidence to support the disabled children's External Working Group for the Children's National Service Framework, at the request of DH; and 'gatekeeping' access to families by staff, exacerbated by the sensitivity of health professionals to the impact of the suspension of, and subsequent disciplinary action against, a key NHS consultant involved with this group. This part of the research has now been completed and a paper detailing the findings submitted to a journal (Beresford *et al.*, forthcoming (b) - Appendix 7).

This research was conceived, and the majority of it was analysed and written up, before the publication of Every Child Matters (ECM) (DfES, 2003, 2004) and the adoption by government of the ECM outcomes framework focusing on five aspects of children's lives against which outcomes should be measured: be healthy, stay safe, enjoy and achieve, make a positive contribution, and achieve economic well-being. This outcomes framework has resulted in considerable work in defining indicators through which progress can be measured at national and local levels (DfES, 2004). However many questions remain as to how these outcomes should be defined for disabled children and those with complex health needs. In view of this, in this chapter we will summarise the results of the research across all four groups in the study (CHN, NS, ASD and DC) under the outcome areas of the ECM framework, and explore three issues:

1. The extent to which these outcomes are relevant or appropriate for disabled children.
2. How the components of these outcomes are defined by disabled children and their parents.
3. Whether the framework omits any aspects of disabled children's lives and their desires and aspirations.

## **3.2 Key findings on desired outcomes for children and young people**

Overall, we found that the ECM outcomes framework was relevant and appropriate for disabled children. Like other children, many of the disabled children we interviewed wanted to be healthy, to have friends and interests, to be part of the local community, to acquire social and self-care skills and future independence, to feel confident and respected by others, and to experience success and achievement. Parents and other informants also wanted this for the children. However, there are certain important caveats. First, we identified a significant omission from the framework and that concerned communication. Second, what an outcome meant for a disabled child could sometimes be very different to what that outcome would mean for a non-disabled child. Third, some outcomes were seen as fundamental because they needed to be achieved before other 'higher level' outcomes could be achieved. These fundamental outcomes were being healthy, being able to communicate and staying safe. Higher level outcomes were those which fell into the categories of enjoying and achieving, making a positive contribution, and economic well-being.

### **3.2.1 Fundamental outcomes**

#### *Being healthy*

Physical health was fundamental for all groups, but the emphasis on the dimensions of physical health varied according to the child's impairment and/or health condition. For many children with CHD and DC, being comfortable and not in pain was central to achievement of any other outcomes, and for some children, having a good span of life was an important issue. For other children, including those with NS or ASD, maintaining health and functioning was important and was seen by parents to be threatened by difficulties experienced in using health services (ASD) and problems with supply and availability in different settings of equipment (CHN and NS). For the children with DC there was a tension between maintaining physical health and abilities against quality of life. The costs in terms of the time, discomfort and risks associated with therapies and other medical interventions had to be balanced against the benefits of continued independence, physical health and/or the ability to continue favoured activities within the context of the fact that the child's life was shortened. The on-going process of degeneration caused these 'costs' to increase at the same time as the length of time the child would be alive decreased.

Emotional well-being was a key concern for parents of children with ASD, amongst whom many found it difficult to assess their child's emotional state. Making a positive adjustment to having a disability or health condition was something that parents across all condition groups highlighted. For children with degenerative conditions, especially those who were able to understand the changes in their health and abilities, emotional support was needed for coping with changes associated

with degeneration and understanding the implications of their diagnosis. All these children also required emotional support in the end stage, particularly to ensure the child did not feel anxious or abandoned.

### *Being able to communicate*

Being able to communicate was seen as fundamental to achieving progress in other areas of life for all groups. For example, for ensuring that children with degenerative conditions were comfortable/pain free and had their basic needs met, for emotional reassurance, and for safety, especially for children who did not use speech and for those with ASD. Both children and parents highlighted the importance of other people who had regular contact with the child (including parents and siblings, teachers, hospital staff, carers and peers) having the knowledge and skills to understand the child's means of communication. Having the ability to communicate was seen as opening up doors to more opportunities, such as socialising, being active and becoming more independent, which in turn help promote a child's feeling of security, confidence and self-esteem.

While maximising communication and communication skills was something that was relevant to all the children, the nature of the desired outcome varied according to the child's abilities and the nature of their condition. Thus among some children, especially those with autistic spectrum disorders, the desired outcome was concerned with wanting the child to want to communicate. In terms of communication skills, for parents of children with severe learning difficulties and some of those with autistic spectrum disorders, the desired outcome was for their child to be able to communicate basic needs. A different group was those children with good cognitive ability but who, for physical reasons, could not speak. Here the desire was for their child to be able to communicate independently and have access to a communication system which gave them greatest opportunities to communicate. Some of the parents of children with degenerative conditions reported having to 'renew' their ways of understanding and communicating with their child as the condition caused on-going degeneration of communication, physical and/or cognitive abilities. The desire of these parents was that there would always be some way by which their child could communicate, and that all the people looking after their child would know how to communicate with the child.

### *Staying safe*

Keeping children safe from exploitation and abusive relationships or physical danger, and the difficulties this poses when children receive care from a number of people, cannot communicate well or lack any sense of danger, was emphasised by parents in all groups. However, the safety of some children was seen to be at greater risk. This was for a variety of reasons including: receiving intimate care from a number of people, being physically disabled, not being able to communicate well or lacking social skills to deal with or avoid potentially 'dangerous' situations, people or relationships.

Staying safe was also talked about in terms of preventing the child having accidents. There were different reasons why a child might be vulnerable to accidents including using inappropriate or unsafe equipment, living in unsuitable housing and/or requiring high levels of supervision.

### **3.2.2 Higher level outcomes**

#### ***Enjoying and achieving***

Getting the most out of life and developing broad skills for adulthood were highlighted by all groups as key indicators of well-being which could only be achieved if the more fundamental outcomes were met. Enjoying and achieving encompasses various areas, each carrying different meanings and additional significance for different groups of disabled children.

#### ***Identity and self-esteem***

For many children feeling 'normal' was important and that was closely linked to being accepted by their peer group. Wanting to look good, wearing similar clothes to others and being able to use attractive and acceptable equipment (boots, wheelchair, and so on) all contributed to how they felt about themselves. Parents also wanted their children to 'look good' to blend in with others and felt that services need to be more sensitive to the child's identity and social integration when issuing the child with equipment, making sure that it is attractive whilst still offering appropriate support. Some children with autistic spectrum disorders, especially those at the severe end of the spectrum, did not appear to be concerned about how others perceived them and did not appear to aspire to integration with their peers. However, their parents wanted them to develop skills so that they could manage and 'blend in' in mainstream situations.

While parents wanted their child to be treated as normally as possible, they thought helping the child experience success by giving them achievement awards for things they have achieved at their own level would boost their self-esteem and self-confidence.

#### ***Socialising and having friends***

Having friends was a priority for many children and was also a common theme when talking to their parents. However, parents of children with autistic spectrum disorders, in particular those with severely affected children, recognised that to have friends their children would first need to have the desire to interact and to learn social skills.

Most children enjoyed talking about friends, but friendship carried different meanings according to the child's communication and cognitive abilities. For children with severe learning difficulties and for some children with communication impairments,

being with a friend was seen by parents as being with peers they liked even where the interaction between them might be very limited. For other children this meant being with people they could interact with more meaningfully. Many of the older children favoured being with their own age group and wanted opportunities to meet other young people from the opposite sex.

Parents differed in whether they wanted their child to develop friendships with other disabled children and/or with non-disabled children. Parents of more severely impaired children tended to aspire to friendships with other children with similar conditions. Parents of children with degenerative conditions where there was no cognitive impairment also wanted their child to have within their social network friendships with children with the same condition. Such friendships were seen as a source of emotional support. Others favoured friendships with more able children in order to give the child the opportunity of having a role model.

While difficulty with social interaction was seen as a key barrier to friendship by parents of children with autistic spectrum disorders, the lack of contact with school friends out of school was seen as a barrier to achieving friendship across all groups. This lack of out of school contact was a source of considerable frustration for some children. All parents believed having friends inter-related to many other areas of the child's life, including taking part in activities, emotional well-being, and developing social and communication skills.

There often came a stage amongst the children with degenerative conditions where interaction with peers was no longer a priority or was no longer appropriate. What became more important were the skills of the person interacting with the child in terms of communication and how best to stimulate and interact with the child. However, even in the end stages, skilled and loving human contact and interaction was seen as fundamentally important to the child's well-being.

#### *Activities and experiences*

Having interests and being able to participate in activities was something that all parents wanted for their child. Many were concerned that their child's 'world' was restricted to home and school and they wanted their child to have greater variety and opportunities in their lives. In particular, many wanted their children to be participating in mainstream activities in their local community. Similarly, many children expressed a desire to be 'doing more'. The only group of children who did not want to expand their worlds was some of the children with autistic spectrum disorders. However, their parents believed that there were long-term benefits for the child if they were exposed to, and took part in, new activities and experiences. The lack of accessible or appropriate facilities and/or the lack of support to assist the child meant that taking part in mainstream activities was often very difficult.

Parents' views differed with regard to the experiences they wanted their child to have. Parents of children with more severe impairments and more limited ability to interact often aspired to their child having opportunities to be with different people and experience different environments so that they would be kept alert as much as possible. Others wanted their children to have the same access to facilities that their non-disabled children use, and have opportunities to go out, learn new skills, engage in age appropriate activities and have a break from family members. Accessing and enjoying everyday mainstream life for as long as possible even though the child's condition was deteriorating was important for children with degenerative conditions. There was a further issue that needed to be addressed for this particular group of children. That is, the importance of finding new activities or new sources of pleasure and enjoyment when the impact of degeneration or failing health meant that previous pastimes were no longer appropriate or enjoyable.

Having experiences of different situations and different people was seen by some parents and informants as not only giving the child a chance to socialise and be active, but also helping the child build his/her confidence and become more independent and able to make choices.

### *Education and learning*

Parents' aspirations for their child's academic attainments varied according to the severity of the condition and associated learning difficulties. All parents wanted their child to fulfil their learning potential. Parents of very severely disabled children talked about learning in terms of their child enjoying a stimulating environment and working towards achieving suitable goals. For those with limited cognitive abilities, acquiring self-care and living skills was often prioritised over academic achievements. However, for children with greater cognitive abilities, parents wanted their child to at least achieve basic skills such as reading, writing and number skills and to have a knowledge (at some level) of the world they lived in.

Many children said that doing well at school was important to them. The majority of children liked school because it provided both learning opportunities and opportunities for play and interaction with other children. For children in mainstream schools and their parents, having a good education was important because they considered it a route to future employment. Children with conditions that did not affect their cognitive abilities particularly raised the issue of not wanting their schoolwork to be affected by having to have time off (sometimes for weeks or months) due to ill-health or for treatments. Children with degenerative conditions needed to have goals and achievements that were appropriate and responsive to the decline in their abilities. In some cases, the children need help in adjusting their expectations for themselves in terms of academic achievements.

### *Self-care skills*

While for non-disabled children independence is often seen in terms of the child being able to do something without help, for many disabled children, for whom this degree of independence is not achievable in certain areas of their lives, independence is seen in terms of the child reaching their potential in their ability to carry out personal tasks and make choices as best as they can (with or without support). This was a key priority among many children and parents across all groups. The extent to which children were independent in self-care varied according to the child's age and the severity of their condition. Among children with autistic spectrum disorders who were independent in their self-care, parents identified more subtle achievements, such as choosing clean clothes, washing sufficiently frequently, knowing what to wear and maintaining appearance. For others, the top priorities were being able to wash, feed and use the toilet independently. Achieving independence in self-care was seen by all parents to impact on other areas of child's life such as self-esteem.

### *Life skills*

All parents shared a desire for their child to become as independent as possible in their daily lives. Central to achieving independence is the acquisition of life skills, such as basic academic, communication and money skills, personal safety, cooking, shopping, being able to go out alone and more generic skills such as making choices, interacting and dealing with people, and dealing with unexpected situations. The nature of the child's condition affected the ease or likelihood of achieving some or all of these skills. As with self-care, for many children in this study independence was seen in terms of children reaching their potential in their ability carry out life skills with or without support. Children described the life skills they wanted to acquire including: being able to make snacks, being able to go out alone, to go shopping independently, and being able to understand the value of money and managing it.

### *Feeling loved, valued and respected*

Parents wanted their children to feel that they were loved and that what they wanted mattered. Treating the child as an individual, involving the child in making decisions about his/her life, and respecting the child's privacy (in a way appropriate to their age) are among things that were said to help raise the child's self worth.

### ***Making a positive contribution***

While some parents were more inclined to talk about here and now situations, many emphasised the importance of planning now in terms of developing skills and expectations for future outcomes.

### *Being occupied/having a job and earning money*

We asked young people over 12 years old and their parents about their future aspirations. Children and young people with degenerative conditions and their parents typically took a day to day approach to life and chose not to look too much into the future and little was revealed in these interviews with regard to adulthood.

Amongst with rest of the sample, having a job and earning money in adulthood was seen as being important by young people who had good cognitive ability and their parents. Parents of young people with more limited understanding wanted their children to be meaningfully occupied and be able to contribute something, however small, when they become adults. The need to develop children's communication skills, including basic reading and writing skills, was seen by parents across all groups to be a necessary step to facilitate that. For parents of the children with more severe learning difficulties who could not see their child ever being able to take on any responsibilities, what mattered was to keep their child occupied and alert.

#### *Feeling involved and having the opportunity to exercise choices*

Being involved and participating in decisions that affect children was high on the agenda for many children and their parents. This ranged from choices about what to wear, how and where they spent their time, planning for the future, to professionals talking to children and giving them choices. Involving children in decisions about their lives was seen by parents to help children understand their condition better and know how to cope with it in the future.

#### *Being part of the local community*

Having the same access to opportunities and activities as non-disabled children and being part of the local community was important to many children and parents across all groups. This might involve using adapted equipment or interpreting play at the child's level to make participation easier for the child. However, for children who attended special school, the location of the child's school and the inaccessibility of local facilities often meant that children did not participate in the local community based activities.

#### ***Economic well-being***

Not all disabled children will be able to make an economic contribution and families with disabled children are more likely to be living in poverty than other families, so the presence of adequate levels of benefits (during childhood and adulthood) is important here. For some young people, having a job and earning money was a desired outcome that would contribute to economic well-being. Employment opportunities and support, and access to transport were seen as key factors in achieving these outcomes.

### **3.2.3 When a child dies**

From this research we have the accounts from a small number of bereaved parents of children with degenerative conditions about their child's death and what they wanted or would have wanted around the time of that death. There was a very consistent set of desires about how this time should be. First, the child should be as free of pain as possible, physically comfortable and with specific symptoms controlled or stabilised. However, any interventions to prolong life should not

compromise quality of life. Second, the child should not feel anxious or be left alone. This could be best achieved by constant, loving physical and verbal contact between the child and his/her carers. Third, the child should be cared for by familiar people who know the child's needs and condition, and the child's system of communication. Finally, the child should be in a familiar place.

### **3.3 Discussion**

The research found that while disabled children/young people and their parents aspire to the same sort of outcomes as non-disabled children, such as having friends and interests, acquiring self-care skills and future independence, the level of achievement expected or desired in all outcomes and the way they prioritise aspirations differs from normative developmental progress and between different children with the same condition, depending on the severity of the condition, age and, for some conditions, the way the condition manifested itself. Consequently the existing normative, developmental models of outcomes are insufficient and, in some cases inappropriate, for disabled children. There is a need to widen the definitions of key concepts in these frameworks to take account of disabled children's views and capabilities. For example, for some of the children with autistic spectrum disorders, the outcome of 'having friends' may not be appropriate but 'developing a desire to interact' is appropriate and relevant. Similarly, academic achievement, achieving full independence and making an economic contribution is not something some of the children in our study can aspire to or achieve. However, that does not necessarily indicate a poor outcome for that child; achievements need to be seen and celebrated within the context of the child's abilities and potential. For example, in modern society, there are a number of opportunities for young people who achieve academically to have these achievements publicly acknowledged and celebrated, not least the graduation ceremonies in universities. Yet, as noted by a parent attending one such ceremony in this university (Russell, personal communication), young people with learning disabilities have no such opportunities for acknowledgement of their achievements. If the outcome indicators for ECM do not provide any means of valuing the achievement of disabled children, this will further compound their exclusion from the priorities of mainstream society.

As well as needing to widen the definitions of the five ECM outcomes beyond normative developmental models, it is also necessary to take account of the fact that the presence of impairment and/or health conditions makes what constitutes these outcomes more complex. This is particularly the case in terms of physical health which, for some disabled children, is much more multi-faceted than simply 'being healthy'. Rather it covers factors such as physical functioning, pain and other features of physical comfort, and minimising or controlling symptoms of ill-health. As with any children, we found differences in the way disabled children and their parents prioritised outcomes, and for most children these tended to be linked to

developmental stage or chronological age. However, among the children with degenerative conditions, it was the state of degeneration that typically had the strongest influence on which outcomes were being prioritised. For these children, the focus was about maintaining the child's quality of life in a situation where the child's abilities were decreasing and their needs and dependency increasing. This meant that specific desired outcomes and the means by which they might be achieved changed over time, although the basic goal or aspiration remained the same. For example, in terms of communication, parents wanted their child to always have a means by which they could communicate. However, the means by which this would be achieved might well change from speech, to using communication aids, and then to hand squeezes, eye movements and facial expressions. The presence of degeneration also affected priorities in an on-going way. Fundamental outcomes such as being comfortable and pain free, and feeling safe and secure, assumed increasing prominence as the condition progressed, whilst other outcomes such as educational achievements, having a range of interests and participating in mainstream community based activities became less important or even inappropriate.

Another key finding of this research is that outcomes have a hierarchical structure with strong interdependence between outcomes. Achievement of some outcomes depends on other outcomes that are fundamental for disabled children having been met first. In this context, there is a significant omission from the ECM framework concerning communication. Whilst for non-disabled children this is often taken for granted, it is a fundamental outcome for children with communication impairments. For example, maximising a child's communication ability, and other people's ability to understand the child's means of communication, opens doors to opportunities to socialise and be active. Similarly, for many children with complex health conditions being comfortable and not in pain is a central part of what 'being healthy' means to them, and is key to them being able to concentrate, interact and take part in and enjoy other experiences.

The interrelationships between the different outcomes and areas of the child's life challenge some of the services currently provided, highlighting the need for multi-agency partnership. Areas such as friendship, skills acquisition, having opportunities to make choices and to take part in a variety of activities are not confined to one particular context and the input provided in that context. Such interrelationships indicate that the same support can contribute to the achievement of different outcomes and similarly the lack of support in any one context can inhibit the achievement of more than one outcome. For example, inaccessible environments and lack of equipment to support a child's mobility in some of the situations the child experienced were frequently mentioned as important barriers impeding opportunities for socialising, being active, learning skills and promoting independence. Finally, interviews indicated that the achievement of many or all outcomes requires both specialist support or interventions and progress towards a more inclusive society so that disabled children are not denied opportunities available to non-

disabled children. However, for some children, the need for specialist support or interventions with respect to achievement in one area of a child's life was seen to be counterproductive in other areas. For example, the perceived value of special schools in developing life skills was seen to be at the cost of the child's contacts in their local community. The findings also highlighted the importance of support for parents to help them to help their children to achieve their desired outcomes. Research has shown that parents with disabled children provide extra care, over and above that of 'the reasonable parent', and it is with this extra care and with learning the necessary skills to support their child's development and deal with any problems that arise that they need support from services (Roberts and Lawton, 2001).



# Chapter 4: Parents' Desired Outcomes

## 4.1 Introduction

As well as identifying outcomes for children and young people the research also sought to identify parents' desired outcomes for themselves. This was achieved through focus groups attended by parents of children of a similar age and with similar conditions and also during the individual interviews with parents. A paper detailing the findings with respect to this aspect of the project has been accepted for publication (Beresford *et al.* (forthcoming b), see Appendix 7). Here the results and discussion sections of that paper are reproduced.

## 4.2 Findings

The outcomes parents described can be conceived as falling into eight areas. These can be seen as forming a framework by which parental outcomes can be understood. The seven areas are:

- 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.

### 4.2.1 Personal identity

Many parents felt that over the course of time 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. However, individual differences in values, preferences and personal circumstances meant there were differences between parents in terms of which aspects of their identity they wished to regain, maintain or obtain.

Overall, there were three areas or activities which parents identified as having a role to play in their sense of identity. These were work, interests, and personal relationships. Some parents had to work for financial reasons, but for others the desire to work did not (only) stem from the financial rewards but also the social benefits and the sense that work provided a different facet to their identity. Having interests, pursued individually or as part of a group, was another way that parents

saw as a way of redressing the balance of their lives and how they viewed themselves. Finally, many parents found they had lost touch with friends and associates and that they had little quality time with their partner or husband. For some parents, being part of a network of friends and/or being someone's wife or partner was very important to them and how they wanted to be.

Parents identified two key factors which were needed to ensure positive changes to their identity. These were having some free time and having access to high quality substitute care for their child. The lack of spare time parents experienced was a result of the child's care demands, domestic work, attending appointments, acting as an advocate for their child, and accessing and coordinating services. In terms of quality substitute care, different sorts of care were needed according to what parents wanted to achieve. The types of care described by parents included sitting services, pre-school day care, short-term care services and after school care. In addition, parents wanted schools to be more able or willing to cope with their child's health and/or behaviour needs so that the likelihood of having to have their child home from school because of problems with health or behaviour was reduced.

#### **4.2.2 Physical and emotional well-being**

The second area where parents identified desired outcomes concerned their physical and emotional well-being. Parents emphasized that they needed to be physically and emotionally healthy in order to properly look after their child, believing there was a strong link between their own well-being and their child's well-being.

Parents' physical well-being was threatened in a number of ways. Back injuries were reported by parents who were having to lift their child. In addition, settling problems, night-waking and/or having to attend to the child's care needs during the night meant many parents were exhausted from years of disrupted sleep. For these parents, having an uninterrupted night's sleep was a priority in terms of an outcome they desired for themselves. As well as these specific threats to physical well-being, for some parents the lack of 'time out' when the child was at home, caused by the nature of the child's condition (for example, having to constantly watch or keep occupied) or their care/nursing needs, was tiring in itself.

In terms of emotional well-being, there were a number of ways in which parents were vulnerable to emotional difficulties. These began at the time of diagnosis and were on-going. First, adjusting to the diagnosis and its implications in terms of the child's and family's life was seen as an on-going issue, with changes in the child's condition and transitions bringing such issues 'back to the surface'. Second, watching the child suffer from ill-health or pain was emotionally distressing. Third, accessing and dealing with services was identified by many parents as stressful *and* distressing. Finally, parents described how knowing that the services their child was

using were inadequate or inappropriate caused considerable anxiety and sometimes despair.

Given the range of issues described here, it is not surprising that parents identified a wide range of ways to ensure positive outcomes in terms of their physical and emotional well-being. In terms of physical well-being, the importance of having appropriate equipment in the house, suitable housing, short-term care, and skills in sleep training were seen as being important. With respect to emotional well-being, parents felt that knowing that responsibility for the care and/or development of their child was being shared with formal support services was key to their emotional well-being. More specifically, professional counselling support, positive and supportive relationships with professionals, and contact with other parents were flagged up as important, as was the need to pay attention to fathers' emotional needs. In addition, there needed to be changes or improvements in specific services or the way services were accessed and delivered more generally.

#### **4.2.3 Feeling skilled and informed**

Feeling skilled and informed was something which parents felt was very important. Positive outcomes in this area were perceived as having a positive impact on parents' feeling of self-competence and control, and their planning and decision-making processes, as well as their child's well-being and development.

The sorts of skills parents mentioned encompassed many aspects of a child's life 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. Though wide-ranging, it is important to note that parents did not want to acquire these skills in order to 'take over' the roles of professionals. In terms of supporting their child's learning and development, they wanted to support the therapeutic or learning input their child was receiving to ensure a consistent approach. With respect to other skills, such as sleep or behaviour management and nursing skills, parents wanted professional support as they implemented these skills.

The information parents wanted to access was equally wide-ranging, though parents varied in how much information they wanted. Types of information described by parents included information about the child's condition, local statutory and voluntary support services, national support services, benefits and other sources of financial support. The times when parents felt they needed information were linked to both predictable (diagnosis, transitions) and unpredictable (unexpected changes in condition, crises) events. What was very clear was that the need for information was on-going and information provision needed to happen in such a way that it was available when parents needed it. A consistent theme from parents' accounts was that, at the moment, accessing information is typically a very difficult and time-

consuming process which serves to make parents feel unsupported by statutory agencies. Key features of any information provision were that the information had to be holistic, easily accessible, accurate and up-to-date, and not confined to local government boundaries.

#### **4.2.4 The balance between caring and parenting**

Most parents felt they spent too much time doing caring tasks and did not have enough 'quality' time with their disabled child or their non-disabled children. The sorts of tasks that fitted into the caring role varied according to the child's condition. Thus among parents of children with complex health care needs caring involved carrying out self-care and nursing tasks. Among children with autistic spectrum disorder, however, caring took the form of supervising their child and managing their behaviour. Parents also saw carrying out therapeutic and educational interventions (where these demanded a lot of input), attending appointments, chasing services, collecting medication, nappies and equipment, as part of their caring role, as opposed to parenting.

Parents not only regretted this lack of quality time in terms of their own experiences as parents, but were also concerned about the impact of this lack of fun, relaxed time on the children themselves and their relationships with their children. Furthermore, given that the disabled child was getting some sort of parental attention as caring tasks were being carried out, it was with respect to their non-disabled children that parents were most concerned.

Two issues were identified as needing to be addressed in order that parents could have more quality time with their children. They needed more time just for parenting and, in some instances they needed someone to care for their disabled child. In addition, any support provided to achieve these aims would need to be such that it made an impact on everyday life and not just one-off or 'special occasions'. A number of ways of reducing time demands on parents were identified. These included help with care and domestic tasks, a laundry service, delivery service for medications, nappies and other equipment, and synchronised appointments. It is important to note here that with regard to help in the home, parents were very clear that they wanted flexibility in terms of the help offered and when it was provided.

Sometimes, in order to achieve some quality time with the non-disabled child(ren), it was necessary to obtain 'substitute care' for the disabled child. This might allow the rest of the family to go somewhere it was not possible to take the disabled child or, more simply, provide an opportunity for time together uninterrupted by the needs and care demands of the disabled child. The sort of substitute care that might be needed varied according to what parents and their non-disabled children wanted to do and included residential short-term care, childminding, and helpers who would look after the disabled child on family outings.

#### **4.2.5 Maintaining family life**

Within the notion of maintaining family life, two quite distinct issues arose. The first was about maintaining a sense of family through shared experiences and activities. The second concerned ensuring the mother-father relationship remained 'intact'.

##### *Maintaining a sense of family*

As well as talking about a desire to spend more quality time with their children, parents also voiced a desire to have opportunities to spend time together and do things as a whole family. Families commonly found that one parent did something with the non-disabled child(ren) while the other did something else with the disabled child. Family trips were not necessarily something parents wanted to happen frequently, but they did feel that occasional whole family outings or holidays were an important and valued aspect of family life.

Happy and successful family outings were something that parents had all tried to achieve and they had very clear ideas about what might need to be in place in order for it to happen. This ranged from access to information about possible venues, accessibility, suitable toilet/self-care facilities, adequate parking facilities, staff at venues being helpful and disability-aware (not just in terms of access but with respect to the needs of children with ASD, for example), and having someone to come along to help out.

##### *Preserving the mother-father relationship*

Although not something raised by the majority of parents, a sizeable minority of parents were greatly concerned about the negative impact having and caring for their child had had on their relationship with their partner. Where the relationship was perceived to be 'under threat', doing something to support or preserve the relationship was often a high priority in terms of a parent's desired outcomes.

A number of different ways of supporting the mother-father relationship were identified by parents. These included meeting fathers' emotional needs and supporting their adjustment to the diagnosis, greater involvement of fathers in consultations with professionals, short term care and/or domiciliary support to release parents from the caring role and domestic tasks, and help with addressing settling and other sleep problems.

#### **4.2.6 Positive adjustment of siblings**

A strong emergent theme from the data related to parents' aspirations with regard to siblings being able to make a positive adjustment to having a disabled brother or sister. They wanted their other children to lead ordinary lives and enjoy everyday childhood experiences, they also wanted there to be a positive relationship between

the disabled child and his/her siblings. This issue was raised by parents of children of all ages and for siblings of children with a range of different impairments.

A number of factors were mentioned which, parents believed, mitigated against their non-disabled children making a positive adjustment to having a disabled brother or sister. First was the way that their lives were restricted or disrupted and differed to children with non-disabled siblings. For example, attending an after school club or class might not be possible because of the difficulty of taking the disabled child along (either because of their care needs, mobility/access issues and/or their inability to wait). Similarly, decisions about whole family activities (for example, days out, family holidays) could be constrained by the disabled child's needs and abilities. In addition, an exacerbation of the health condition or child's behaviour meant activities were curtailed or plans changed. Some parents also believed their other children's friendships and peer relations were affected by having a disabled sibling due to teasing and/or a reluctance to bring friends home. All these situations led parents to feel their non-disabled child(ren) were missing out, and they were concerned about the siblings' reactions to this and its long term impact on their adjustment.

Second, parents also wanted the relationship between the disabled child and his/her sibling(s) to be positive. However, unpredictable and/or unsocial behaviour, communication difficulties, the disabled child not being able to get to the places where the sibling was playing or spending time, the sibling being involved in caring for the child (for example, self-care tasks, nursing, watching over or supervising), the attention and time demands on parents associated with caring for the disabled child, and a lack of positive whole family experiences were all factors which parents felt threatened the sibling-sibling relationships.

There were a number of ways which parents felt would help siblings' adjustment. These included 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.

#### **4.2.7 Practical and financial resources**

The presence of disability meant these families were more likely to experience an insufficiency of financial and practical resources such as suitable housing, aids and equipment, and domestic support (for example, laundry service, cleaner). Most mothers were not in paid employment thus reducing family income compared to other families. Coupled with this was the fact that a lot of the things their disabled children required, for example, specialist toys and equipment and suitable leisure activities, were more expensive than similar 'mainstream' items. In addition, many parents reported problems with their housing. The type of problem varied according to the nature of the child's impairment and included difficulties with access in and out

of the home, lack of bedroom space, lack of safe outside play space, small bathrooms, and the homes not being suitable for equipment (for example, hoists, tracking) to be installed. Finally, the high demands placed on parents by the child's care needs meant the housework and home maintenance took low priority. Some types of impairment (such as child's disruptive behaviour or health requirements for a clean environment) added to the amount of housework and maintenance that needed doing.

Some of the families participating in this study had access to practical and/or financial resources which helped them as they coped with the 'extra-ordinary' demands associated with caring for their child. Families without such resources wanted to feel they had the practical and financial resources needed to properly care for and bring up their child and the rest of the family. As well as the lack of resources being a source of stress in itself, their absence was also seen as a barrier to achieving other outcomes.

#### **4.2.8 Experiences as a service user**

The final aspect of this framework of parental outcomes concerns parents' desires in relation to being a service user and how that makes them feel. Two distinct types of service process outcomes were identified:

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

##### *A sense of working in partnership with services*

Parents wanted to have a sense that they were working in partnership with services to achieve the best for their child, and that responsibility for this was shared between themselves and services. They wanted to have their expertise as parent and carer of their child recognised and valued and to be involved in decision-making. Concrete evidence of such a partnership would be seen in 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.

##### *Having confidence in the services being used by the child*

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 staff who understood about the child's condition and were skilled in meeting their needs, the service being a positive experience for the child, the child being treated with respect, continuity of staff providing the service, and the service being reliable.

### 4.3 Discussion

The purpose of this research was to develop a framework of desired outcomes for parents caring for a disabled child. The types of outcome identified by parents participating in the research included desired outcomes for themselves (personal identity, physical and emotional well-being, feeling skilled and informed, the balance between caring and parenting), desired outcomes for their families (maintaining family life, positive adjustment of siblings), desired outcomes in terms of the resources they and their family had available to them (practical and financial resources), and desired outcomes of the experience of being a service user.

The wide-ranging nature of these outcomes indicates the pervasive impact of caring for a disabled child can have on the lives of families and therefore the importance of *properly* supporting parents and families in this situation. The findings also highlight inadequacies in current systems of identifying the support needs of parents, where the focus lies mainly on parenting capacity *per se*.

In addition, the findings point to limitations and anomalies in the way support to parents and families is conceptualised and provided by services. First, at the moment most 'parent support' services are provided to the child (for example, short term care services, help with care of the child in the home), and are therefore typically high-cost, specialist services. Second, these sorts of services may help parents achieve some, *but not all*, of the outcomes they desired and may not be helping parents address what they regard as their more important desired outcomes. The lack of an outcomes-focussed approach within the assessment process is a key reason for this. Third, other services provided to the child may, incidentally, yield important positive outcomes for the parent, but without a focus on parental outcomes the extent to which this happens, or not, will not necessarily be identified or prioritised by services. There remains a lack of recognition within the organisational structures of statutory agencies supporting families with disabled children that the well-being of children is inextricably linked to parental well-being, and therefore directing resources to supporting parents is a 'legitimate' way of helping children to achieve positive outcomes.

Parents identified a raft of other forms of support or interventions which could enable them to achieve their desired outcomes where the child was not the 'recipient' of the service or intervention. These included: skills training, information provision, formal and informal sources of emotional support, domestic and home maintenance help, home delivery of medications and other consumables, workers to assist on family trips, sibling support groups, financial support, provision of appropriate equipment, and adequate housing. Changes in the way services are organised or provided was also cited as means by which desired outcomes could be achieved, including

confidence in the quality of services, working in partnership with professionals, and coordination of appointments.

It is worth noting here that some of the forms of support parents were asking for are the types of interventions where evidence does exist in terms of their effectiveness. For example, various models of skills training for parents (for example, sleep management, generic coping skills) have been found to be effective (Kirkham, 1993; Quine, 1993; Gates, 2001; Wiggs and Stores, 2001; Feldman and Werner, 2002). Similarly, the provision of relatively small financial grants to enable families to acquire domestic equipment (for example, washing machines, tumble dryers) or to have a holiday has been shown to have a significant effect on mothers' levels of stress (Beresford, 1993). There is also evidence on good practice in terms of information provision (Mitchell and Sloper, 2000). In terms of service organisation, recently completed research comparing different models of care coordination and key working has highlighted the benefits of key workers to parents as well as providing evidence on how best to set up and provide a key worker service (Greco *et al.*, 2005). It is clear from this body of evidence, and what is known about what goes on in practice, that services do exist for parents which make a difference to their lives and help them to achieve the outcomes they desire for themselves. The difficulty therefore appears to be in ensuring that such services are accessible to all families who need them, and are a permanent part of the package or menu of support services available to families regardless of where they live. Every Child Matters (Department for Education and Skills, 2003a), the Children's National Service Framework (Department of Health/Department for Education and Skills, 2004b) and the Early Support Programme (Department for Education and Skills, 2003b) are clearly levers to redressing this situation.

Identifying the agency(ies) or department(s) responsible for assessing and/or providing some of these sorts of support is, perhaps, uncharted territory and certainly less clear compared to other groups of carers. However, the growth in multi-agency working and the development of Children's Trusts and the Early Support Programme provides opportunities to bring together support for children's and parents' well-being and ensure that coordinated service provision encompasses the needs of both parents and children.

A distinction between parents and other groups of carers can be seen within policy and practice. Parents are still thought of as different to other groups of carers. To some extent this is what parents want (especially parents of younger children), preferring the identity of 'parent' over that of 'carer' (for example, Beresford, 1994), but this can lead to inequity. Thus assessments under the Carers and Disabled Children Act 2000 have been relatively more widespread among non-parent carers than parents (Arksey *et al.*, 1999) and, as referred to earlier, it appears that the Carers (Equal Opportunities) Act 2004 will perpetuate the way parents are dealt with as a separate to other types of carers. However, comparing the findings from this

study to research on non-parent carers' desired outcomes (Bamford *et al.*, 1999) reveals some clear commonalities. These include: having a life outside of the caring role, having a sense of shared responsibility, being supported and equipped in the caring role, and being able to adjust to the situation. The question therefore is whether, although perhaps unpalatable to some parents, in order to improve the range of support provided to parents less of a distinction needs to be made between parents of disabled children and other groups of carers.

A clear finding from the research was that parents differed in their priorities in terms of the ways they wanted to change or improve their lives, and what would help them to achieve those aims or goals. This suggests that systems to support parents need to be flexible and responsive to individual situations. One route to helping parents achieve their desired outcomes would be Direct Payments which, potentially, can allow parents and carers to bring into place the sort of support they need to achieve the outcomes they desire. At the moment, however, parents of disabled children form a very small proportion (just under seven per cent) of those receiving Direct Payments (Commission for Social Care Inspection, 2004). Plans for individualised budgets outlined in the Strategy Unit's report on 'Improving the Life Chances of Disabled People' (Cabinet Office, 2005) would also appear to provide a way to address the need for individualistic systems of support for families. It will be interesting to monitor the way families use individualised budgets if and when they are introduced.

Finally, one clear limitation from this research, as with many pieces of research on families with a disabled child, was the low level of involvement of fathers in the project. In addition, the extent to which it was possible to identify factors which influenced parents' priorities in terms of their desired outcomes was limited due to the exploratory nature of the project. Intuitively, it is likely that priorities will shift and change over time and will be in response to changes in the child's condition, the family situation and individual factors that these families typically experience (Beresford, 1994). Larger scale quantitative work which sought to explore these issues using the framework identified through the research reported here would be very useful.

# Chapter 5: The Development Phase

## 5.1 Objectives of the development phase

The objectives of the development phase were as follows:

- To explore whether the notion of an outcomes-focussed approach is appropriate and can be implemented within the context of services for disabled children.
- To work with staff and parents to develop tools for collecting information about outcomes that can be used in practice.
- To pilot and evaluate the use of these tools in practice.

## 5.2 The development work

### 5.2.1 The development phase: Area A

#### *The preliminary stage*

In November 2003, a multi-disciplinary workshop was held in Area A to feed back the findings of the research which had explored desired outcomes for children with autistic spectrum disorders and their parents. The workshop was attended by 25 professionals working in social services, health, education and the voluntary sector and included frontline practitioners and managers. In addition to sharing and reflecting on the research findings, the purpose of the workshop was identify a group of individuals who would be interested in taking the project forward into the development phase.

The outcome of this was that managers from health, social services and education, health practitioners and representatives from local voluntary groups volunteered to meet to discuss the development phase. This meeting took place in March 2004. At that meeting the decision was taken to focus on the well-being of parents of children with autistic spectrum disorders. It was decided that the aim of the development phase would be to create a tool to assess desired outcomes for parental well-being which could be used:

- by professionals working in different disciplines and settings
- for individual assessment and service evaluation purposes
- and was relevant to parents of children of all ages.

The group then identified senior and frontline practitioners who would form the 'task group' to work on the project.

### *The task group*

The constitution of the task group included: representatives from the autism outreach service, a head teacher from a special nursery and a head teacher from a special primary school, a senior occupational therapist working in child and adolescent mental health, a social work practitioner, a manager of a service coordination scheme and representatives from a local parent/carer organisation. One member of the research team assumed responsibility for organising and facilitating the meetings and introducing existing tools and approaches as resources to their deliberations. The researcher also took responsibility for drafting up the tool into a Word format and dealing with subsequent changes and edits.

### *The development of the tool*

The tool was developed over the period May to October 2004 during which four meetings were held, with email and postal 'discussion' between meetings. Members of the group also consulted with colleagues and parents in between meetings about the way the tool was developing. Most members of the group attended all the meetings. There was a lot of interest and enthusiasm in the group and this was reflected in the way they consistently carried out 'between meeting' tasks, such as consulting with colleagues or making comments on draft versions of the tool. At the stage of joining the group, one member was wanting to have a tool which could be used to evaluate a service whose funding was to be reviewed in the near future, this added impetus to the group's work.

The meetings themselves covered the following:

- on-going input from the researcher about outcomes and an outcomes-focussed approach
- re-consideration of the research findings in order to identify areas of parental well-being to be covered by the tool
- identification of the potential uses of the tool and its necessary features
- consideration of tools being used in other settings. Here, one tool particularly appealed to the group. It was being used by another local authority in the context of family support services and consisted of recording specific, concrete outcomes desired by family members and the use of rating scales to record progress in terms of achieving these outcomes
- discussion of issues such as length of the tool, lay-out and wording
- drafting and redrafting the tool
- discussion about requirements for accompanying documentation – a guide for workers and parents was produced as a result
- planning the piloting of the tool.

### *Reflections on the process of developing the tool*

Members of the task group in Area A were mostly unfamiliar with each other. However, they quickly formed as an energetic and productive group. They enjoyed

the way the task they were working on differed from their normal work but also helped them to reflect on their everyday practice. The parent members of the group were fully included and their views and opinions given weight and responded to. They all valued the multi-disciplinary nature of the group and the opportunity to meet other professionals (or parents) working with the same population of children. The meetings rotated between the different workplaces of task group members. This supported the process of the group learning about other professions' roles with respect to children with autistic spectrum disorders and the need for an holistic approach to support these families.

The input of parents to the development of the tool was invaluable, particularly with respect to the wording used, issues of lay-out and the need for an information sheet for parents. The group also valued the input of the researcher in terms of organising meetings, acting as secretary to the group, keeping the group 'on track', facilitating discussion about the notion of outcomes and the outcomes focussed approach and identifying and sharing with the group existing tools being used in other areas which collect outcomes information.

#### *Training for the pilot work*

At the end of October 2004 a multi-disciplinary, half-day training session was held for all those who might be involved in piloting the tool. The training covered the principles of outcomes-focussed practice as well as specific work on the tool. The training was conducted by a member of the research team.

#### *Piloting*

Piloting of the tool took place between January and July 2005. The tool was piloted in three contexts:

- at the time of core assessment by the disabled children's team located in social services
- for assessment and on-going work with parents of pre-school children using an autism outreach service provided by the specialist education service
- with parents of teenagers attending an information and support group provided by CAMHS.

The aim was to pilot the tool with around thirty parents with a child with an autistic spectrum disorder (approximately ten from each context). The final sample size for the pilot was considerably smaller than this, with the tool being piloted on just 13 parents, see Table 5.1. The reasons for this small sample size included time available for the pilot, lack of staff time, parents' willingness to be involved and a lack of referrals to a service. In addition, in one context a lack of senior management support meant the project did not have sufficient status to support the achievement of the required sample size. Furthermore, this meant that there were no agreed

supervisory structures in place in this agency, which led to difficulties with respect to the competencies of some of the staff involved in the pilot.

**Table 5.1: Sample for piloting of the tool in Area A**

<i>Context</i>	<i>No. of parents*</i>	<i>No. of staff</i>
Disabled Children's Team (Social Services)	5	4
Autism Outreach Team (Education)	6	2
CAMHS	2	1
<b>TOTAL</b>	<b>13</b>	<b>7</b>

\* all mothers

Table 5.1 also shows that seven practitioners piloted the tool. Of these, four practitioners piloted the tool with two or more parents while the remainder only piloted the tool with one parent.

During the pilot phase the task group met on two further occasions to monitor and feed back progress to the researcher. In addition, a joint workshop with the other research site was held in York in March 2005. As well as serving to re-motivate the staff involved, it also provided the task group with a further opportunity to review the progress of the piloting.

#### *Evaluation*

Staff and parents who had used the tool were interviewed between July and September 2005 by researchers who had not been involved in the research or development work in this site. All the staff involved in the pilot and nine of the parents agreed to be interviewed. The findings from that evaluation were fed back to the task group at a second joint workshop in November 2005. Details of the methods used to evaluate the pilot are in Chapter 2. The findings of the evaluation are reported later in this chapter.

#### *The tool*

A copy of the tool can be found in Appendix 8. The purpose of the tool was:

- to facilitate and then record a discussion between parent and worker about parental well-being
- to identify and record specific and achievable desired outcomes with respect to parental well-being
- to identify and record actions to be taken by the parent and worker to achieve the desired outcomes
- to provide a means by which progress towards achieving desired outcomes can be recorded, along with factors which have impeded or supported that process.

It was envisaged that tool would be completed by the worker either during or after a discussion between a parent and worker (over one or more sessions). A copy of the completed tool would be given to the parent.

The tool comprises an A4 sized stapled booklet. The first three pages are used to record background information about the family, contact with other services and information about, and consent to, sharing information contained on the form with other agencies. There is also space in this preliminary section to record any extraneous comments.

The main body of the tool consists of four sections: 'physical well-being', 'feeling skilled and informed', 'emotional well-being' and 'how services make me feel'. These four areas of well-being were derived from the findings of the research phase. Each section occupies two facing A4 sheets. The left hand sheet provides a detailed definition of that aspect of well-being and records the parent's view on the current situation and their desired outcomes. A rating scale (0-10) is used to indicate the importance of changing or improving that aspect of well-being. One or more desired outcomes are then recorded. Rating scales are used to record the parent's view on how far they are from achieving each outcome. The right hand page records the actions to be taken in order to achieve each desired outcome, including the person who will take the action, and by when. The bottom part of this page is provided for reviewing purposes – either at the end of using a service or at a review meeting. It allows perceived barriers and facilitators to achieving desired outcomes to be recorded as well as any new desired outcomes.

In addition to the tool, a one-page information sheet for parents was developed for sending out in advance of the discussion (see Appendix 8). There was concern amongst the task group that parents might find it hard to think about desired outcomes as opposed to needs. Providing prior information was seen as a way of addressing this issue. A two-page guidance note for staff was also prepared (see Appendix 8).

## **5.2.2 The development phase: Area B**

### *The preliminary stage*

In December 2003, a multi-disciplinary invited workshop was held in Area B to report back the findings of the research phase regarding desired outcomes for children with complex health care needs and children who do not use speech to communicate and their parents, and to identify a steering group who would be prepared, with support and input from the research team, to take the project forward into the development phase. The workshop was attended by 33 professionals representing health, education, social services and voluntary organisations, including managers and front line professionals (for example, physiotherapist, speech therapists), consultant paediatricians, and representatives from Sure Start, Barnardo's and MENCAP.

### *The steering group*

Following the workshop, managers from health, education, social services, as well as health practitioners and staff from voluntary organisations volunteered to meet to discuss the potential areas for development work. Thirteen people attended, mostly senior professionals but also some front line staff. This meeting took place in February 2004. At that meeting the participants acknowledged that it was not clear whether the existing documents used for assessment, care planning and review encouraged identification of the intended outcomes of services. The decision was therefore taken to focus on assessment and review tools currently used with a view to integrating an outcomes approach into the existing recording tools.

Representatives from different agencies and teams agreed to send their existing documents to the research team to be analysed, as the starting point, against the desired outcomes research had identified for children and their families. Documents submitted by Social Services included initial and core assessments and placement agreements (included an anonymised completed assessment), review forms and locally devised 'Abilities and Goals' documents. The PCT Community Children's Team also submitted their continuing care needs assessment documents. The research team's analysis found that these documents did not support the identification of outcomes for children and parents. While the main areas of the child's life were covered (except for communication), there was no clarity about the outcomes desired in those areas, and review documents gave no timescales and indication of who was responsible for actions identified. The group agreed that identifying outcomes happened spasmodically and that it currently relied on good practice and what was needed was a system which would ensure that outcomes were consistently and thoroughly covered.

A 'task group' was then identified by the steering group to work on the project drawing up an outcomes approach. Altogether six steering group and two task group meetings took place within the development phase of the project. A member of the research team assumed responsibility for facilitating the meetings.

### *The task group*

Central to the project was the involvement of staff and service users as part of the ongoing consultation process. One of the main responsibilities of the task group was to ensure that the revised tool would fit in with local policies and views on good practice, while identifying potential barriers to the implementation of outcomes focused practice. These sessions also allowed staff to raise responses and questions about the project. Members of the task group included: representatives from social services (care management team, respite centres, and Shared Care), education (special school), Community Children's Nurse, Independent Reviewing Officer and parent representatives. Most members of the group attended all the meetings. The notes from the meeting were sent to those absent to ensure continuity.

### *The development of the outcomes focused tools*

The tool was developed over the period May to October 2004. In addition to steering group and task group meetings, the researcher held email discussions and individual meetings with staff and parents in between the meetings. The task group was encouraged to consult with their colleagues and other parents about the main points they felt useful to consider, both in terms of the content of the tool and its structure. The researcher took responsibility for drafting up the tool and dealing with subsequent changes and edits and reporting it back to the steering group for their approval.

The meetings covered the following discussions:

- participants' overall impression of the current assessment and review tools and views on which aspects were not satisfactory and why
- consideration of the research findings on desired outcomes for children and parents
- views on any additions to make to the outcomes list developed by SPRU research and any of the outcomes that seemed to be problematic and why
- research team's review of the current assessment tools used in Area B
- discussion on how to move forward
- discussion of an outcomes focused model and tool used in an authority that had been involved in another part of the SPRU outcomes programme (Harris *et al.*, 2005) and assessing its usefulness in collecting outcomes information for children and parents in Area B
- ideas about what needed to be included in a tool developed for Area B
- discussion of the draft tools, and guidance notes on how to use the revised tool for workers and parents
- discussion of the staff training needs in using the tool and in communication with disabled children
- the importance of supporting parents to feel informed
- discussion of different versions of mock-ups carried out to demonstrate how the form could be used in practice
- piloting strategy.

The steering group decided that the outcomes focused forms developed would be used initially as a separate document and not as part of the core assessment carried out under the Framework for the Assessment of Children in Need. The final decision on how to use the tool in the future would be made after the piloting was completed.

### *The tool*

A copy of the tool can be found in Appendix 8. The purpose of the tool was:

- to facilitate and record a discussion between parent, child (where possible) and worker around areas of importance for child and parental well-being

- to identify the areas of the child's life that the child or parent wants to change/improve or maintain
- to identify the areas of the parent's life that s/he wants to change/improve
- to identify SMART (specific, measurable, achievable, realistic and time limited) outcomes to achieve
- to identify and agree actions to achieve these aims through support/intervention, referral and/or parental action
- to review the progress (or not) in achieving those aims, along with factors which impeded or supported that process.

It was envisaged that the tool would be completed by the worker with the child and his/her parents over one or more sessions. A copy of the completed tool would be given to the parent. The tool consists of:

- what children and parents want to achieve: a means to explore outcomes desired by the child and parents
- Action Plan: a tool to record desired outcomes and actions
- Review Plan: a tool to review progress in achieving desired outcomes
- information sheet for parents: this would be given to parents in advance of meeting in order to help parents understand the outcomes approach
- guidance note for workers: to clarify terms and provide assistance.

What children and parents want to achieve: this section is divided into areas of the child's life derived from the findings of the research phase. Each heading contains a description of what it is. The purpose is to encourage a child and his/her parent/s to think about key areas of the child's life they might want to change or maintain and possible aims. The summary section provides the space to detail those outcomes that the professional, child and his/her parents agree to work towards. This is completed in discussion with the child and his/her parent/s. If possible, major outcomes are divided into sub-outcomes that are the steps necessary to achieving them. The summary section also provides the space to record who is to undertake specific actions. This may include the worker, a referral to another agency, the child and/or his/her parents. The child and his/her parent/s rate how important different outcomes are to them. The section 'Desired outcomes for parents/carers' is used in the same way as the previous section except that it ascertains parents' views about what they want to achieve in their caring role. The 'summary of assessor' section is where the professional judgements are recorded. This also provides a space to record any differences of opinion between child, parent and professional.

The Action Plan: the format of this form mirrors the summary section of the 'What children and parents want to achieve' document. The Action Plan aims to provide a clear easy to follow summary of goals to be met, what actions have been agreed, the person/agency responsible and a target date. The plan is to be signed by the child (if appropriate) and his/her parent/s and be copied to them in a format of their choice.

The Review Plan: The review document follows the same format as the earlier documents. It provides space to identify whether or not an outcome has been achieved and if not, why not and what action is required and who will act. It also includes a section to detail any new or unmet outcomes. If the child and/or his/her parents' situations have changed dramatically, it may be necessary to complete additional 'What children and parents want to achieve' and action plan documents. The review document should be copied to the child/parent.

#### *Training for the pilot work*

In December 2004, a multi-disciplinary, half-day training session was held for all those who might be involved in piloting the tool. The training covered the principles of outcomes-focused practice as well as specific work on the tool. Three mock examples of completed forms of '*What children and parents want to achieve*' were also demonstrated to the group. The training was conducted by a member of the research team. Thirteen people took part in the workshop. They included representatives from the Children with Complex Health and Disability Team (CCHDT) assessment team (4), Community Children's Nursing Team (2), two respite centres (4), education (2) and parents (1).

#### *Piloting*

The piloting of the tool took place about three months later than planned between March to July 2005. The delay, which in effect reduced the time available to pilot the tool, was mainly due to the difficulties in setting up the pilot. Despite a high level of support from people involved in the steering and task groups, when the tools were ready for use it was clear that there were some issues in terms of how they fitted into current systems, who should be doing what and in which context piloting should be done.

To begin with, the steering group felt it would only be feasible to pilot the tools in the context of current social services assessment. There were issues regarding the care plan and review practice which made piloting in those areas difficult at that point in time. The development phase of this project coincided with new developments taking place in Area B, such as refining the core assessment to suit the 35 days time scale, changes with regard to direct payments and introducing an electronic system, and the care management team felt it would be hard to introduce and adopt a new approach alongside those developments. This had implications for staff involvement in piloting. Initially the project aimed to pilot the tool with around 30 families. However, difficulties mentioned above, coupled with the limited research time scale and parents' willingness to be involved, all contributed to having to pilot the tool on a considerably smaller number of families. In the meantime, members of the steering group decided that it would be beneficial to use the tool to re-assess children using short-term care from two respite centres who had been in the service for a number of years but who had not had recent assessments. Here the tool would be used to identify desired outcomes and ways of achieving these outcomes across the whole

of the child's life and not just in terms of the input provided by the respite centres. Consequently, the tool was piloted on twelve families in two contexts (see Table 5.2):

- as part of the initial/core assessment by CCHDT care management team
- to re-assess children using short-term care from two respite centres. Piloting was carried out by the respite team with input from the Children's Community Nursing Team and Education.

**Table 5.2: Sample for piloting the tool in Area B**

<i>Context</i>	<i>No. of parents*</i>	<i>No. of staff</i>	<i>Stage at which piloting used</i>
The care management team (CCHDT-Social Services)	3	2 (one in support role)	Initial/core assessment
Respite centre 1 with input from Health	5	2 (including one nurse)	Re-assessment
Respite centre 2 with input from Education	4	4 (including one teacher)	Re- assessment
Total	12	8	

\* *All mothers*

Table 5.2 shows that eight practitioners were involved in piloting the tool. Of these, five practitioners piloted the tool with two or more families, two only piloted the tool with one family and one was only in a supervisory role. In three cases (within the CCHDT) the pilot was used as part of the initial (one case) and core (two cases) assessments, while in the remainder it was used as a re-assessment of the child. Out of 12 children only one child was directly involved in the piloting of the tool. In three cases, the section on the child's views was left blank on the form. In three other cases the child's teacher had put down the child's views as they saw it and in the remaining cases, only parents' views about the child were recorded.

During the pilot phase the steering group met twice to monitor progress. The researcher offered to visit the staff involved to discuss any difficulties they may have been facing. One of the respite centres requested a further visit. Further feedback was received from the other teams involved via email and telephone conversation.

### *Evaluation*

Staff and parents involved in the piloting stage were interviewed between July and September 2005 by a researcher who had not previously been involved in the project. All of the staff and nine of the parents agreed to be interviewed. The methods used to evaluate the pilot are detailed in Chapter 2.

## 5.3 Results of the evaluation of the outcomes tools

In this section, key issues emerging from the evaluation of the tools in both areas are reported. General issues about the outcomes approach, which applied to both areas, are reported first, followed by separate reports on the two different tools.

### 5.3.1 Understanding of and views on the outcomes approach

#### *Staff understanding of the outcomes approach*

A key issue in evaluating the pilot was whether staff who piloted the tools with families fully grasped the concept of the outcomes approach and what it aimed to achieve. An initial examination of the staff interview transcripts revealed that there were considerable differences in terms of how much staff understood the concept of outcomes and the way the approach might help in the assessment of a child and family.

To evaluate the pilot, therefore, the research team felt it was appropriate, at the outset, to rate from interview transcripts (which included questions about understanding of outcomes) whether or not each staff interviewee fully understood the approach and to explore the barriers to understanding. Two researchers examined the staff interview transcripts separately to assess staff understanding. Agreement was reached in the first instance for 11 out of the 15 staff interviewed. Agreement for the remaining four staff was reached through further examination of the transcripts and discussion between the researchers. Ten staff were rated as having understood the approach and five were judged as not having understood it.

Two key barriers were identified to staff being able to understand the outcomes approach:

- Lack of exposure to the concept of outcomes  
The level of involvement in the project seemed to be a key deciding factor for staff understanding the concept. The analysis showed that staff who had more involvement, either through the task groups or in using the tool with more families, had a better understanding of the approach. Out of five staff who did not seem to have understood the approach, four used the tool only once and one used it twice. A few staff reported that the more they used the tool the more confident they became. Out of 10 who were judged as understanding the approach, five used it with more than three families, three used it with two families and only one used it with one family. As only two staff members did not attend training (one who was rated as understanding and one as not understanding) it was not possible to identify any effects of training *per se* on understanding. However, three staff, one of whom did not attend the training, felt they needed to have clearer instructions in a step-by-step approach telling them exactly what was needed.

- Lack of on-going input  
Two of the staff who had attended a training workshop but who did not seem to have understood the approach felt there was a long gap between the training and using the tool. They felt it would have been helpful if they used the tool soon after the training when the ideas were fresh in their mind. A few staff said learning opportunities to develop understanding whilst using the tool were under-exploited. Three staff who had attended the training (two of whom were judged as not understanding the approach) reported that time restrictions made it difficult to give the pilot the attention it needed. One of these (who understood the approach) who was in a supervisory role felt that she did not have a chance to be proactive in supporting the staff in her team and her support had rather been on an ad hoc basis. One of the practitioners who had attended the training, but was judged as not having understood the approach, felt she was unclear as to who to turn to for advice if she had difficulties. She said that she was not sure how to go about filling in the form so decided to do it the way she always had done. These findings flag up the importance of training and support to workers who are being asked to adopt an outcomes-focussed approach.

#### *Parents' understanding of the outcomes approach*

From examination of the parents' interview transcripts, it was evident that, as with staff, some interviewees had not fully grasped the purpose of the outcomes approach; some interviewees asked questions that showed little understanding and others expressed ideas that demonstrated an underlying confusion. Researchers thus categorised interviewees into two groups: a) those who appeared to have understood the outcomes approach, and b) those who had not. It was hypothesised that parental understanding of the outcomes approach would be related to the understanding of the member of staff who worked with them.

Two researchers coded the interview transcripts separately for parental understanding of the outcomes approach. Agreement was immediately reached for 15 out of 18 parents and agreement for all parents was subsequently reached through discussion. Eight parents appeared to have understood the approach, and ten appeared to not have understood it.

Parental understanding of the outcomes approach was then matched to understanding of the professional who had administered the questionnaire to them. To some extent, parental understanding tended to correspond with professionals' understanding of outcomes. Thus, when a professional understood the outcomes approach and administered the questionnaire to parents, there was a slight tendency for those parents to also understand the approach. Out of a total of 18 parents, for 11 parents parental understanding matched the understanding of staff. In eight cases both the worker and the parent understood the approach and in three cases neither the worker nor the parent did. However there were seven mismatches. In all seven cases the member of staff who worked with the parent understood the

outcomes approach but the parent did not. There are several potential reasons for mismatch, although it is difficult to establish with certainty what these are. Potential reasons for mismatch that emerged from the analysis were:

- parental trauma such as divorce, illness, depression and feeling overwhelmed by events. Parents who were going through a traumatic time may have been unable to focus on desired outcomes and on the future
- professionals' lack of communication to the parent, perhaps due to lack of time
- poor understanding of a complex concept. The concept of outcomes may have been genuinely difficult to comprehend for some families.

#### *Staff views on the outcomes approach*

In this section, we concentrate on reporting the views of staff who were rated as understanding the outcomes approach, as a lack of understanding of the approach makes assessment of the use of the approach difficult.

The analysis showed that staff who had a good understanding of the outcomes approach were generally positive about adopting the approach in their work and felt that it had many advantages. Most staff reported that it is a refreshing way to look at what families want and how to go about supporting them, and it has the potential to add clarity to their work. By being holistic and shifting the emphasis from 'what is available' to families' aspirations, staff felt that the approach has the potential to shift the power back to the family and let the worker be less directive about how families should be supported. Most staff reported that the outcomes approach is empowering for both parents and staff by supporting more creative thinking in identifying 'solutions'. It is empowering for parents as it gives them the chance to stop and think about themselves and identify what they can do to help their situation. Some staff said that sometimes sitting down with someone and trying to unfold their situation was half the battle for parents. It was felt to be empowering for the staff as it helps them get a better idea of what it is they are working towards and thus work more effectively and identify the impact of their work on families. Some felt that the breaking down of the outcomes makes it easier to identify service and non-service solutions.

Encouraging parents to give a broader view of their situation would have the likely consequence of revealing more in-depth information that could otherwise be missed in the assessment. This in turn would help plan more targeted action, which could then be reviewed to track progress. A professional from Social Services department had this to say:

... it's the outcomes that we should always look at, I don't think the Department looks at outcomes often enough. What we do is we put services in and then we review the services, we constantly review the services but we don't ever actually review any outcomes, we don't you know, what are the consequences of our assessments.

In terms of disadvantages of using the approach, a number of staff were concerned that encouraging parents to think about their life in a broader sense and beyond the existing services might raise parents' hopes and expectations. This was related to staff's fear that parents will feel let down if outcomes they have identified are not met. As one interviewee put it:

... I have to push the families to say well what do you want for yourself ...and it might not even happen which is, is a bit of a let down for the parents really because the family are admitting what they want for themselves and then you say "Well I'm sorry we can't provide it".

However, most staff reported that bringing together data on aspirations is positive as it helps identify gaps in services and inform service planning. Furthermore, some staff argued that becoming more creative about solutions has the potential to take dependency off services rather than put extra demands on them. Another key disadvantage of using the outcomes approach for most staff was that it may produce more paper work and be more time consuming.

In terms of the applicability of the outcomes approach in everyday practice, staff involved in core assessment felt that it would be useful to incorporate it into the assessment and review process. However, they felt that its success was largely dependent on whether it was culturally acceptable within the bureaucratic framework. This would include staff having time, knowledge and support to administer it properly and whether the agencies were able to work in a multi-disciplinary manner. Staff not involved in core assessment also said they would like to take an outcomes approach in their work in order to know what exactly to look for when helping families.

#### *Parents' views on the outcomes approach*

In this section, we concentrate on reporting the views of parents who were rated as understanding the outcomes approach. The analysis of parent interviews showed that parents who had a good understanding of the outcomes approach were positive about it. Many parents felt that filling in the tool with their worker had helped the worker to understand their situation better. The tool had encouraged discussion among them and had helped the staff member to have a deeper knowledge and understanding of the family situation. Staff and parents had put several hours aside specifically to discuss both longstanding and new issues the family confronted and this had been valuable. Together they had looked at the whole picture of the family's circumstances and made sure that all aspects of the family's life were covered.

Some parents also felt that the tool helped both them and their worker to 'think outside the service box'. When staff encouraged parents to think in terms of outcomes rather than in terms of what services they wanted, parents said they became more able to focus on the wider picture of what they wanted to achieve both for themselves and for their child. Some parents said they had reflected upon issues that they had not thought about before, for example the necessity of spending more

time with their spouses and partners, or re-organising their day in order to have more time for themselves. One parent felt that thinking in terms of outcomes rather than services had changed the way she raised her child. She had realised that she wanted her child to go to bed at night, rather than falling asleep on the sofa and then be carried to bed. She also wanted the child to feed himself. She felt that she was responsible for teaching her child to accomplish these goals. By the time of the interview, the parent had been successful in helping her child achieve both of these goals and she felt that her family's life had improved considerably as a result of this.

A number of parents also felt that having written their goals down on the form, knowing that they would be reviewed, was an incentive to do something in order to make sure those goals were achieved. Parents were also able to look back on the achieved goals and feel a sense of accomplishment at having made some steps forward. As one mother put it:

I do look at it and think: I've done that, so that's good really it's what you've filled out, oh I've achieved that, I can put ten on there if I want to now.

### **5.3.2 Views about outcomes for parents**

As the concept of exploring what outcomes parents aspire to achieve for themselves was new for both staff and parents, the interviews explored their views on this.

#### *Parents' views*

All parents felt it was a new experience for them to be asked questions which were about themselves. A few felt the interview should have been focusing on the child. One parent in Area B said:

...she were asking about me and things but .. to be honest it's like when you have a disabled child you're not you any more, you're that child's mum and that's all it is, you know, you give up your life basically.

However, others felt it was useful to focus on their own aspirations because there was a clear link between their well-being and their child's well-being. The more relaxed they were, the better they could control difficult situations and support their disabled child. Some felt asking parents what they want 'gives parents an identity' as it can be difficult as a parent to accept that you have needs too. Some parents reported professionals often ask general questions like 'how are you coping', whereas with the outcomes tools they explored areas of their lives in much more depth. However, most parents reported that they could only do that if they thought their child was settled, when they were too worried about their child it was difficult to think about themselves. Although some found it hard to think about themselves, if they were able to do this they felt it helped them clarify in their own minds what the important issues were that they wanted to make progress on. Most felt staff had played a useful role in facilitating the identification of outcomes and what steps to

take. A few said it was the first time they ever thought about themselves. A few reported that the discussion made them 'get up and do something about it' and this resulted in some positive changes.

#### *Staff views*

Staff involved in carrying out core assessment said their current work does involve finding out about parents but normally they would rely on parents offering information to them and let conversation happen more 'naturally'. However, using the outcomes focused assessment would give parental well-being a proper focus and flag up issues that would not necessarily be identified through child-focused assessment by offering more structured way of gathering information. One interviewee commented:

... I think it helped jog our memory a little bit of, you know, things that we might not have thought of asking...

A number of staff involved in respite centre based reassessment in Area B reported that the recommendations they currently get for the child through the core assessment do not always give them enough details about the child and the family to know what they should look for. Finding out more in-depth information about parents helped them get to know the families better and have a clearer idea as to how best to help the parent and the child.

Like parents, staff felt that finding out about parents desired outcomes seemed like a new experience for parents. Almost all staff said that they experienced difficulties in getting parents to think about themselves and they often had to push parents to be more assertive about their rights. The most difficult area for parents to think about was said to be their emotional and physical well-being. This was because parents felt guilty to think about areas so central to their own needs, whereas other areas such as feeling informed and skilled were seen to be more about supporting the child.

### **5.3.3 Views about outcomes for disabled children**

#### *Parents' views*

This section reports the views of parents in Area B where tools were developed to gather outcomes information for both the child and parent. The analysis of data from parents' interviews revealed that much of what they talked about in relation to their child revolved around their experiences of accessing and using services. The researchers carrying out evaluation interviews had to remind parents that they were not evaluating the services families used.

A number of parents felt that it was useful to talk to their worker in such detail about their child as it gave the worker a better understanding of the child's life and a more complete picture of their child than did their previous assessment experience. However, some parents felt it would not be appropriate to use the tool for a newly

diagnosed child or a child who is terminally ill, as their parents might be just coming to terms with the diagnosis and not able to look too far ahead.

A few parents, mainly those with children with severe cognitive impairments, thought their child would not be able to participate in thinking about outcomes. A number of parents felt it was important for the child to be involved and it would be possible to do that if the worker knew the child's method of communication. A few parents valued the child's involvement independently from that of their parents as it would give the child privacy.

#### *Staff views*

Like parents, staff felt that the outcomes approach supports getting a more complete picture of the child and makes the assessment more child focused. However, a key concern for some staff was how to get the views of children with cognitive impairments or children with no verbal communication. In 8 out of 12 cases in this pilot, the views of children were given by their parent, teacher, nurse or respite worker. In three cases the section was left blank. Only one child was directly involved. One staff interviewee said had it not been for the time constraints, she would have been able to get some of the children's views:

... if I had had more time I could have probably got something from them... although they can't speak them, and express themselves verbally they can in other ways... to get the child's views you would need an awful lot of time with the children, with the type of children that we were looking at, and that was difficult to deal with in the timescales really...I'm just conscious that...I failed in getting the child's views really that's how I felt, I were really conscious of that.

Most staff felt that parents generally had difficulties thinking outside the services they might want for their child and they had fixed ideas about what they wanted for their child. However, they reported that using the outcomes approach had usefully uncovered areas in children's lives that would previously not have been covered and the breaking down of the outcomes gave some parents some ideas about what they could do to help their child.

### **5.3.4 Findings from the evaluation: The Parental Well-being Tool (Area A)**

#### **Parents' views of the tool**

Although as part of the pilot staff were asked to give parents a copy of the completed tool, this varied. Five parents had a copy of the completed form, two could not remember whether they had been given it or not and two had not been given it. For those who did not have or were not able to find the completed form, the interviewer gave this to the parent at the start of the interview (parents' consent for the research team to have copies had been obtained before the interview).

Overall five of the nine parents interviewed were judged to have a full understanding of the outcomes approach. Six parents viewed the tool positively (but this is not to

say they did not report difficulties or concerns as well), and three were ambivalent. Two parents in this latter group indicated a poor understanding of the outcomes-focused approach. The parents' experiences or views of the tool can be divided into: difficulties; factors which will influence the usefulness of the tool; positive features; and outcomes of using the tool.

### *Difficulties*

- **Layout and appearance**  
In terms of physical appearance, three parents found the format confusing and/or the language unclear. This made it difficult to understand the purpose of the form.
- **Rating scales**  
Over half the parents found the rating scales hard to use. They found it difficult to equate a single rating scale with the way feelings or a situation can fluctuate from day to day or can differ between contexts.
- **The use of action points**  
A key part of the tool was a record of action points which the worker or parent would implement in order to achieve a desired outcome. A couple of parents found this very hard to do, partly because they felt they did not know enough about possible options and/or sources of support.

### *Factors influencing the usefulness of the tool*

- **The worker**  
Parents believed the worker was critical to the effectiveness of the tool. This was both in terms of helping the parent to understand the purpose of the tool and the outcomes-focussed approach as well as steering the parent through the form.

Most parents regarded the tool as a means of facilitating and recording a discussion. As a result they believed that there needed to be a positive and trusting relationship between a worker and a parent if the tool is to be used effectively.

- **Parents' ability or willingness to think about themselves**  
Almost all parents said the process of completing the tool was the first time professionals had focused on their well-being and, to some extent, the first time they themselves had done this. Typically they were pre-occupied with getting the best for their child and prioritising his or her quality of life over their own. It was a new experience and, for this reason, some found it a difficult task. However, a number of parents said the tool 'gave them permission' to do so and relieved feelings of guilt and selfishness.

- **Timing**  
A few parents observed that care was needed in terms of identifying the right time to use this tool with a parent. This was for a number of reasons. First, it had the potential to raise issues which the parent might not have faced before. Second, it demanded parents to have the capacity to identify and follow through actions to achieve their desired outcomes. Third, a typical coping strategy for many parents is to adopt a day to day approach, particularly in times of crisis, and the tool requires parents to take a longer term view.

#### *Positive features*

Two features of the tool were identified by parents as being particularly positive and 'unique' in their experience.

- **The process of completing the tool**  
Parents reported that the tool facilitated the process of discussing different aspects of their well-being. It had enabled them to clarify their thoughts about their situation and to think beyond 'service solutions'.
- **Recording**  
Parents were very positive about the process of recording in writing their aims (or desired outcomes) and the resulting action points. They felt it signified a commitment to action and change – on the part of their worker and themselves. Parents also valued the way they could track and record progress in achieving their aims. Those who had a copy of the tool reported it to be a source of encouragement in the way it recorded progress and felt that it was evidence of a shared commitment to change between themselves and their worker.

#### *Outcomes of using the tool*

Six of the nine parents interviewed were able to name specific things that had changed about their lives as result of the process of using the tool, discussing their desired outcomes with their worker and identifying actions they could take to achieve desired outcomes. For example, one mother had implemented a plan to achieve time for herself by setting aside an hour and half before she picked her child up from school; one had identified an outcome of looking after herself and had joined a gym and arranged to go away for a week with a friend; and another, whose desired outcome was to feel more skilled and informed in relation to her child, had set up a network of parents at school 'to keep the information flowing' and was planning for these parents to get together in school holidays with their children.

#### **Staff views of the tool**

Five of the staff who were involved in piloting were positive about the tool. The remaining two had mixed feelings. These two had been classified as not having a full understanding of the outcomes approach. All but one of the staff said they would

use the tool again – either in its entirety or particular sections or features. Many felt the tool had wider applications – both within services for disabled children and other children’s services.

### *Difficulties*

One member of staff found the form confusing and difficult to use. In contrast, others found it easy to use. The period of time between training and actually using the tool, and the fact that some staff only used the tool once, meant it felt unfamiliar. Staff noted that some parents found it difficult to talk about themselves. The length of time taken to work through the tool was also seen as a problem by some staff.

### *Benefits of the tool*

- **A facilitator**  
The positive aspects of the tool were typically spoken about in terms of the way it provided ‘a way in’ or facilitated a conversation with a parent. Staff believed the tool helped them to clarify with the parent what they wanted to achieve. Two members of staff working in social services believed it generated more detailed information than would be yielded through the core assessment process.
- **Promotes a sense of partnership**  
Some felt the tool supported a sense of partnership. Recording actions to be taken by the worker and the parent on the same form was seen to promote this sense of working together, one worker likened it to a ‘joint contract’.
- **Supports the identification of non-service solutions**  
Staff also believed the tool also helped them and parents to identify non-service and parent-led solutions. They felt this was empowering for parents – moving them from a passive role as a receiver of services to actively seeking to manage their situation.
- **A visible record**  
The system of tracking progress and recording achievements provided in tool was seen as valuable. Not only could it be a source of encouragement for parents (and staff) it was also a means by which a worker could evaluate or monitor the impact of an intervention.

### *Concerns*

Finally, a number of concerns about using the tool were raised by staff. It was noted that working through the tool could take a long time. There was also a risk of raising expectations or the parent setting unrealistic aims. With respect to the latter point, staff pointed to the role of the worker in helping the parent to set realistic and achievable aims.

### 5.3.5 Findings from the evaluation: The ‘What Children and Parents Want to Achieve’ Tool (Area B)

#### Parents’ views of the tool

As in Area A, staff were asked to give parents a copy of the completed tool. However, only one parent in Area B had received a copy of the completed form, one could not remember whether she had been given it or not and seven had not been given it. For those who did not have the completed form, the interviewer gave this to the parent at the start of the interview (parents' consent for the research team to have copies had been obtained before the interview).

Overall three out of nine parents interviewed in the pilot were judged by the researchers as having grasped the outcomes approach and the remaining six demonstrated a lack of understanding of what the tool was aiming to do. Four out of nine parents felt the tool was useful. These included all three who understood the approach. Of the rest, two were of the opinion that completing forms is unhelpful as they never seem to make any difference. The remaining three parents did not express any strong views on this.

#### *Difficulties*

- **Appearance and lay out**  
While three parents said that they had no problem filling in the form, three other parents felt that the form looked ‘overwhelming’ and that they needed a professional to help explain the language. One parent thought having the form in a table format was intimidating. Another parent felt that the words ‘goal’ and ‘achievement’ were inappropriate to use for a child who is seen as not developing further. Two parents said it was repetitive going through the whole form when they knew exactly what they wanted from services.
- **Involving children**  
Involving children proved to be a problem in the pilot (see section 5.3.3). Some parents suggested making the information sheets and outcomes tools more attractive, using bright colours and happy faces, to make them more accessible for the child’s use.

#### *Factors influencing the effectiveness of the tool*

- **Timing**  
Two parents said the form would not be appropriate for parents of a newly-diagnosed child or a child who is terminally ill. It would be most helpful to use the form when the family is more settled.

- The worker  
Almost all parents emphasised the importance of the worker knowing the family before using the tool with them. Some felt that using the tool improved their relationship with the worker.

#### *Positive features*

- The process of completing the tool  
Parents valued their involvement in completing the form, one parent said it was helpful to be able to see every word written on the form rather than professional filling in the form 'behind closed doors'. This would avoid things being misinterpreted or put down wrongly.
- The holistic approach  
Most parents valued the tool being comprehensive in terms of covering all important areas of their child's life, although a few parents commented that some of those areas did not apply to their child.
- Valuing outcomes for parents  
The tool was felt to put value on what parents need by looking at the child separately from the parent.
- Recording action points  
The process of clarifying what is to be done and who will take action, including what parents need to do, was seen as helpful.

#### *Outcomes of using the tool*

None of the parents in Area B were able to identify any changes that had come about as a result of the process of using the tool and discussing their desired outcomes with their worker.

#### **Staff views of the tool**

Overall five out of eight staff involved in piloting of the tool viewed the tool as positive, but felt its effectiveness was largely dependent on other things being in place. Three of these were not currently involved in carrying out core assessments but had the experience of using the recommendations made by the core assessment for the children they look after. All five viewed the tool as an improvement on tools they currently used and felt it would be useful to have parts or the entire tool incorporated into the core assessment. Some felt parts of the tool were best placed in the Care Plan and the review process. On the other hand, two staff were mostly concerned about inviting parents to set outcomes which were not within their remit, and one person felt that the approach was positive but not new and they were already using this approach but in a different way, so the tool would not give them anything

different. The three staff in this latter group were among those who indicated a poor understanding of the outcomes approach.

### *Difficulties*

- **Appearance and lay out**  
While appreciating that the tool covers all key areas for parents and children, three staff felt that it looked 'too-in-depth and too long'. Two staff felt it would be repetitive going through the whole form with parents when you know there are only a few things that the family would want to change. One felt the boundaries were not clear and sometimes the same thing could go under different headings. Two staff said that the form was 'segmented' (having too many headings), the child's views should come first and the language of the form was hard for some parents to understand.
- **Involving children**  
As mentioned earlier, only the views of one child were accessed directly in the pilot; however three staff mentioned that given more time, they would have been able to involve children more.

### *Factors influencing the effectiveness of the tool*

- **Multi-disciplinary working**  
All staff who had a positive view about the tool stressed that for the tool to be useful, agencies needed to be signed up for it and own it collectively.
- **Staff training needs and support**  
While all staff valued the importance of involving children in the process, they felt that they needed training and adequate time to get children's views.
- **The process of completing the tool**  
A few staff mentioned that the language of the tool made it difficult for the parents to fill in the form themselves. This highlighted the critical role of the worker in the process.

### *Positive aspects of the tool*

- **The holistic approach**  
Almost all staff mentioned that the tool covered all important areas of children's lives. They also felt that by taking a holistic approach the tool encouraged parents to give a broader view of their situation and think of the family as a whole.
- **A facilitator**  
Staff felt that the tool aided clarity in exploring what the families want, through opening up discussion and breaking down desired outcomes into the steps

needed to achieve them. It also improved transparency in communication between parents and professionals.

- Supporting the identification of non-service solutions  
The tool was felt to encourage parents and staff to be creative in identifying service and non-service solutions.
- Helping parents to think about themselves  
Looking at the child separately from the parent was felt to help parents to think about themselves.

### **Concerns**

Four staff were concerned that using the outcomes tool raises parents' expectations and services might not be able to meet these. However, only two felt that it would be problematic and 'a very idealised view of life' to move away from a focus on what is available in services. Others viewed it as a positive way forward to look beyond what families received and what was available.

### **5.3.6 Issues for professional practice**

As noted in previous sections, staff and parents raised a number of issues for professional practice about how, when, with whom and by whom the outcomes approach and tools should be used. There were no differences between the two areas in the issues raised, so these issues are drawn together in this section.

For some parents, it was important that the professional who discussed outcomes with them already knew them well. They would not have felt comfortable with a stranger asking questions on topics which could be sensitive. Some professionals also thought that the approach should only be used after they had built up a relationship with the family. However, one felt that the using the outcomes tool could be a good way of getting to know the family:

...other times you have to spend quite a lot of time getting to know parents and I think a tool like that with those sort of families, it would be really useful as a chance to sit down, we're going to do this piece of paperwork, you could use it quite formulaically in some ways prescriptively....this is the issue we need to discuss, these are the sorts of things other parents raise, and I think this could be a real sort of benefit in, you know, starting those conversations...

Both staff and parents raised issues about timing. Parents felt that they would have found it upsetting to talk about outcomes when they were going through difficult times, for instance after diagnosis, when the child was terminally ill, after significant life events such as divorce or when depressed. Staff also felt that it would not be

appropriate to use the approach at times of crisis and high parental stress when the main need is for support to deal with the immediate issues.

In area B, where the outcomes for both children and parents were explored, many professionals were concerned about how to access children's views on the outcomes they wanted to achieve. In fact, only one child (who was verbal) was directly consulted. In other cases, staff relied on parents and/or teachers to give the child's views and in three cases, there was no discussion of what outcomes the child might desire. Staff recognised that relying on others to define outcomes children wanted to achieve was not ideal, but cited lack of time and skills in communicating with children who do not use speech as the main reason for this. This is consistent with findings of other research that the views of children who have communication impairments are rarely included in reviews (Franklin and Sloper, 2005).

The importance of having enough time was also raised by staff in relation to whether they could incorporate an outcomes approach into their work in the future. A number commented that their discussions with parents had been time consuming (ranging from an hour to over three hours). However, one professional who used the outcomes tool with a number of parents noted that less time was taken as she got more familiar with the approach. The majority of staff interviewed thought that the outcomes tools could be used with other groups of parents and children, such as looked after children, and across other specialist and mainstream settings. However, the proviso was that staff needed to have adequate time to have meaningful discussions with parents and children.

An important issue in the use of outcomes tools with families is ensuring that parents have a copy of the completed forms. As highlighted in sections 5.3.4 and 5.3.5, although all staff in the pilot had been asked to give or send copies of the completed forms to parents, practice on this varied both within and between the two areas, with all but one of the parents in Area B saying that they did not have a copy of the completed form. This negates one of the key purposes of the approach, which is for parents in discussion with workers to identify desired outcomes (for parent and/or child) and set out the actions that one or both of them will take to achieve these outcomes. These actions will not necessarily be service-led, but if the parent does not have a copy of the agreed actions, it seems less likely that they will either implement the actions themselves or be enabled to monitor the actions that were agreed for the worker. In this respect, it is significant that in Area B no parents were able to cite examples of changes that had occurred as a result of the use of the outcomes tools.

### **5.3.7 Mainstreaming the approach**

Members of the task groups and staff involved in piloting the tools were asked for their views about the issues that needed to be addressed if tools such as those developed in this project were to become part of everyday practice.

A fundamental issue appeared to be the need for change in the organisational culture of services from a needs or service led approach to an outcomes-focussed approach. Supporting changes in the way people work also requires on-going, high quality training and supervision. In addition, the way that an outcomes-focussed approach drives a holistic approach means that systems for multi-agency working need to be in place.

The issues relating to professional practice described above were also identified as needing to be addressed in mainstreaming the approach. The issue of the participation of the child in the process was not resolved in this project and is likely to require the development of tools, working across agencies and accommodation within the bureaucratic process to allow for proper consultation with the child.

## **5.4 Discussion**

### **5.4.1 Limitations of the study**

This part of the study evaluated the development and use of two tools designed to promote an outcomes centred approach and to record desired outcomes for parents and, in one area, children and actions to be taken to achieve these outcomes. However, before discussing the results of this evaluation, its limitations should be borne in mind. First, the primary purpose was to evaluate the tools themselves and the way they support an outcomes-focused approach to assessment as opposed to the extent to which they promoted an outcomes-focussed approach in terms of the way children and families were supported and the services they received. Second, the sample size for both staff and parents was very small, and even within this, many staff had only used the outcomes tools once. Third, the time lag between training for staff on the outcomes approach and tools and using the tools was long and may have been a factor in the lack of understanding of the approach demonstrated by some staff. Fourth, only one disabled child was involved in the pilot so we are not able to comment on the use of the outcomes approach with children themselves. All these factors were due in part to the difficulties of implementing a system in practice within the confined timescales of a research project. This issue has also been identified in other research as problematic (for example, Harris *et al.*, 2005; Qureshi, 2001a; Sloper *et al.*, 1999; Marsh and Fisher, 1992) as the timetables of services, who have other priorities that may override their commitment to the research at times, do not fit easily with the tight deadlines of research projects.

### **5.4.2 Implementing an outcomes approach**

There were clearly some problems in staff and parents' understanding of the concept of outcomes. Both had been more accustomed to a culture of being assessed to receive a service, such as respite care, rather than trying to ascertain what they aspired to achieve for the child or parent from service provision. However, among those who did understand the outcomes approach, views were positive. It was felt to promote a more in-depth and holistic understanding of the family, and to empower staff and parents to 'think outside the box' in identifying what could be done to achieve desired outcomes. In a few cases, actions had been identified which had brought about changes in families' lives by the time we interviewed them. Typically these were not actions which required the input of specialist services. In addition, services and parents themselves have generally concentrated on what should be done for the child and parents have not been encouraged to think about what outcomes they aspire to achieve for themselves. Many parents and staff found this a useful exercise and, having done it, recognised its importance in that parental well-being is so closely linked to the support parents can provide for their children and so to child well-being.

Nevertheless, there were considerable barriers to implementing the outcomes approach. As Qureshi (1999) notes the existing culture itself can be a barrier to change and both anxiety about performance and the 'we do it already response' (Marsh and Fisher, 1992) was demonstrated in the pilot areas. In addition, lack of time, lack of support and, in one area, problems in multi-agency working were identified as barriers. Although the project had some success in promoting the outcomes approach, more time and resources, and a strategic commitment would be needed to achieve such a change in culture.

### **5.4.3 Usefulness of the outcomes tools**

Two different tools were developed in the project to explore outcomes. It is difficult to compare these as they were implemented in different areas and one covered both parent and child outcomes while the other focused solely on parents. There is some indication that the more structured tool used in Area A was slightly better received, although a few parents found the rating scale difficult, and it was only in this area that changes were identified as a result of using the tool. Some workers in both areas thought that the tools supported the identification of non-service solutions and welcomed the holistic approach, looking at all areas of children's and parents' lives, and working in partnership with parents to identify desired outcomes and ways of achieving these. However, this approach caused anxieties among staff if they felt they would be talking about areas that were not within their remit. It is interesting to note that despite the active involvement of parents and professionals on both steering groups, difficulties with language and layout of the tools were noted by parents and staff.

A problem that arose in both areas was that many staff did not give parents a copy of their completed tool and action plan, despite that fact that they had been asked to do this. This was a particular problem in Area B where only one of the nine parents interviewed had a copy of the completed tool. If parents are to follow through on actions they have identified for themselves and monitor progress on actions identified for services, then having a copy of the action plan is essential. It is also worth noting that, in Area A, those who did have a copy of the tool reported it to be a source of encouragement in the way it recorded progress and evidence of a shared commitment to change between themselves and their worker.

Staff in both areas could see wider applications of the tool for other groups of children and families, but also had concerns about the time taken to complete the tools with families. They were also concerned about raising expectations that could not be met, but recognised the role of the worker in helping parents to set realistic aims.

In conclusion, this part of the project met with some success in developing tools and implementing an outcomes approach in two areas, but the limitations of time were a constraint on the project and thus we are not able to draw any firm conclusions about the tools. Further development and piloting would be needed before the tools could be recommended (or not) for practice.

# Chapter 6: Conclusions and Implications for Policy and Practice

## 6.1 Strengths and limitations of the study

The findings of the research revealed the desires and aspirations parents and other carers hold for disabled children and young people with a range of conditions, and in a more limited way, the research explored the desires and aspirations of the children and young people themselves. The children who were the focus of this project are groups who are often seen as 'hard to reach' and as causing concerns for service providers. A key aspect of an outcomes focussed approach is that outcomes should be defined by users themselves (Department of Health/Department for Education and Skills, 2004a). Both a strength and a limitation of the study is the involvement of children. Whilst we were able to obtain the views of a range of children, and the methods used proved encouraging in facilitating communication with children who did not use speech, involvement of some groups was very limited: these included children with autistic spectrum disorders, especially those with more severe levels of impairment, and children with severe cognitive impairments. Obstacles to the involvement of these groups are difficult to overcome. Abstract and future issues central to the concepts of desires, aspirations and outcomes have little meaning for some of these children because of limitations of their cognition. Whilst there is a need for further research on developing appropriate methods of communication in order to obtain the views of disabled children, it seems likely that for some children it will always be necessary to rely on the views of those who know the child well. In many cases, this will be parents, but parents do not see children in all situations they encounter and the inclusion of 'other informants', such as teachers and care workers, in this project was extremely useful in providing a broader view.

The approach taken in the project was to ascertain what children liked and valued in their lives and, if possible, what they would like to change, so gaining an idea of positive outcomes that have been achieved and are valued. Whilst this was successful, the information was limited by the amount of time we were able to spend with the children. Two visits were undertaken with each a family, first an interview with the parent(s) during which the child's communication needs were discussed and, if possible, the researcher met the child, and second an interview with the child. In most cases, this interview took place on one occasion only. However, it is likely that with repeat visits (not possible within the resource constraints of the project) it would have been possible to build up a fuller picture of children's views and also approach some more sensitive issues, such as sexual relationships, that were not raised in the project. Similarly, repeat interviews with parents may also have allowed exploration of such sensitive issues. In addition, although the project covered a broad age range,

it was cross-sectional, and thus could not track changes over time in aspirations and priorities, or how these relate to the child and family's development, changes in the child's condition and family situation and other individual factors.

Disabled children are not a homogeneous group, and in this project we chose to focus on certain groups of children. This means that the results of the research do not necessarily apply to other groups who were not part of the project. Children with special educational needs, such as children with moderate learning disabilities or emotional and behavioural difficulties, may have different views on the outcomes they aspire to and the ways they prioritise these.

A strength of the project is that it set out to develop a framework of desired outcomes for parents caring for a disabled child, a topic which has been neglected in the frameworks of outcomes for children. However, this was also subject to the limitations described above, and also the low representation of fathers in the sample.

The development and piloting of the tools to promote discussion, recording and monitoring of outcomes was limited by the amount of time available for this and the small sample size for evaluation. Whilst there were positive views about use of the tools among parents and staff, a number of problems were identified both in promoting understanding of the outcomes approach and in the use of the tools themselves. Therefore, we were not able to draw any firm conclusions about the tools, and further work would be needed to inform any wider use of the tools in practice.

## **6.2 Lessons about methods – implications for practice**

One of the challenges of this project was to develop methods to support and facilitate the direct participation of the children and young people. For some children incorporating visual and interactive elements to a relatively standard interview schedule was all that was required. Thus pictorial maps of a child's life and 'tasks' such as rating different areas of their life and using a scenario by which the child 'waved a magic wand' over areas of their life they wanted to change were used to facilitate interviews with children who were verbal and did not have significant cognitive impairment. However, it was also necessary to develop approaches tailored more specifically to the needs and abilities of children who did not use speech to communicate and children with autistic spectrum disorders. The methods developed have been described elsewhere in the report (see Chapter 2 and Appendix 4). Although the methods developed were for the purposes of research it is possible to draw out implications for practice both in terms of the actual methods developed and our experiences of using them.

A key difficulty encountered in the research phase was that the symbol systems being used by some of the children do not have the capacity to explore more abstract notions and aspirations. These systems are typically used to convey information to the child or allow them to express views or choices about quite concrete things. It was therefore necessary in this project to devise a specific tool for use with children who did not use speech to communicate which was able to explore more abstract concepts. This is likely to be the same in assessment situations where the practitioner wants to explore a child's desired outcomes.

Cognitive abilities (including memory, conceptual abilities and the ability to self-reflect) affect the process by which desires and aspirations are formed. Some children may not have desires and aspirations about their lives beyond their current situation and/or very familiar situations and experiences. Care was therefore taken to pose questions which were appropriate and meaningful and this required an understanding of the child's condition and abilities. Again, in practice situations where a child's views are being sought, these issues need to be taken into account.

Life experiences also affect desired outcomes held by individuals. A lack of exposure or a lack of knowledge about options and opportunities limit an individual's world view. Research has shown that disabled young people typically have low self-expectations for their lives (for example, Beresford, 2004) and this will inevitably be reflected in their aspirations. This needs to be borne in mind when recording and interpreting children and young people's views. One of the reasons why 'other informants' were used in the project was to bring a different perspective on the child. The fact that many of the 'other informants' had a lot of experience of disabled children or children with a particular condition often meant their views about the child's abilities and future were more 'ambitious' than the views of the parent.

It is also important to bear in mind the time taken to work with some groups of disabled children. Developing the methods used for children who did not use speech to communicate or had autistic spectrum disorders took time and involved widespread consultation with professionals working in a range of disciplines. The basic methods then had to be adapted for a specific child. Finally, and with respect to the children who did not use speech to communicate, the 'interview' itself typically took longer than interviews with other groups of children.

A key implication of the experience of conducting the research is that parents (in particular) found it hard to move away from talking about services and to think about their child in terms of desired outcomes. The research team came across this in the research and development phases. The findings from the pilot work conducted in the development phase suggest that professional skills and understanding of the concept of outcomes are the key to parents being able to think about their desired outcomes for their child as opposed to needs and services.

Finally as noted in section 6.1, there was not scope within the project to conduct more than one interview with each participant. The view of the research team was, however, that conducting more than one interview would have resulted in children and parents feeling able to discuss more emotional or sensitive topics, or to discuss them in greater depth. Indeed, for the children with autistic spectrum conditions this may have increased the range and quality of the data across all the topics covered. It is worth noting here that a finding from one of the sites involved in the development phase was the need to have an established relationship before discussing outcomes with parents. This supports the idea that, optimally, a discussion about outcomes should take place within the context of an existing relationship.

### **6.3 Desired outcomes for disabled children compared to other groups with social care and support needs**

A number of different groups of people with social care and support needs have been included within the programme of work on outcomes carried out by the Social Policy Research Unit. Earlier projects have explored the views of young adults with physical and sensory impairments (Bamford *et al.*, 1999), and older people who are ill or disabled, about their desired outcomes (Qureshi *et al.*, 1998). The research reported here has been concerned with disabled children and young people who differ from these other groups in terms of age and stage in the life course. The sample also included a wider range of impairments and health conditions.

Despite the differences between these groups there are some clear commonalities in terms of desired outcomes. All three groups identified desired outcomes in the areas of personal cleanliness and comfort, physical health and functioning, social contact, participation in activities, choice and control, personal safety, and psychological or emotional well-being.

However, there were also differences and these were largely due to life stage, type and/or severity of impairment, or living circumstances. Thus, living in a clean and comfortable environment was a key theme from the accounts of adults and older people but not something raised by disabled children and young people and their parents, except with respect to short-term care facilities. Similarly, while maintaining or supporting independent living and financial well-being was a key outcome area for younger disabled adults, in terms of disabled children and young people the emphasis was more on achieving independence with respect to self-care and the development of life skills which would enable the child to live as independently as possible in the future. Finally, the issue of communication was a much stronger theme with respect to disabled children and young people compared to the other groups. This was obviously influenced by the types of impairments represented in the research. However, it is worth noting that communication was raised as an issue

across the entire sample of disabled children suggesting that this is an area where difficulties are likely to be experienced in terms of achieving desired outcomes.

Two areas which emerged strongly within the children and young people's data, and do not appear in the findings of the research with the other groups, concern learning and experiences of achievement. These were seen as very important areas of disabled children and young people's lives, including those with very severe impairments and those with degenerative conditions. All the children and young people represented in the research were seen as having the potential to continue to learn and develop, and parents and children wanted this potential to be explored.

#### **6.4 Outcomes for parents compared to other groups of carers**

The earlier research in the programme referred to above also explored carers' outcomes (Qureshi *et al.*, 1998; Bamford *et al.*, 1999). The range of methods used in the different pieces of research, and the fact that the earlier research did not exhaustively cover all groups of carers, means that care should be taken when drawing comparisons between parents' desired outcomes and other groups of carers' outcomes. However, there do appear to be a number of areas which both parents and other groups of carers highlighted as being important outcomes. These include having a life apart from caring, maintaining emotional and physical well-being, and having sufficient financial and practical resources. In addition, parents and carers want to have a positive relationship and work in partnership with professionals, and to have confidence in the services the child or cared-for person was using. One area which was raised by carers but not parents was wanting to feel the services they were using provided value for money. This probably reflects differences in the way services are organised and/or the types of services being used.

In addition, there were issues which appear to be specific to the situation faced by parents. This seems to be due to the fact that the caring was taking place in the context of a number of different relationships (that is, partner-partner, parent-child, child-sibling, parent-other children, the family unit) and that parents often had other parenting responsibilities. Thus parents highlighted the importance of siblings' outcomes both in terms of their childhood not being restricted and making a positive adjustment to having a disabled brother or sister. They also wanted to maintain a sense of family through shared experiences and activities and to ensure the mother-father relationship stayed in tact.

Finally, whilst parents and carers both talked about wanting to feel informed and knowledgeable about the cared-for person's condition and services, for parents this particular outcome extended to feeling skilled about supporting the child's physical, social, cognitive and emotional development and also competent, where necessary, to deal with the child's health and nursing needs.

## 6.5 Key implications for policy and practice

The results of the research provide some indications of where changes or developments in policy and practice on supporting disabled children and young people and their parents are needed.

Despite emphasis within policy initiatives on outcomes focused practice and user-defined outcomes, evidence from this research raises important questions about the relevance of outcomes frameworks based on normative developmental models for assessing outcomes for disabled children and young people. Clearly there is a need to widen the definitions and indicators of key concepts in these frameworks to take account of disabled children's views and capabilities. The findings of this research show that while disabled children and young people aspired to and prioritised the same sort of outcomes as their non-disabled peers, the actual meaning attached to outcomes and the level of achievement expected or desired in all outcomes could, and often did, differ from normative developmental indicators.

This research also showed that changes in the condition or impairment, and/or progress through developmental stages, affected both the actual outcomes being aspired to, and the priority given to outcomes in the different areas of the child's life. This means that desired outcomes and the means by which they might be achieved are likely to evolve or change over time. This has implications for the role of services in achieving outcomes, indicating that regular reviews of desired outcomes and the support services being provided are needed. It also highlights the importance of taking an individualistic approach to outcomes assessment.

There also needs to be greater recognition that outcomes have a hierarchical structure and that achievement of so-called 'higher level' outcomes is only truly possible when the fundamental outcomes (physical health and comfort, emotional well-being, being safe, having a means to communicate and being understood) have been achieved. Whilst the ECM framework addresses some of these fundamental outcomes it must be noted that communication is not explicitly covered within the framework. Given that the majority of disabled children have some difficulty with communication, this represents a clear limitation of the ECM framework in terms of its applicability to disabled children. Similarly, there can be a hierarchical structure within a single outcomes category. This is illustrated by the role of pain in the 'being healthy' category. When children are in pain, it affects many areas of their lives (Committee on Psychosocial Aspects of Child and Family Health, 2001). This applies to all children, but many groups of disabled children are more likely to experience periods of pain, because of their medical or physical condition, and are less likely to be able to express this. If interventions to minimise pain are not implemented, or are not successful, then other aspects of 'being healthy' (for example, healthy lifestyles, exercise and emotional health) are also at risk (as well

as the extent to which outcomes in other areas of their lives can be achieved). The Children's National Service Framework advocates that children have a right to appropriate prevention and control of pain. Yet, assessment and management of pain in children is still underdeveloped (Joughin and Law, 2005). It is heartening to see that the Department of Health Children's NSF Research Initiative has a specific topic on pain. Hopefully, evidence from research commissioned on this topic will lead to better pain management. But for this to happen, it is necessary for all services in contact with disabled children to be aware of and alert to the possibility of pain, and to work together to ensure that appropriate steps are taken to prevent or deal with it. Specific recognition of the importance of pain in the ECM category of 'being healthy' could help to promote this.

The findings of this research also indicated that, although disabled children and their families typically prioritise the 'ordinary', everyday outcomes to which non-disabled children also aspire, unlike most non-disabled children the achievement of some or all of these outcomes may require specialist or extra support or intervention. The extent to which these needs for support map on to statutory agencies' views of their responsibilities for disabled children's development and well-being is debatable. In addition, the interrelationships between outcomes in the different areas of a child's life challenge the way services are currently provided, highlighting the need for multi-disciplinary assessments and multi-agency working to help children to achieve their desired outcomes. Furthermore, evidence from this research suggests that desired outcomes (for example, being able to communicate, spending time with friends) are sometimes achieved in one situation (that is, school) but not in another situation (that is, home). In order to *properly* achieve many of the outcomes identified, input or interventions are required in all relevant contexts or situations. Again this is likely to require a multi-agency approach from the assessment process onwards.

The importance of supporting parents to help their children to achieve their desired outcomes was also highlighted by this research. While the role of parents is recognised within the strategy to achieve the ECM outcomes for children, the focus is mainly on support needed *from* parents, rather than the support parents need *themselves*. This research provides evidence on what outcomes parents prioritise for themselves in order to support their role in caring for their children. The development work on implementing tools for assessing parental outcomes also points to the important role of professionals in helping parents to think about and discuss their own well-being, and identify actions that can be taken to improve this. It was significant that in the area where actions had been identified that brought about changes in parents' lives, these were largely actions that parents undertook themselves, but the process of completing the outcomes tool and their discussions with the worker around this had helped them to see what they could do to change things.

Evidence from the development phase of the project suggested that collecting information about children's and parents' outcomes is possible. In addition, evidence from the site which piloted the parental outcomes tool shows that when such assessments include the identification of ways to achieve desired outcomes positive changes can be made to parents' lives. It was not possible within the scope of this project to observe and examine a more widespread implementation of an outcomes-focused approach within disabled children's services. However, the conclusions drawn from the development phase suggest that adopting an outcomes-focused approach requires a change in the organisational culture of services (from the level of individual practice upwards) from a needs or service led approach to an outcomes-focused approach. The experiences of conducting the development phase would suggest that, amongst other things, the following need to be in place:

- a commitment of resources and time
- conceptual clarity about the outcomes focused approach
- enthusiasm and commitment among professionals at all levels to an outcomes-focused approach
- on-going and high-quality training, support and skills development and supervision for staff
- tools and associated resources which support outcomes-focussed assessments and reviews
- time and resources for proper consultation with the child
- an understanding of the issues relating to professional practice about how, when, with whom and by whom the outcomes approach and tools should be used
- multi-agency structures and ways of working which focus on outcomes services are aiming to achieve for each child and family.

## **6.6 Implications for future research**

This research was a first attempt to explore the outcomes disabled children and their parents aspire to achieve from support services. As noted in section 6.1, there are a number of limitations to the data, some of which could be addressed in further research. Research which explores children's and parents' views in a series of interviews would enable a wider and more detailed picture of their aspirations, particularly in areas which are sensitive and not easily discussed in an initial interview. Such areas include young people's sexuality and relationships, and aspirations around end of life (we explored this in a small number of interviews with parents whose children had died). This approach would also allow more exploration of the views of children, such as those with ASD, for whom involvement in the research was particularly difficult.

In addition, longitudinal research would allow exploration of changes in aspirations and priorities over time and in response to changes in children's and families'

situations. The outcomes frameworks developed in this research would provide a useful starting point for such research. In this context, there is a need for both further in-depth qualitative research and larger scale quantitative work on parents' views which could usefully build on this. As noted in section 6.1, future research should explore the views on outcomes of children with a broader range of disabilities, including children with moderate learning disabilities and emotional and behavioural difficulties, and their parents. Research is also needed which looks at fathers' and siblings' aspirations for outcomes of support services.

A clear finding from the research was that both parents and children differed in their priorities in terms of the outcomes they aspired to and what would help them achieve their goals. This points to the need for support to be flexible and responsive to individual situations and values. Direct payments and individualised budgets have clear potential to allow families to put in place support they need to achieve the outcomes they desire. At the moment, parents with disabled children only form a small proportion of those receiving direct payments (Commission for Social Care Inspection, 2004) and the extent to which the pilot areas for individual budgets will engage with families with children is not yet clear. However, it will be important to explore the ways families use individualised budgets and how this relates to the outcomes they aspire to achieve.

One area which was touched on in this study but could usefully be the subject of a separate research study is the issue of outcomes of transition to adulthood and adult services. Both parents and young people spoke of their aspirations for the young person's future, particularly having a job and earning money and, for more severely disabled young people, being meaningfully occupied. Existing research indicates that transition to adult services is highly problematic for many disabled young people (Beresford, 2004), but there is a lack of evidence on outcomes, particularly for groups such as young people in residential schools and out-of-authority placements (Fletcher-Campbell and Parther, 2003).

This project developed and piloted two tools to facilitate discussions about outcomes and record and monitor desired outcomes and plans for achieving these. This was only a small pilot study and there are currently plans in the areas involved in the study to build on this work and develop the tools further. Monitoring and evaluation of these developments would provide valuable information and could lead to stronger conclusions about the use of the tools in practice.



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