

Progress map summary



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

Number 4 Version 1

June 2009

Improving the well-being of disabled children (up to age 8) and their families through increasing the quality and range of early years interventions

Key research messages

The most effective interventions:

- are tailored to the child and are family-centred
- take place in natural homely surroundings and take the family's environment and resources into account
- are structured, and are the right intensity and duration
- aim to develop parent-child relationships as well as support child development.

High-quality pre-school education can reduce the need for special education at primary school, especially for the most disadvantaged children.

Key workers improve the quality of life of families with disabled children by ensuring quicker access to support and benefits, helping to reduce parents' stress.

Services can compensate for social disadvantage.

The most effective services are seamless, coordinated and easy to navigate.

This progress map summary includes key research findings from the C4EO knowledge review. This knowledge review examines the evidence of the effectiveness of early years interventions for disabled children. It addresses the following questions about early years interventions:

- Do they bring improvements in outcomes for children and families?
- Which are most effective, for which groups of children?
- Which do parents think are most effective?
- What factors/conditions are necessary for successful outcomes?

There is considerable evidence on what parents want, although much less on children's views. A consistent message is that parents feel more competent and confident when they receive family-centred services delivered by skilled, knowledgeable and efficient professionals. Mothers appear to undertake the bulk of the caring, and key worker systems reduce their stress levels.

Parents and children alike want better information about service availability and appreciate web-based information – if parents help to develop the online resources they are likely to be better targeted.

Implications from the research for local service improvement

Early years intervention should:

- **take place in ‘natural’ surroundings**, and be delivered through a seamless and integrated inter-agency service
- generally, **be characterised by structure, intensity and duration**
- use **evidence-based behavioural programmes**
- **deliver high-quality pre-school education** for all disabled children, which research suggests can reduce subsequent special educational needs (SEN) diagnoses in primary school
- **support parents** by offering family-centred early interventions that are sensitive to the environment and capacity of the child and their family
- be cautious about large-scale investment in new approaches without **clear evidence of improved gains**
- **use electronic media** to deliver teaching packages and information to parents and children
- **introduce key worker services**, particularly for those receiving multiple services as these appear to produce better family relationships, quicker access to benefits and reduced parental stress
- **ensure that services address child–parent relationships** as well as narrower child developmental goals
- **integrate early years intervention** for disabled children into an overall strategy for improvement in children’s services
- **provide more intensive services** to compensate for reduced functioning in families caused by family structure, social disadvantage or parental impairment.

Challenge questions

These challenge questions are tools for strategic leaders to use in assessing, delivering and monitoring the effectiveness of early years interventions in services for disabled children. They are based on the key research messages from the knowledge review. 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. We are 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 is the first version and 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

- Are there effective performance management systems in place across partnerships?

- Do you have partnerships in place to identify families with disabled children at an early stage, and do you use this data to plan, organise and deliver services?
- Has your partnership developed a simple organisational service model, which is straightforward to navigate?
- Are your services for disabled children fully incorporated into your wider children's services approach?
- Do you have integrated processes for early identification of families that would benefit from pre-school interventions?
- Do you have a strategy to ensure that staff keep up to date with and use (electronic) digital media to provide families with education packages and information?
- Do you ask parents about their satisfaction levels and how they would like to see services develop and improve?

Integrated strategy

- How do you ensure that there is early identification of, and services offered to, disabled children and their families? How do you know it is effective?
- Have you ensured that you allocate additional resources so that disadvantaged families receive the intensive support they need?
- Do you have key staff (a champion, a lead member and commissioners) in place?
- Have you developed criteria for services that are structured, and of the intensity and duration that families need?
- Do you provide high-quality pre-school education to all disabled children?
- Do you have measures in place to assess new interventions and programmes against robust evidence of improved outcomes for disabled children and their families?

Integrated processes

- Have you developed effective and sustainable key worker systems?
- Do you have a needs assessment process for disadvantaged families to ensure they receive the range and intensity of services required?

'Do you have a needs assessment process for disadvantaged families to ensure they receive the range and intensity of services required?'

Integrated frontline delivery

- Are staff trained and supported to deliver a key worker system?

How do you ensure that:

- Staff from all relevant agencies/professions are engaged and working together?
- Staff include a focus on parent satisfaction, promoting child-parent relationships and family-centred services, as well as child developmental goals?
- Staff offer parents information on specific conditions?
- Staff provide services in 'natural' homely and familiar settings?

Impact on outcomes

- How do you know that the steps you have taken are having a positive impact on children and families in your local area?
- Have you asked children and parents whether services are making a difference to them?
- Have you put measures in place to determine how services are making a difference to the lives of disabled children and families in your local area?

What is the issue and why is it important?

More children with complex needs are now surviving early childhood, and improvements in health care also mean that children are being diagnosed at a younger age. This is increasing the demand for early interventions. Early interventions are actions which are taken early in life, or at diagnosis or onset.

It is essential that early interventions take place because they can lead to better long-term outcomes, both for parents and for children. By improving child development and preventing crises, early interventions may also reduce any subsequent demand for more costly specialist services later on.

Currently six per cent of children under five have a disability or long-term health need. The most common are speech and language delays, learning disabilities, autistic spectrum disorders, epilepsy, and hearing and visual impairments.

Early interventions include support and services provided by a range of agencies, which means that there needs to be effective multi-agency partnership work, in particular between local authorities and primary care trusts (PCTs). Early identification, rapid response and coordinated services are the cornerstones of DCSF strategy.

In England, Early Support (ES) is the DCSF/Department of Health flagship programme that is aiming to improve multi-agency services to families with very young disabled children. The evaluation of the ES Pathfinder programme identified six priorities:

- better initial assessment of need
- better coordination of multi-agency support
- better information and access for families
- improved professional knowledge and skills
- service review as a means to promote service development

- partnership across agencies and geographical boundaries.

The ES Pathfinders also tested guidance on how to coordinate and deliver early interventions, as well as working in partnership with families.

This knowledge review aims to provide additional evidence of 'what works' to support the forthcoming mainstreaming of the ES programme.

What does the research show?

Research in this area has not yet identified which interventions work best for which groups of families. Most research has focused on pre-school children. Few studies have compared different approaches, and of those that have, most have only found modest differences. Most interventions have been trialled with a wide range of children,

leading to a wide variation in outcomes, and inconclusive results.

The research also lags behind changes in practice. The recent shift to a family-centred approach requires new forms of evaluation that assess the impact on parents, children and the family unit. However until now, most studies have only assessed the impact on child development.

The research evidence is strongest in identifying the characteristics of services that parents most value. However, professionals do not always share the same views as to which service outcomes are most important.

Key workers improve the quality of life for families with disabled children by ensuring quicker access to benefits and support, and reducing levels of parental stress. Effective key workers have good counselling and communication skills, are able to work in partnership with parents and children and also respect their expertise. They also have specialist knowledge of different conditions. Key workers therefore should have regular training as well as high-quality supervision and support.

'Key workers should have regular training as well as high-quality supervision and support.'

Web-based information offers parents instant, 24-hour support, that can be usefully focused on specific issues or problems.

High-quality pre-school centres improve children's cognitive development and reduce the need for special education at primary school – especially for the most disadvantaged groups of children.

Neonatal interventions for low birth weight babies are only effective in the short-term – because other associated factors, such as poverty and social exclusion, may have a far greater impact than any disability or impairment.

Early years interventions are not meeting the needs of the most disadvantaged. The greatest benefits are experienced by families with the highest levels of social capital, education and income. Therefore services need to compensate for social disadvantage.

Successful approaches to service development:

- integrate the improvement of early years interventions into a strategy for improving children's services as a whole
- consider philosophy and principles, rather than just eligibility
- aim for simplicity in service design and partnership arrangements.

Limitations of the evidence base

While there is substantial evidence that early years interventions improve outcomes for children and families, it is still uncertain as to:

- how long the gains last
- whether the gains are a direct or indirect result of the intervention
- whether simpler interventions could deliver as much or even more benefit.

Most of the research focuses on children aged 0 to three. There is little information on interventions for children aged five to eight.

Family studies are primarily concerned with mothers. Relatively little information is available on fathers.

Most of the evidence comes from studies in the USA, though more UK studies are emerging.

Some small studies of poor quality report overly positive findings. These are not replicated by more rigorous research. Some approaches still require more scrutiny to substantiate the claims that have been made. Large-scale investment in new approaches therefore requires robust evidence of genuine benefit.

Many of the most successful studies were undertaken as pilots and may have been disproportionately well-staffed and resourced. It may be a challenge to replicate these results in mainstream practice.

Views of key stakeholders

Based on the research evidence, parents value services that:

- provide support at the time of diagnosis
- provide access to information and advice
- make assessments which consider and meet whole-family needs
- set targets and identify developmental milestones
- provide evidence of achievements
- offer ideas and suggestions for activities
- develop parents' skills
- ensure rapid and easy access to services that are joined-up and coordinated
- provide information to help parents make informed decisions about treatment options
- enable parents, especially mothers, to enter or return to work
- reduce the time for the 'statementing' process.

'Web-based information offers parents instant, 24-hour support, that can be usefully focused on specific issues or problems.'

Further reading

Mackin, H., McEwen, J., Newman, T. and Slowley, M. (forthcoming 2009) *Improving the well-being of disabled children (up to age 8) and their families through increasing the quality and range of early years interventions*, London: C4EO (available at www.c4eo.org.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