Progress map summary

Ensuring all disabled children and young people and their families receive services that are sufficiently differentiated to meet their diverse needs

Key research messages

Research in this area is very limited and often has a narrow focus, with few studies of interventions and their outcomes.

Very little is known about the profile of disabled children in England, with data not collected in a systematic or routine way. However:

- The most pressing problems affecting some disabled children from BME backgrounds are poverty and social disadvantage, which appear to have a greater influence on the prevalence and impact of disability, than ethnicity.

- Asylum-seeking families may not report their child's impairments for fear this may affect their immigration status. Their child's needs may therefore be hidden.

- Key workers have been shown to improve families' relationships with services, speed up access to benefits, and to reduce parents' levels of stress.

- Many parents believe that earlier intervention would have prevented the need for an away-from-home placement.

This progress map summary includes key research findings from the C4EO knowledge review. The knowledge review aims to find out about the diverse needs of different groups of disabled children and their families, and whether services are meeting these needs. It addresses the following questions:

- **What is known about the profile of disabled children in England?**

- **What are the specific needs of disabled children:**

  - **from black and minority ethnic (BME) backgrounds**

  - **in asylum-seeking families**

  - **with complex needs**

  - **living away from home?**

- **How are the needs of different groups identified?**

- **Is there evidence they experience different outcomes?**

- **What works to improve outcomes for these groups?**

The review draws on studies which interview young BME disabled people, who report strong and positive cultural identities but a high degree of consciousness of stigma associated with their disability.

Implications from the research for local service improvement

Any future collection of national data on disabled children should aim to:

- develop a clearer definition of disability, and in particular develop more refined ways of describing the restrictions experienced by disabled children

- where possible, collect the information from children themselves and not by proxy from adults.

In terms of providing services to meet the needs of different groups of disabled children, the evidence suggests that:

- many disabled children and their families have similar needs. However, meeting these needs will require different approaches, depending on individual circumstances

- achieving positive outcomes for disabled children requires an assessment and response to the whole family and consideration of all the social and environmental factors likely to have an impact.

Staff working with specific groups may require specialist skills and knowledge. However, being able to respond creatively and flexibly to meet the needs of every disabled child should be a feature of all mainstream services.

While sensitivity to culture-specific needs is required, care should be taken not to assume that all members of a particular group have the same needs.

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Challenge questions

These challenge questions are tools for strategic leaders to use in assessing, delivering and monitoring the ways in which the needs of disabled children from differentiated groups are met:

- from black and minority ethnic backgrounds

- in asylum-seeking families

- with the most complex needs

- when living away from home.

They are based on the key research messages from the knowledge review, where there is strength of evidence for effective outcomes and the strategies to support them. The challenge questions are structured using the model of whole-system change from the Every Child Matters agenda, as described by the Department for Children, Schools and Families (DCSF): integrated governance, systems, strategy, processes, frontline delivery and child outcomes. C4EO does not wish to be prescriptive by choosing one framework over others, recognising that a range of models to support systems change is available. C4EO is currently undertaking further work to identify and describe systems change models and tools which relate to this complex agenda, and may be adapted for use by strategic leaders within Children's Trusts and local authority children and family services.

The knowledge review posed questions about parents' views of service effectiveness and outcomes. This is important in the context of the Disabled Children's Service Indicator – NI054 – which will measure parents' experiences of services for disabled children in terms of information, transparency, assessment, participation and feedback. Many, if not all, of these areas are covered in the content of the progress maps and the challenge questions.

This progress map and challenge questions will be revised and updated following feedback from sector specialists, experts in the field, the regional knowledge workshops and other C4EO and sector activity.

Integrated governance

- Has your partnership developed an 'across-agency' and 'across-sector' audit of provision, to discover which services are currently accessed, or otherwise, by different groups of disabled children?

- How do you involve parents of disabled children in your partnership?

- Has your partnership considered how to offer the intensity and different types of support that may be required by certain groups of disabled children?

Integrated strategy

- How does your partnership plan services to meet the needs of different groups of disabled children?

- How do you involve parents, children and young people in planning your services?

Integrated processes

- Have you adopted commissioning and practice policies to ensure that children in residential settings can stay as near to home as possible? How do you monitor this?

- How do you find out what children and young people themselves think, particularly younger disabled children? How does your partnership support children with communication difficulties to make themselves heard?

- How do you integrate these views into your decision-making processes?

Integrated frontline delivery

- How do you train and support your workforce to include the needs of different groups of disabled children when making assessments, and formulating and monitoring care plans?

- How do you ensure parents play an equal part in identifying decisions about and meeting the needs of their child?

- Is there a key worker for all children and families receiving services from multiple agencies with complex needs?

- Do staff support asylum-seeking families with isolation, communication difficulties, housing and income maximisation, which are all key issues for this group?

- Do staff try to ensure that children needing residential care are only placed away from home when it is a positive informed choice?

Impact on outcomes

- Do you know if different groups of children and families in your local area think that services meet their needs, and what should be offered that currently isn't?

What is the issue and why is it important?

Disabled children and their families are likely to have diverse needs depending on the impairment, the family's culture, language and ethnicity, and their physical and social environment. These diverse needs may need to be met in different ways. Services need to meet individual family circumstances.

Some families are not receiving the specific services they need, which results in poorer outcomes for the children; this is a breach of their human rights.

Adapting services to better meet the needs of different groups of disabled children and ensuring greater equality in outcomes are both key objectives in a number of government policies including the Children's Plan, Every Child Matters and Aiming High for Disabled Children. The National Service Framework for Children, Young People and Maternity Services, the Children Act 2004 and the Disability Discrimination Act 2005 also require substantial improvements in the way disabled children and their families are served.

'How do you find out what children and young people themselves think, particularly younger disabled children?'

The principle of services flexibly and creatively responding to individual circumstances should be applied to every disabled child, irrespective of their background.

What does the research show?

A number of group-specific findings emerged about the needs of specific groups of disabled children: black and minority ethnic (BME) disabled children, disabled children in asylum-seeking families, children with the most complex needs and children living away from home. These are described on page 4.

Research in this area is very limited and often has a narrow focus. There are virtually no studies of interventions and their outcomes. The limitations of the studies conducted to date include:

- Views of children and adults are often mixed. Where children have been surveyed, only teenagers and young adults have been included. Virtually no information is available on the views of younger children.

- Research with BME groups is stronger on problems than needs and is focused on learning disabilities and Muslim South Asian populations.

- Studies with asylum-seeking families mainly focus on mental health, particularly psychological disorders resulting from past trauma.

- Studies of children in residential care focus on residential schools. No studies compare the outcomes of residential care with services, or compare different forms of residential care.

'The evidence suggests greater attention should be given to asylum-seeking families' current disadvantage, rather than to any past trauma.'

The profile of disabled children in England

Very little is known about the profile of disabled children in England. The data is not collected in a systematic or routine way. The information available is therefore of little value in understanding different needs or in planning and evaluating services.

The evidence that is available suggests that:

- boys outnumber girls

- across the different age bands, there are more disabled children in the 12–15 age group, and fewer in the under-five age group

- some BME groups experience a disproportionately higher (or lower) rate of certain impairments. There are many different reasons for this, not necessarily related to ethnicity.

BME disabled children

The most pressing problems affecting some disabled children from BME backgrounds are poverty and social disadvantage. These factors appear to have a greater influence on the prevalence and impact of disability than ethnicity.

The needs of most families are basically the same. Differences lie in the capacity and willingness of services to respond. BME groups experience more difficulties in referral and access to services, as well as racism, bullying and poor staff attitudes.

BME families are less aware and make less use of specialist disability services. Information about services is rarely available in a language or format that all families can understand.

The factors specifically associated with positive outcomes for this group include:

- collaborative relationships between families and services, which recognise any cultural differences as a source of strength

- language and culturally-specific information, to help families make choices and to be involved in decision-making

- a diverse workforce and provision of interpreting and translation services.

Disabled children in asylum-seeking families

Asylum-seeking families may not report their child's impairments for fear this may affect their immigration status. Their child's needs may therefore be hidden.

Many of these families have unmet care needs and struggle to cope with unsuitable housing, being isolated and communication problems.

Many factors affect the experience of these families, not just their asylum-seeking status. The evidence suggests greater attention should be given to their current disadvantage, rather than to any past trauma.

Disabled children with complex needs

Children with complex needs are defined either as a) children with severe and multiple impairments, or b) children who require support from a complex network of agencies. These may not be the same groups of children.

Children with severe and multiple impairments commonly experience communication difficulties, lack of social contact and lack of consultation over their preferences. However, this is not unique to this group.

Children who require support from multiple agencies need:

• an effective key worker who provides support and helps with accessing services. Key workers have been shown to improve families' relationships with services, speed up access to benefits, and to reduce parents' levels of stress

• effective case coordination – this in turn depends on effective collaboration between agencies, and between families and professionals, as well as ensuring the child participates in decision-making

• more effective transition planning between children's and adults' services. Children with complex needs often require life-long support and experience difficulties in accessing services as young adults.

Disabled children living away from home

The largest numbers of children in residential homes are teenage boys diagnosed with emotional and behavioural difficulties, children with more complex needs, and children with very challenging behaviours. A disproportionate number are from lone-parent households.

Some disabled children in residential homes receive poor-quality care. The main problems they experience are lack of social contact, communication difficulties and lack of choice. Some local authorities fail to protect and promote disabled children's welfare, even though they are more vulnerable to abuse.

The child's needs and preferences are not often considered. The decision to place them in a residential home is frequently due to inadequate local service provision, rather than a positive choice.

Residential care can be a valuable service for some disabled children. Social relationships, independence and life skills can be improved. However, even in the best cases, most parents want residential placements closer to home. Many children would also rather live at home. Many parents believe that earlier intervention would have prevented need for an away-from-home placement.

What's missing from the evidence base?

There are major gaps in the evidence base because of the lack of:

• government-sponsored cross-sectional and longitudinal surveys designed specifically to collect data on childhood disability

• studies designed to test or compare interventions for different groups of disabled children.

Views of key stakeholders

Children and young people from BME backgrounds do not think that poverty is more of an issue for them than for other groups of disabled children, but asylum-seeking children report that it is a pertinent issue for them. The level of benefits that these families receive is low and means that nutrition and health may be compromised.

Children with communication difficulties think that their choices are particularly limited and that they need extra support to make their wishes known.

Children living away from home feel particularly vulnerable and that they are not respected as much as other groups of children. They find it difficult to defend their point of view and that they do not always get support to do this.

'Children with communication difficulties think that their choices are particularly limited and that they need extra support to make their wishes known.'

Further reading

Department for Children, Schools and Families (2004) *Children Act 2004* (available at **www.dcsf.gov.uk/childrenactreport**)

Department for Children, Schools and Families (2004) *Every child matters* (available at **www.dcsf.gov.uk/everychildmatters**)

Department for Children, Schools and Families (2007) *Aiming high for disabled children* (available at **www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/AHDC**)

Department for Children, Schools and Families (2007) *The children's plan: building brighter futures* (available at **www.dcsf.gov.uk/childrensplan**)

Department of Health (2004) *National service framework for children, young people and maternity services* (available at **www.dh.gov.uk**)

Newman, T (forthcoming 2009) *Ensuring all disabled children and young people and their families receive services which are sufficiently differentiated to meet their diverse needs*, (available at **www.c4eo.org.uk**)

Office of Public Sector Information (2005) *Disability Discrimination Act 2005* (available at **www.opsi.gov.uk**)

What is a progress map summary

The progress map (a web-based tool) is being developed by C4EO to provide easy, interactive access to the best available knowledge for children's services. Printed progress map summaries include key research findings from the C4EO knowledge review, challenges for children's services and key stakeholders' views. This is version 1 on this topic; there will be two more progress map summaries as knowledge (particularly from practice) develops during the course of C4EO's work on the disability theme. The progress maps and knowledge reviews can be found at **www.c4eo.org.uk**

Centre for Excellence and Outcomes in Children and Young People's Services (C4EO)

Funded by the DCSF, C4EO has been established to help transform outcomes for children, young people and their families. It will do this by identifying and coordinating local, regional and national evidence of 'what works' to create a single and comprehensive picture of effective practice. To find out more and to look at our resources, please visit **www.c4eo.org.uk**