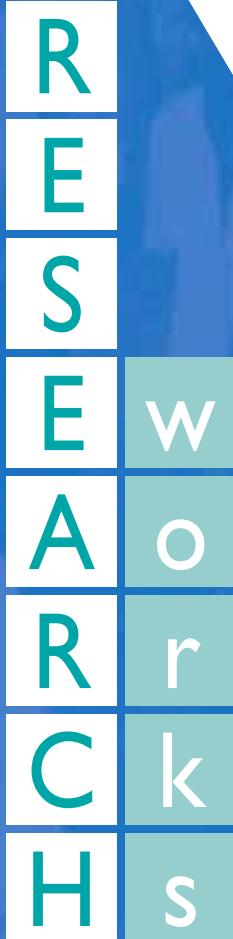


Outcomes for Disabled Children

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Recent policies provide a context within which agencies are expected to deliver services which achieve the best possible outcomes. The Every Child Matters (ECM) outcomes framework – focusing on the five outcomes of be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being – is central to all policy for children. However, it is unclear how these outcomes should be interpreted for disabled children. This research explored what outcomes disabled children¹ and their parents wish to achieve from service provision. The key findings were:

- ▼ Disabled children aspired to the same sort of outcomes as non-disabled children. However, what these outcomes meant, the way they were prioritised, and the level of achievement expected, often differed from non-disabled children.
- ▼ Outcomes in certain areas of children's lives – physical and emotional well-being, communication and safety – were seen as fundamental and needed to be addressed before other outcomes could be achieved.
- ▼ Children and parents identified outcomes in areas of the children's lives they wanted to progress and also areas where they wanted to maintain the existing situation.
- ▼ The research concludes that there is a need to widen definitions of key concepts within the ECM framework to take account of disabled children's views and capabilities.

1. For brevity the term 'children' is used to cover children and young people aged up to 18.

Background

The government's Every Child Matters (ECM) 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. However, there is a dearth of research on what outcomes disabled children and their parents' desire from support services. This research explored the views of children and their parents from four diverse groups for whom the achievement of the ECM outcomes as currently defined may be seen as problematic: children with complex health care needs (CHN); children who do not communicate using speech (NS); children with autistic spectrum disorders (ASD) and children with degenerative conditions (DC).

Findings

Desired outcomes identified encompassed the five dimensions of ECM. Like other children, many of the disabled children we interviewed wanted to have friends and interests, be part of the local community, acquire social and self-care skills and future independence, feel confident and respected by others, and experience success and achievement. Parents also wanted this for the children.

However, there were important differences. First, ECM does not emphasise the importance of communication at all ages. Second, what an outcome means for a disabled child could sometimes be very different from what it means for a non-disabled child. Third, some outcomes were seen as fundamental; they were basic requirements that needed to be achieved before other 'higher level' outcomes could be achieved (*see Box 1*). Fourth, outcomes need to be conceived both in terms of progress or achievements but also in terms of maintenance, for example of physical functioning or a valued aspect of life.

For disabled children, important aspects of the ECM outcome '**being healthy**' were ensuring or maintaining physical and emotional well-being.

For many children, being comfortable and not in pain was central to achievement of any other outcomes. Maintaining health and functioning was also important and could 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 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, many of whom found it difficult to assess their child's emotional state. 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 these changes. Parents also stressed the importance of meeting these children's emotional needs in the end stage, particularly to ensure the child did not feel anxious or abandoned.

Being able to communicate was seen as fundamental to meeting desired outcomes in other areas of life for all groups. 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. Apart from giving the child a 'voice', having the ability to communicate was seen as opening doors to more opportunities, such as socialising, being active and becoming more independent, which in turn help promote a child's feeling of security and self-esteem.

Keeping children safe from exploitation, 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 children might be vulnerable to accidents including using inappropriate or unsafe equipment, living in unsuitable housing and / or requiring high levels of supervision.

Enjoying and achieving encompassed various inter-related areas:

Socialising and having friends Having friends was a priority for many children and their parents. However some parents of children with ASD recognised that to have friends their children would first need to have the desire

Box 1

Fundamental outcomes

- Physical and emotional well-being
- Communication
- Personal safety

Higher level outcomes

- Enjoying and achieving
- Making a positive contribution
- Economic well-being

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to interact. The lack of contact with school friends out of school was seen as a barrier to achieving friendship across all groups, and was a source of considerable frustration for some children.

Activities and experiences Having interests and being able to participate in activities was something 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. Most parents expressed the desire for their children to participate in mainstream activities in their local community. The exception was some parents of children with degenerative conditions who reported their children were no longer able to cope with such situations. Many children also expressed a desire to be 'doing more'. 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.

Education and learning Parents' aspirations for their child's education varied according to the severity of the condition and associated learning difficulties. All parents wanted their child to fulfil their learning potential. For those with limited cognitive abilities, acquiring self-care and living skills and enjoying a stimulating environment 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. Children with complex health conditions did not want their schoolwork to be affected by having time off due to ill-health or for treatments. Parents of children with degenerative conditions noted the need for educational goals to be appropriate and responsive to the decline in their abilities.

Self-care and life skills While for non-disabled children independence is often seen as the child being able to do something without help, for many disabled children, this is not achievable in certain areas of their lives. Managing self-care tasks as independently as possible, with or without support, was a key priority among many children and parents across all groups.

Independence was seen in terms of children reaching their potential in carrying out life skills with or without support. The life skills children wanted to acquire included being able to make snacks, go out alone, handle money and manage unforeseen circumstances when out and about.

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) were among things said to make children feel valued.

Identity and self-esteem For many children feeling 'normal' was important and was linked to being accepted by their peer group. 'Looking good', wearing similar clothes to others and being able to use attractive equipment (boots, wheelchair etc.) contributed to how they felt about themselves. Parents wanted services to be more sensitive to the child's identity and social integration when issuing with equipment, making sure that it is attractive whilst still offering appropriate support. They also stressed the importance of the child experiencing success, and having their achievements recognised.

Making a positive contribution

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. 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 local community-based activities.

Feeling involved and having the opportunity to exercise choices Being involved in decisions that affect their lives was important 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 and decisions about their care and treatments.

Economic well-being Having a job and earning money in adulthood was seen as important by young people with good cognitive ability and their parents. Employment opportunities and support, and access to transport were seen as key factors in achieving these outcomes. Parents of young people with more limited understanding wanted them to be meaningfully occupied and be able to contribute something when they become adults. 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 is important.

Implications

Normative, developmental models of outcomes are insufficient for disabled children. There is a need to widen definitions of key concepts in these frameworks to take account of disabled children's views and capabilities. For example, full independence and making an economic contribution is not something some of the children in our study can 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. In addition, it is important that an outcomes framework recognises that, sometimes, the goal is not progress but maintaining a particular level of physical functioning or ensuring a child can continue enjoying treasured aspects of their everyday lives.

The strong interdependence between outcomes indicates that particular attention should be paid to fundamental outcomes. For instance, communication is important throughout the age range for many disabled children. Maximising a child's communication ability, and other people's ability to understand the child's communication, opens doors to opportunities to socialise and be active.

The interrelationships between the different outcomes highlight the need for multi-agency partnership in services. Areas such as friendship, skills acquisition and opportunities to make choices do not take place in one particular context. Thus the support needed to help a child achieve these sorts of outcomes needs to be provided in many contexts. In addition, failing to address one outcome can impact on other outcomes in different areas of the child's life. For example, inaccessible environments and lack of equipment to support a child's mobility were frequently mentioned as barriers to socialising, being active, learning skills and promoting independence.

Finally, 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.

Methods

Individual interviews and observation were used to obtain 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, and interviews with other informants (e.g. teachers and care staff) to collect information from perspectives other than those of parents. Ninety-five families took part in the project representing a total of 100 children. Within each group (CHN, NS, ASD and DC) there were approximately equal numbers of children in three age bands (0-6yrs; 7-11yrs; 12-19yrs). Ninety mothers and 18 fathers participated, including seven bereaved parents in the DC group. 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.

Further information

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