DISABILITY

KNOWLEDGE REVIEW 1

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

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

The Centre for Excellence and Outcomes in Children and Young People's Services (C4EO) identifies and coordinates local, regional and national evidence of 'what works', to create a single and comprehensive picture of effective practice in delivering children's services. Using this information, C4EO offers support to local authorities and their children's services partners, working with them to improve outcomes for children, young people and their families.

It is focusing its work on nine themes:

- Early Years
- Disability
- Vulnerable (Looked after) Children
- Child Poverty
- Safeguarding
- Schools and Communities
- Youth
- Families, Parents and Carers
- Early Intervention, Prevention and Integrated Delivery

C4EO works with a consortium of leading national organisations: the National Children's Bureau, the National Foundation for Educational Research, Research in Practice and the Social Care Institute for Excellence.

The Centre is also supported by a number of strategic partners, including the Improvement and Development Agency, the Family and Parenting Institute, the National Youth Agency and the Institute of Education.

There is close and ongoing cooperation with the Association of Directors of Children's Services, the Local Government Association, the NHS Confederation, the Children's Services Network, the Society of Local Authority Chief Executives, Ofsted and the regional Government Offices.

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

Tony Newman

Jessica McEwen

Helen Mackin

Martha Slowley

(Barnardo's Policy and Research Unit)

Data annexe and data appendix by:

Marian Morris

Karen White

Caroline Bergeron

(National Foundation for Educational Research)

Barnardo's

BELIEVE IN CHILDREN

Contents

Acknowledgements

Summary

Aiming high for disabled children (HM Treasury and DfES 2007) has stressed the need for coordinated support, preventative health services, material and emotional support for parents and siblings and the overall improvement of practice. This knowledge review tells us what works in improving the wellbeing of disabled children (up to age 8) through effective early years interventions. It is based on a rapid review of the research literature involving systematic searching, analysis of key data, validated local practice examples and views from people who services and providers. It summarises the best available evidence that will help service providers to improve services and, ultimately, outcomes for children, young people and their families.

Key messages from our knowledge review

Managers working at a strategic level should:

- ensure that early years services consider the needs of the whole family and are delivered in 'natural' surroundings, through a seamless and integrated inter-agency process

- develop services that are characterised by structure, intensity and duration so that gains made by children are built on and sustained

- favour programmes which the current evidence base indicates are most likely to result in positive child outcomes

- prioritise high-quality pre-school education which the evidence base suggests can reduce subsequent acquisition of an SEN label in primary school.

- support parents by delivering family-centred early interventions that are sensitive to the environment and capacity of the child and their carers, with special attention to the needs of mothers

- be cautious about large-scale investment in new approaches unless there is clear evidence of improved gains of sufficient magnitude to justify the resources and time demanded

- use electronic communication media to deliver teaching packages and information to parents and children

- introduce comprehensive key worker services; these are associated with better family relationships, quicker access to financial benefits and reduced parental stress

- ensure that services address child–parent relationships as well as addressing specific child developmental goals

- integrate early years intervention for disabled children into an overall strategy for improvement in children's services.

Who are the key stakeholders?

- disabled children aged under 8 years
- parents and carers of disabled children aged under 8 years
- professionals involved in the planning and delivery of services to young disabled children including those working in:
  - early years centres
  - child care partnerships
  - voluntary, independent and private sector organisations
  - children's centres
  - nurseries, schools and playgroups
  - both specialist and mainstream local authority children's services
  - primary and specialist health care services
- policy makers.

Their contributions are valuable in the process of improvement

- **Disabled children under 8 years** require effective and well-timed interventions which should be delivered in an appropriate location. As well as attention to any developmental delays, interventions should prepare children for entry to educational settings by addressing barriers to social interaction and communication with peers. The intensity of an intervention should be proportionate to the extent of need.

- **Parents and carers of young disabled children** require interventions that anticipate problems as well as responding to crises.

  "One of the difficulties faced by parents in the early years is the delay in service provision and the 'wait and see' approach taken by the medical profession and some early education centres. Mostly parents know when their child is not progressing at an average rate and they need professionals to take note of what the parent is saying and act on it." (Mother)

  They need interventions that address the needs of the whole family, not just the disabled child, and which are integrated and seamless. Mothers remain, in most cases, the primary carers and their engagement is vital to their children's development. Effective early years services will have a positive impact on parental, and especially maternal, mental health and capacity to cope.

- **Professionals** must ensure that early years services for disabled children are not developed in isolation but are embedded in and considered alongside other strategic agendas in health, education and mainstream Children's Services. As more affluent and better educated families tend to benefit more from early years services, particular attention should be paid to both assessment and service delivery to more disadvantaged families of young disabled children. Early intervention is not a substitute for later or ongoing intervention – both will often be needed.

- **Policy makers** must ensure that investments are made in approaches which are based on the best evidence for effectiveness, and to remove barriers to integrated working which divert organisational energy away from the improvement of service delivery to families. Action to address broader social issues, including poverty, housing and transport, is necessary alongside direct services to children and their families.

What data is available to inform the way forward?

Local and national datasets are publicly available on the prevalence of disability, including by background characteristics (such as age, gender and ethnicity). Meanwhile, the Disabled Children's Services National Indicator (NI 54[1]) measures parental experiences of services provided to disabled children, based on a national sample survey of parents. NI 54 results became available from 2008–09. There are also datasets relating to the social and living circumstances of disabled children and their families. These datasets provide useful monitoring data that can be tracked over time, such as on the prevalence of disability.

At present, however, there is little publicly available information about the impact of early interventions on improvements in the wellbeing of disabled children (up to 8) and their families.

C4EO's interactive data site enables local authority and health service managers to evaluate their current position in relation to a range of key national indicators, and to easily access publicly available comparative data on disabled children.

The evidence base

Parts of the evidence base are strong, especially in relation to the overall efficacy of early years interventions and their effectiveness in relation to some specific impairments. There are large numbers of high quality studies, including randomised controlled trials and systematic reviews which, with some exceptions, suggest that we can be confident that well managed and co-ordinated early years services to disabled children and their families can produce very positive results.

However, some gaps remain, notably an absence of:

- **information on children from five to eight years** – the large majority of the studies address the situation of pre-school children

- **robust data on outcomes for parents or other family members** – the size of this evidence base does not reflect the importance of overall family welfare to the wellbeing of the disabled child

- **data on fathers** – the large majority of studies on parental views feature the opinions and experiences of mothers

- **empirical studies based on UK sources** – the highest quality studies are disproportionately of North American origin

- **long-term outcome studies** – it is not clear, in some areas, the extent to which gains made in the pre-school period are retained in later childhood and early adulthood

- **studies that compare the effectiveness of different approaches** – some specific impairments may be treated with a number of different approaches, the respective advantages of which are often unclear

- **studies that explain why apparently similar children experience different outcomes** – not all children benefit equally from interventions and more knowledge is needed to ensure that each child receives a service that is tailored to their specific developmental needs.

Review methods

This knowledge review is the culmination of an extensive knowledge gathering process. It builds on a scoping study and research review, which are available on the C4EO website.

Research literature was identified through systematic searches of relevant databases and websites, recommendations from our Thematic Advisory Group, and considering studies cited in identified literature ('reference harvesting'). The review team used a 'best evidence' approach to systematically select literature of the greatest relevance and quality to include in the review. This approach attempts to eliminate bias in the selection of literature, to ensure that the review's findings are as objective as possible.

Data contained within the data annexe were obtained by a combination of search methods but primarily by obtaining online access to known Government publications and access to data published by the Office of National Statistics.

The review also contains examples of local practice sent in from the sector, which have been assessed and validated by specialists in the field of child disability. The full versions of all of the practice examples contained within this review, and those published since the review was written, are available on the C4EO website.

Evidence has also been gathered from service providers during discussion groups at C4EO knowledge workshops. Evidence from service users was collected via consultation with a small number of disabled children and young people, and parents of disabled children and young people. Service users and/or providers are contributors to many of the studies included within the review too.

1 Introduction

This review aims to draw out the key 'what works?' messages on improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities. It addresses four questions, which were set by the C4EO Theme Advisory Group (TAG), a group of experts in disability policy, research and practice. These questions are:

- Do early years interventions lead to improvements in outcomes for disabled children and their families?
- Which early years interventions are most effective for particular groups of disabled children?
- Which features of early years interventions are considered to be most effective by parents?
- Which factors or conditions are required (e.g. factors relating to the parent, the child and the intervention) for successful outcomes for disabled children, young people and their families?

Reviews on improving disabled children and young people's access to positive activities, and ensuring that services are sufficiently differentiated, are also available on the C4EO website.

The reviews are based on:

- the best research evidence from the UK – and where relevant from abroad – on what works in improving outcomes for children and young people
- the best quantitative data with which to establish baselines and assess progress in improving outcomes
- the best validated local experience and practice on the strategies and interventions that have already proved to be the most powerful in helping services improve outcomes, and why this is so
- service user (parent and young people) and provider views on 'what works?' in terms of improving services and outcomes.

C4EO has also commissioned primary research into the effectiveness and costs of early identification and intervention for sleep problems and the effectiveness and costs of different modes of delivering behaviour management interventions to parents of disabled children.

C4EO will use the reviews and research to underpin the support it provides to those people working in the children's sector, to help them improve service delivery, and ultimately outcomes for children and young people.

Definitions of key terms

The following definitions were agreed by the Theme Advisory Group:

- Disability is defined in the Disability Discrimination Act 1995 as: 'a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities' (GB. Statutes 1995) and in the Children Act 1989 (GB. Statutes 1989): '…blind, deaf or dumb or suffers from mental disorder of any kind, or is substantially and permanently handicapped by illness, injury or congenital or other such disability as may be prescribed'.

- As this review focuses on younger children, the issue arises of risks to normal development that may or may not result in long-term impairment. Consequently, an additional definition has been used, that issued by the Department for Education and Skills and the Department of Health for the Early Support Pilot Programme: 'A child under 3 years of age shall be considered disabled if he/she: (i) is experiencing significant developmental impairment or delays, in one or more of the areas of cognitive development, sensory or physical development, communication development, social, behavioural or emotional development; or (ii) has a condition which has a high probability of resulting in developmental delay.' The second part of this definition justifies the review of strategies to moderate the impact of low birth weight and other neonatal risk factors for developmental delay.

- An 'early intervention' is defined for the purposes of this review as a service delivered to children from birth to eight years old, focusing on generic support to the child and family and excluding medical interventions and therapies and interventions for sleep and behaviour problems.

- The term 'outcomes' is interpreted broadly in relation to the five Every Child Matters outcomes: be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic wellbeing.

Types of evidence used

The research included in this review was identified through systematic searching of key databases, reference harvesting or recommendations from the TAG. All research included has been appraised to ensure that the evidence presented is the most robust available. The review also contains examples of local practice that have been gathered from the sector and assessed as having a positive impact on outcomes by specialists in disabled children (See Appendix 5 for C4EO's Validated local practice assessment criteria.)

Evidence has also been gathered from service providers during discussion groups at C4EO knowledge workshops. Meanwhile, evidence from parents, carers and young people has been collected via group interviews (see Appendix 6 for more details of the process). Data contained within the data annexe was obtained by a combination of search methods but primarily by obtaining online access to known Government publications and access to data published by the Office of National Statistics.

The methodological strength of outcome studies was guided by the Maryland Scientific Methods Scale (Farrington *et al* 2002), though it should be noted that few studies were located that met Level 4 or Level 5 criteria (see Glossary of research terms). The higher the level, the more likely it is that the intervention described has resulted in the results reported.

Level 1   –   Correlation only

Level 2   –   Pre-post test only

Level 3   –   Controlled trial + pre-post test

Level 4   –   Controlled trial + pre-post test, replicated, with controls for extraneous variables

Level 5   –   Randomised controlled trial

Strengths and limitations of the review

Strengths of the review include identifying the best available evidence from research and national datasets to inform specific questions; comprehensive and documented searching for relevant information; an analysis of the quality and strength of evidence; and guidance from an advisory group on the issues of greatest importance in early childhood research, policy and practice.

Limitations of the review include the very tight deadlines which the review had to meet, which limited the ability of the team to extend and develop the evidence base through reference harvesting and hand searching, that the review was limited to English-speaking countries only and the limited numbers of parents, carers and young people who were given the opportunity to comment on the review conclusions.

2. Context

It should be noted that this review was written before the current coalition government was elected in May 2010. Contemporary early years intervention strategies are intended to identify disabled children or children at risk of disability as early as possible, deliver remedial support and equalise access to support services. The evidence that early screening, diagnosis and intervention leads to better long-term outcomes has been the primary driver for legislative, technical and organisational change. While the importance of early intervention applies to children of all ages, the Department for Children, Schools and Families (DCSF, now the Department for Education) and the Department of Health (DH) place particular emphasis on rapid and effective responses to child disability by local authorities and primary care trusts (PCTs) in the early years.

Aiming high for disabled children: better support for families (HM Treasury and DfES 2007) highlights the need for coordinated support at key transition points, services that can:

- prevent deterioration of health, stress on parents and siblings, and reception of children into care

- provide equipment, short breaks, sleep programmes and support behavioural management

- enable the sharing of knowledge and benchmarks of good practice (pp 35–36).

Similarly, *Aiming high for disabled children: delivering improved health services* (NHS Confederation 2009) stresses the importance of high quality health services to disabled children and their families – some 18 per cent of England's children. Key areas identified for improvement in 2008/9 to 2010/11 are palliative care, short breaks, community equipment and wheelchairs (p 4).

Access by disabled children to child care has also been identified as a national priority. The Childcare Act 2006 (England and Wales. Statutes 2006) places a duty on local authorities to have particular regard to provision of child care places to disabled children, an initiative currently being piloted through the *Disabled Children's Access to Childcare Strategy (DCATCH)* (DCSF 2009a). Recent statutory guidance issued to Children's Trusts has stressed the need to prioritise disabled children, especially with regard to the provision of information, consultation and support (DCSF 2010a). As with all children, safeguarding is an ongoing priority[2].

Early identification, rapid response and coordinated services are also the cornerstones of the special educational needs (SEN) strategy (DfES 2004) and for children facing more general difficulties (DCSF 2010b). The Disability Discrimination Act 1995 (GB. Statutes 1995) requires early years settings to make reasonable adjustments in order not to treat disabled children less favourably. Similar duties

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[2] For more information, see *http://www.c4eo.org.uk/themes/safeguarding/default.aspx?themeid=11&accesstypeid=1*

apply to all schools (DfES 2005). Practice guidance for professionals working with disabled children under 3 years old expects the needs of most disabled children to be met within the family setting.

Historically, substantial numbers of children with impairments have remained undetected prior to school attendance. These children are disproportionately from families with higher levels of social disadvantage. As well as impairments with a clear physical or neurological origin, other impairments which cause considerable challenges to both families and services – notably attention deficit hyperactivity disorder (ADHD) – are an increasingly important target for early years services. The average size primary care trust (population 340,000) will have:

- 7,800 children with asthma, 300 with epilepsy, 100 with diabetes, 35 with sickle cell disease and 300 with cystic fibrosis

- 7,500 5-15 year olds with a diagnosable mental disorder

- 4,000 with a physical disability, 130 of whom will require wheelchair services

- just under 1,000 children with Autistic Spectrum Disorder (ASD).

(DH and DCSF 2009 p 65)

Sure Start local programmes, serving children under 4 years old, report the highest incidence of need as being speech delay, followed by behaviour issues, autistic spectrum disorders (ASD), development delay, hearing or visual impairment and Down's syndrome (Pinney 2007).Some factors associated with disability are more common, sometimes substantially, in certain groups, particularly those affected by serious social disadvantage, for example, low birth weight (less than 2,500 grams). These babies are almost four times more likely to have a special educational need (SEN). A specific disability may be less damaging to a child than poverty and related issues such as poor housing, low parental educational standards, income deprivation and social exclusion.

In England, Early Support is the Department for Children, Schools and Families (now Department for Education) and Department of Health's flagship programme for the improvement of multi-agency services to families with disabled children from birth to 3 years old. An evaluation of the Early Support Pathfinder programme identified a number of priorities, including better initial assessment of need, coordination of multi-agency support and improved professional knowledge and skills (Young *et al* 2008). Particular factors driving the concern for effective early support are the increase in numbers of children with complex needs surviving the neonatal period combined with our increased capacity to detect and diagnose impairments earlier (University of Manchester and University of Central Lancashire 2006). For example, median age of diagnosis of deafness has been lowered over the past decade from almost two years to three months (DfES and RNID 2003). These issues are embedded in two key policy documents: *Together from the start: practical guidance for professionals working with disabled children (birth to third birthday) and their families* (DfES and DH 2003), and *Developing early intervention/support services for deaf children and their families* (DfES and RNID 2003). Service provision should include healthcare, educational and therapeutic support, culturally appropriate emotional and practical

support to the family, access to childcare and opportunities for the family to lead a 'normal' life (DfES and DH 2003 pp 9–10). These principles are replicated in guidance for children with SEN (DfES 2004) and children with ASD (DfES and DH 2002).

The principles of the various statutory guidelines and instruments driving early years policy for disabled children are, to a large degree, consistent. However, as early years policies primarily focus on children from birth to three years old, the knowledge base across the full age parameters of this review (birth to eight years) diminishes as children grow older.

Finally, there has been substantial investment in, and commitment to, parent participation in the generation and scrutiny of policy and practice at all levels. This process is seen as an essential vehicle to ensure that future support structures are more closely focused on the needs of families.

3. The evidence base

Compared to many other fields of child welfare, the evidence base supporting early intervention with disabled children is relatively strong. There are large numbers of high quality studies, including randomized controlled trials and systematic reviews which provide a high degree of confidence that some approaches are likely to be more successful than others. The initial scoping review identified 566 possible relevant sources. This was reduced to 313 following an examination of study abstracts and further reduced by the application of the agreed study quality criteria (Farrington *et al* 2002; Spencer *et al* 2003). With the addition of a number of harvested studies and TAG recommendations, the final number of studies and reports cited in this review is 95. Of these, 59 are outcome studies which address the four specific questions posed by the review, though it should be noted that several of these studies are themselves reviews of substantial bodies of relevant literature and the remainder are policy documents and practice guidelines. Fifty one per cent of these outcome studies were carried out in the UK, 35 per cent in the USA and the rest in other countries, primarily Canada, Australia and Scandinavia.

In terms of answering the questions reviewed, we can respond as follows.

Do early years interventions for disabled children and their families actually lead to improvements in outcomes?

While there is substantial evidence of improved outcomes for children and families resulting from early years intervention, uncertainty remains over:

- the extent to which gains persist

- whether gains are a direct or indirect consequence of the intervention

- whether more or equally important gains can be achieved with interventions requiring lower levels of technical expertise

- the optimum age at which an intervention should commence.

Despite early years intervention generating a substantial research literature, clear evidence linking specific outcomes, interventions and populations remains elusive. For some populations, notably children born very prematurely, gains resulting from early intervention have been disappointing. Early years intervention also depends on accurate early diagnosis. Where diagnostic techniques are less well-developed, the costs and benefits of intervening before the type of degree of impairment has been established with any degree of certainty are not always clear.

Which early years interventions are most effective for particular groups of disabled children?

The evidence base suggests that the most effective responses:

- achieve a balance between technique, teaching style, and sensitivity to the child's environment, and are delivered in an appropriate location

- use electronic communication media to deliver teaching packages and information in format- and audience-specific modes

- include family-centred interventions that accommodate the reality of the child's environment and can be delivered with a minimal level of demands on parents

- utilise key worker services, which are associated with better family relationships with services, quicker access to benefits and reduced parental stress

- moderate the risk of social exclusion by helping children communicate with their peers

- invest in evidence-based early years intervention approaches which have been proven to result in positive gains for children and families.

Which features of early years interventions are considered to be most important by parents?

There is often a lack of congruence between outcomes studies and user views in some early years studies, especially early years support that has just focused on measurable child centred outcomes. This is not unusual in health and social research. High levels of parental satisfaction may only partly be related to the successful accomplishment of child-focused goals. Family-focused, compared to child-focused approaches, need to accommodate different perspectives and have multiple measurements of success. Nonetheless, a consistent message was that parents valued family-centred services delivered by skilled, knowledgeable and efficient professionals, especially where key workers were part of the overall package and maternal reduction in stress was achieved. One point of contention between clinicians and parents is diagnostic timing; parents sometimes report being aware of a developmental delay but having difficulty eliciting a sufficiently urgent professional response.

Overall, we know a great deal about what service features are valued by parents. However, parental and professional views on effectiveness may continue to vary as the parties may not necessarily share the same perspective as to what constitutes the most important outcomes.

Which factors/conditions are required for successful outcomes for disabled children, young people and their families?

The evidence base is consistent in that many studies conclude that both involvement and outcomes in early years intervention services is inversely related to social capital – better educated, richer families with higher levels of informal social support and positive family functioning received more effective support and reported better outcomes. Families who have greater difficulty negotiating the involvement of services will benefit more by pro-active needs assessments than just being asked what they want (Mahoney and Filer 1996).

The biggest gaps noted in the evidence base include:

- information on children aged 5–8 years – the large majority of studies concern infants

- robust data on outcomes for parents or other family members – the majority of data is child centred

- data on fathers – studies on 'parents' can be more accurately described as studies of mothers

- UK empirical studies – these are emerging, but the database is still shallow; the main source of data at present is from studies conducted in the USA

- long-term outcome studies - particularly those that can separate the effects of early intervention from social disadvantage

- studies that compare different approaches and evaluate their respective impact

- studies that explain the reasons for variations in outcomes within the same intervention groups.

Clear linkages between specific approaches and specific conditions are only partially visible in the research literature and major advantages of one approach over another emerge infrequently. The majority of highly positive findings derive from model programmes which may be disproportionately well staffed and resourced – the challenge remains to replicate these results in mainstream services. Overall, the aspiration to achieve a menu of impairment- or group-specific interventions which services may confidently use to choose the optimum approach – a frequently stated goal in both the US and UK research literature – is not yet a reality.

A further gap in the evidence base – our limited knowledge of effective strategies to moderate sleep disorders – is being addressed through primary research commissioned by C4EO from the Social Policy Research Unit (SPRU) at the University of York[3].

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[3] For more information, visit *http://www.c4eo.org.uk/disabilityresearch/default.aspx?themeid=8&accesstypeid=1*

4. What do service users and providers tell us about what works?

The experiences of parents and carers and those providing services to children and their families have much to add to our knowledge of 'what works' in narrowing the gap in outcomes for young children through effective practice in the early years. Service users and providers contribute to much of the research evidence presented in subsequent sections. However, it is important to remember that this section is drawn from group discussions with parents and carers and, separately, with local service providers, to discuss key issues affecting children's learning in the early years. It is therefore based on their experiences and opinions rather than the research evidence on which the rest of this review is based.

Stakeholder views were gathered and summarised through a Parents and Carers Panel, two focus groups and consultation with disabled children and young people and a series of knowledge workshops that were held to discuss the findings that emerged from the *C4EO Disability Research Review #4* (Newman *et al* 2009). Composition of the delegates is described in Appendix 6.

The key messages emerging from this dialogue:

- **Parents and carers** want to receive holistic, flexible and integrated services that are prevention- not crisis-driven.

- **Young people** want early years services to adopt a 'can-do' rather than a 'can't do' approach to child disability and to focus on growth potential rather than risk factors.

- **Professionals** emphasise the need to embed and link early years services for disabled children into other strategic agendas in health and education.

Views from parents and carers

The research literature on parental views, as discussed in other sections of this report, primarily means maternal views. Feedback from parents on the review findings replicated this lack of balance. The Parents and Carers Panel comprised 19 parents of disabled children, 4 fathers and 15 mothers. Of the 27 substantive comments made by parents summarised below, only three were from fathers.

Messages from the Parents and Carers Panel were as follows:

Services should focus on the family, as well as the disabled child. Services should be individualised, locally based and support the whole family.

> *'I agree with the statement that whole family interventions are preferred and that parents are satisfied with sensitive and responsive support … this may not necessarily bring about a major impact on developmental progress, but it is certainly fundamental to the parent's ability to 'cope' and this emotional stability must surely have benefits for the disabled child.' (Mother).*

Evidence and measures of success should be appropriate. Concern was expressed that highly motivated and well resourced groups promoting a particular approach – especially based on behavioural principles – can achieve a position of domination at the expense of approaches based on relationships that are harder to evaluate.

Integrated services are valued. Whether described as a key worker service or not, parents were clear about the stress and frustration caused by multiple and repetitive contacts with services and how much integrated services are valued – where they exist.

Disclosure should be sensitive and appropriate: Where poorly handled, disclosure of a child's impairment may cause serious long term harm to the parent-child relationship.

Service should be inclusive: Pre-school services still have a long way to go in managing the integration of disability and difference in their environment

Parents' views on their personal experience of the quality and range of early interventions varied widely, as one would expect. Among the comments made were:

- Pre-school settings are well informed and pro-active at including people and helping parents and carers.
- Key worker systems are non-existent in some areas.
- There is poor or non-existent provision for disabled children at many nurseries.
- Parents have to fight for support that should be an automatic entitlement. Success may depend on being well educated or having a strong advocate or family network.
- Child Development Centres do well at diagnosing conditions or providing continuing care/advice to families. Their specialist nursery provision can provide outreach into mainstream early years settings and assist in the transfer of a child into primary school.
- Child Development Centres in the same areas seem to run slightly differently and speaking to parents, experiences differ wildly. There seems to be a need to identify best practice and roll this out consistently.
- More Children's Centres with more organised activities for disabled children are needed, also local authority holiday schemes.

Comments by parents on most valued early years interventions included:

- Non-funding led discussions about a child's individual needs and opportunities.
- Support given to the parents (and parental relationships) and siblings (as young carers) of a disabled child that recognises the enormous physical and emotional stress placed on families as a whole.
- Support that is delivered before not after the family reaches crisis point – having an immediately available source of support other than the GP.
- Good and positive communication during early diagnosis.

- Flexible support - for some families it may be to have an unbroken night's sleep, whereas for others it may be to have support and advice on how best to encourage their child to develop.

- Access to local mother and toddler groups that welcome disabled children.

- Easy access to information, choice of provision, choice of venue for service delivery including the opportunity to have 'in home' services.

- A major problem for parents in the early years is the delay in service provision and the 'wait and see' approach taken by the medical profession and some early education centres. Mostly parents feel they know when their child is not progressing at an average rate and they need professionals to take note of what the parent is saying and act on it.

Examples of effective practice interventions suggested by parents included:

- An annual parent weekend for families of children under the age of 8, providing talks, workshops and information. Parents stay in a hotel from the Friday night until after lunch on the Sunday, listen to speakers on a range of topics relating to their child's condition, and also have the chance to share experiences and get to know other parents who have a child with similar difficulties, including Down's syndrome, autism, visual impairments or hearing impairments.

- A Child Development Centre which works on the same site (or even in the same building) as a Children's Centre. This reduces the level of segregation that some families experience.

- The use of weekly 'play therapy' sessions, where the child attends with a parent and the atmosphere is one of a parent and baby/toddler group, but there are relevant professionals in attendance. This fosters an holistic approach to the child's disability, provides a route into Integrated Assessments and (just as importantly) establishes a support network of similarly affected parents.

Views from children and young people

Unsurprisingly, young people themselves were the least well-represented constituency in terms of numbers. The total number represented was 14. However, powerful and consistent views were expressed, some agreeing, and some disagreeing with the recommendations in the research review. Some views related specifically to the questions posed in the review, others to more general issues associated with disability. Some of the views expressed on early years issues include:

- While it was agreed that services should take place in natural surroundings, address the whole family and not be delivered by lots of different people, there was a lack of confidence that the resources needed would be available.

- What children do and how much they do of it is crucial – young people criticised the excessive amount of "free play" where learning was slow or non-existent.

- Results matter - approaches that encourage the tracking of progress and the pursuit of targets was seen as a good idea.

- More investment in pre-school work would result in fewer difficult issues when children enter school.

- Investment in new approaches should depend on evidence of effectiveness, but innovation should not be stifled.

- Information technology is important but should not be seen as a replacement for the care and attention of a person.

- Key workers are a vital resource, but a fear was expressed that the role is bolted on to existing work thus weakening its impact.

- Home school liaison is important, as it gives parents an understanding of what their child does and will do. Young people agreed that help getting their parents to understand and support them more would have helped a lot when they were younger.

Among the general themes were:

Expectations: Young people complained of having their dreams and aspirations dispelled because they have impairments. Adults, they felt, were too quick to point out the limitations imposed by their impairments, for fear they would be hurt and disappointed by failure. These negative beliefs were internalised at an early age. Young people recognised they might not always succeed in achieving their ambitions, but as one girl commented, "let me have the dream".

Vulnerability: Young people felt they are wrapped in cotton wool and over protected, from both physical and emotional experiences. One young person told of being advised not to read "The Secret Garden" or "Heidi", as both stories feature recovery from physical impairment. Young people felt professionals spend more time telling their parents what they cannot, rather than what they can do and underestimated their ability to cope with difficulties.

Learning: Young people said special schools indirectly promoted separateness. They felt isolated by just being with other disabled people and this impacted on how non-disabled young people view them. Lack of educational support and aspiration could lead to de-skilling. Provision needs to be enabling – making reasonable demands of young people rather offering undirected support.

Visibility: There was a frustration from those young people whose impairment was not immediately evident; they feel misunderstood and less supported in some situations. One young person described being asked to get off a bus because the driver did not believe he was disabled and did not accept his pass.

Views from service providers

A total of 170 delegates attended the knowledge workshops. Service providers were asked to consider three questions:

1. What are the key strategic issues that need to be addressed in order to increase the range and quality of early intervention services for disabled children?
2. What opportunities or levers are available to you to make an impact in this area?
3. What examples can you share from your local area?

The main themes in their answers to these questions are summarised below.

What are the key strategic issues that need to be addressed to increase the range and quality of early intervention services for disabled children?

- **The long view** Time is needed to agree and evaluate meaningful outcomes, especially hard-to-measure outcomes and those which are long term.

- **Diversity** Parents have a wide variety of views, experiences and desired outcomes, which challenges services to find ways to accommodate all these different perspectives. Professionals have differing agendas, spending priorities, needs criteria and understanding of which children are most in need of early years services.

- **Change** The culture of organisations must be changed to accommodate new methods of working – integration, common language and outcomes, and joint commissioning. Investment in workforce development requires a range of expertise that can be deployed to the appropriate level of need.

- **Funding** Clarity is needed over funding sources and their ownership. There is a need to balance the search for new funding streams with creative and innovative use of existing resources.

- **Co-operation** Closer liaison is needed between education and social care to reduce the need for out-of-county placements; information technology needs to be rationalised and standardised in order to facilitate effective information sharing; a common language must be developed; more investment in key worker services is required; early years work needs to be joined up with other strategic agendas, such as teenage pregnancy, and better use must be made of the skills of health visitors, especially in reaching families who find it hard to access early years services.

- **Listening** More ways must be found to involve and listen to disabled children – Aiming High was perceived by some as being too parent-focused.

- **Gaps** There is an absence of support for 6–8 year olds; a lack of a common definition of disability; an absence of information – both parents and commissioners do not always know what is or might be available; the expansion of nursery education has led to a decline in playgroups and a corresponding lack of networking opportunities for parents.

- **Action:** There is a need to develop a flexibility of response without necessarily having a specific diagnosis, to move away from reactivity towards pro-activity and to clarify the difference between the lead professional and the key worker.

What opportunities or levers are available to you to make an impact in this area?

- **Statutory frameworks** The National Service Framework, Aiming High and the Common Assessment Framework; Local Area Agreements and Comprehensive Area Assessments; duty to create early year's networks and Children's Centres.

- **Integration** Lead professionals; service champions; key research commissioned by local authorities based on parental priorities; integrated locality working; the opportunity to develop and an evidence base for integrated working; the creation of joined up services through effective commissioning and workforce development; Department for Children, Schools and Families (now Department for Education) guidelines and advice.

- **Users** Parents and young people are powerful change agents – time must be invested in consultation and partnership working.

- **Outcomes** Use of outcomes and targets to make service performance transparent; opportunities to reach common understanding of what priorities should be; effective needs assessments will lead to optimum allocation of resources to user-led priorities.

- **Services** Many existing examples of effective pooling of budgets; embedding of the Team Around the Child and Early Support approach; Service Level Agreements have sharpened focus of interventions; key worker services report highly promising feedback from parents; opportunities to break down professional culture, for example by enabling child minders to support children with complex needs; development of direct payment schemes; practice-based commissioning – a chance to use freed up resources to promote early intervention and direct support to those most in need.

Given the unique response of individuals to the experience of disablement, it is not claimed that the views summarised here, especially those of parents and children, are fully representative of the broader population. However, the comments made will undoubtedly resonate with large numbers of stakeholders. It is encouraging that, while problems of delivery clearly persist, stakeholders shared a broadly similar view of what constitutes effective support structures for young disabled children and their families, and these views largely corresponded with the research base.

5. Do early years interventions lead to improvements in outcomes for disabled children and their families?

Key messages

- Effective early years intervention addresses the family context and is delivered through a seamless inter-agency service.
- Early years intervention is more likely to work when programmes are characterised by structure, intensity and duration.
- Early intervention cannot inoculate highly vulnerable infants against all future difficulties
- Early years intervention for children with autistic spectrum disorders shows promise, but impacts may be more moderate than has sometimes been claimed.
- Effective pre-school education can reduce the likelihood of a subsequent special educational needs (SEN) assessment in primary school.
- Parents report significant long-term benefits from family-centred early interventions, though the most benefits from early intervention are reported by the least disadvantaged families.

This section is based on evidence from 17 studies. Seven are from the UK, seven from the USA and one each from Canada, Australia and the Netherlands. Relevant comments from parents and carers received during the feedback process are included in the following sections where these illuminate consensus or disagreement on pertinent points.

The most notable feature of the research reviewed is the focus on pre-school children. The bulk of the research relates to children aged from birth to three years, as this covers the main diagnostic and initial intervention period.

5.1 What is 'early intervention'?

Definition of early intervention

'*Early intervention consists of multidisciplinary services provided for children from birth to five years of age to promote child health and wellbeing, enhance emerging competencies, minimize developmental delays, remediate existing or emerging disabilities, prevent functional deterioration and promote adaptive parenting and overall family functioning. These goals are accomplished by individualized developmental, educational and therapeutic services for children provided in conjunction with mutually planned support for their families.*' (Shonkoff and Meisels 2000 pp XVII–XVIII)

'Early intervention' can be taken to mean either:

- action taken early in life.
- action taken early in the onset or at the diagnosis of impairment.

While this review is concerned with interventions in the early years, the timing of an intervention remains important. The plasticity of the brain up to age 6 to 8 months means the child may be optimally equipped at this age to deal with developmental challenges.   Parents have expressed a clear preference for as early a diagnosis as possible (Slade *et al* 2009). However, the nature of the challenge might still be unclear and not all the 'at-risk' population may, in fact, develop the disorder, making intervention unnecessary and possibly harmful. Both the timing and the nature of the intervention are crucial; action can be both premature and unnecessarily delayed. In all cases, interventions should match the intensity of need. Furthermore, early intervention should not be seen as an 'alternative' to later intervention – in many cases, continuing support, often long term, will be required (Statham and Smith 2010). Each approach has its advantages and disadvantages. The way in which this issue is handled may have a long term effect on the relationships between parents and professionals.

 '*Better communication is needed - there is often very poor communication from professionals in terms of early diagnosis and support.*' (Mother)

'*Support needs to come much earlier as it is often only received once a family reaches crisis point.*' (Mother)

Diagnosis and treatment of many disorders normally occurs during the pre-school period. This has the advantage of greater diagnostic certainty and more clarity over the aims of treatment but the child may be less well placed to take advantage of remedial programmes.

> *'..the way in which the parents of disabled children are given news about a diagnosis should be looked at. Through my training with the Face2Face befriending network[4] I have found that if parents are given the news of their child's diagnosis in a negative way it can affect their whole perception of their child's future and capabilities. All parents have a different emotional response and this can upset family stability.'* (Mother)

While more sophisticated diagnostic procedures have partly addressed this dilemma, for example in relation to hearing impairments, the need to balance the relative risks involved remains. Therefore, while early intervention can take place at any time in childhood, the large majority of early intervention activity is initiated during the first three years of life.

5.2 Matching needs with interventions

Recent US and UK reviews of early years intervention research (McCollum 2002; Webster *et al* 2004) have suggested that the key question to be asked across the whole early years intervention field is 'what works for whom?' That is, how can specific interventions be matched to particular family needs and circumstances in order to successfully achieve the desired outcomes. Two principles drive this approach:

1. Children's development is context-specific and should accommodate and utilise the home environment rather than be purely child-focused. This requires working with the child in 'natural' rather than clinical settings, that is, in the settings in which early years interventions will and are being used. Early years interventions are therefore individualised and shaped to accommodate family routines.

2. The inter-dependent relationship between different services, their coordination and seamless integration, and the transitional arrangements required have become central to policy and practice, and are held to be strongly associated with effectiveness and positive outcomes.

> 'I agree with the statement that whole family interventions are preferred and that parents are satisfied with sensitive and responsive support. This was certainly my experience … this may not necessarily bring about a major impact on developmental progress, but it is certainly fundamental to the parent's ability to cope and this emotional stability must surely have benefits for the disabled child.'(Mother)

The test of principles and policies is whether they result in positive outcomes for children. Outcome studies depend on clearly defined study populations, interventions and outcome measures. Overall, the research literature on early years interventions

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[4] See http://www.face2facenetwork.org.uk/

for disabled children is relatively rich in well-constructed outcome studies. These are, however, mostly of US origin, largely reflecting the strong emphasis on early years interventions over the past 40 years following the introduction of the Headstart programme[5]. They are also primarily short-term, examining outcomes achieved following the conclusion of a programme or after a short, usually less than 12 months, follow-up. One of the leading researchers on early years interventions in the USA (Guralnick 2005) has identified the key structural features of effective early years intervention programmes as follows.

- an early intervention system is informed by a child developmental framework and centres on families

- integration and coordination takes place at all levels

- children and families participate in the programmes

- early detection and identification procedures are in place

- surveillance and monitoring is on-going

- all parts of the system are individualised

- evaluation and feedback processes are maintained

- accommodation of cultural differences is factored in

- services are evidence-based

- services are based on a systems perspective, which recognises the relationships between all the component parts.

As in the USA, the focus of early years interventions in the UK has shifted from a child-focused to a systems approach (Carpenter 2007). The aims of evaluation have changed accordingly to embrace the impacts on the family system and not just on the developmental needs of the child.

The whole family context of early intervention is a considerable departure from earlier models that primarily focused on child developmental gains. While this remains a core goal, it is now recognised that gains for the child are intimately associated with gains for the family as a whole.

5.3 Does early years intervention work?

The effectiveness of early intervention programmes had been recognised by the mid-1980s. It was thought that intervention effectiveness was based on more parental involvement, earlier intervention, more structure and greater duration and intensity. However, the majority of the evidence was based on studies of at-risk and disadvantaged children. It was not clear whether the same conclusions applied to disabled children and their families.

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[5] Headstart is a United States Federal programme, begun in 1965, which provides comprehensive early child development services to low income children, their families and communities.

Though somewhat dated, a key comparison and analysis of the results of 74 outcome studies concluded that early years interventions resulted in moderately large and immediate impacts on disabled children (Casto and Mastropieri 1986). Studies reviewed included 'mental retardation' (44 per cent), orthopaedic disabilities (29 per cent), speech and language impairments (8 per cent), emotional disturbances (4 per cent), hearing-impaired (2 per cent) and general developmental delay (2 per cent). Many, but not all prior beliefs in programme characteristics were confirmed by the review, in particular:

- the degree of structure was highly relevant, with more structured programmes performing better

- intensity and duration were found to be strongly related to programme effectiveness – longer and more intense programmes had larger effects.

On the other hand:

- parental involvement was not always essential for success – programmes utilising parents were not more effective than those that did not.

- an earlier age at start of intervention was not as crucial as previously believed; data did not always support the notion that 'earlier is better'

- while early years interventions may have an overall positive effect, not all children will benefit equally.

'I feel it is inevitable that the children who will gain most from these interventions will be those from families with the highest levels of social capital, education and income in the same way that in most cases a pre-school child with no major difficulties in these families will in general progress more prior to starting school.' (Mother)

A 'one size fits all' approach in terms of achieving equivalent outcomes is not indicated by the research base. Effectiveness studies need to examine which kinds of programme produce developmental progress for specific children and families (Shonkoff *et al* 1992). Rather than assert that early intervention programmes 'work', the question asked should be 'what kinds of programmes are most effective in producing specific outcomes for families with particular characteristics?'

5.4 Autistic spectrum disorders (ASD)

The recent substantial increase in the numbers of children being diagnosed with ASD has led to a large number of outcome studies either exclusively, or predominantly, populated by children (primarily males) with ASD. As ASD is typically not diagnosed until 18 to 24 months, it is difficult to know whether or not earlier interventions would prove more successful. While substantial claims have been made for highly intensive programmes, primarily developed in the USA by Ivar Lovaas (these studies pre-date the 1985 inclusion bar for this review and are hence not discussed), more recent trials have moderated claims of highly positive outcomes (Ospina *et al* 2008).

> *'To access support and services parents have to be proactive and to fight for support that should be an automatic entitlement. To receive support parents often also need to be well educated or to have a strong advocate or family network.' (Mother)*

A comparison of a more and less intensive intervention based on the Lovaas method found greater gains achieved by the intensive intervention group and similar gains for children with ASD and pervasive developmental disorder (PDD) (Smith *et al* 2004). The intensive treatment group performed significantly better than the parent training group on IQ, visual-spatial skills but not language development, adaptive behaviour or behavioural problems where little differences between groups were reported. Few differences were noted between the ASD and PDD groups, although differences may have been concealed due to the small sample size. Parents in both groups described similar levels of satisfaction with their interventions and similar moderate gains. Significant benefits were found to accrue as a result of early intervention for both children with ASD and PDD, though these benefits were not as great as previously reported. Interestingly, parental satisfaction with outcomes did not differ, despite the lower level of gains in the control group.

> **Validated practice example: Nottinghamshire Children and Young People's Partnership: The Early Communication and Autism Partnership (ECAP)**
>
> **What is it?** Developed from an initial pilot programme for young children with autistic spectrum disorder, the project is an integrated intervention, jointly planned by the local authority, the NHS and the Nottingham Regional Society for Adults and Children with Autism (NORSACA). It has been positively evaluated by a three-year action research project (Chandler *et al* 2002).
>
> **What does it do?** The core service provides an initial assessment and individual programme, weekly home visits, a series of 8–10 multi-agency parent workshops, booklets giving practical advice and ongoing support and training.

> **Why is it different?** Key features of the intervention are the level of intensity, the high degree of team specialisation and access to expert advice.
>
> **What has it achieved?** Inclusion rates of children using ECAP services in mainstream Foundation Stage provision is 95 per cent. Children have progressed in terms of communication and social interaction, parents report increased confidence and staff in early years and school settings report progress by pupils.

The relationship between programme intensity and positive gains has been confirmed (Rickards *et al* 2007), though the persistence of parental stress despite these gains is a notable finding. Nonetheless, child outcomes in more well-controlled studies have not replicated the early optimism of major gains. It is unclear at what point the marginal gains made, through additional intensive interventions, diminish beyond the point where they remain a worthwhile investment of time and resources.

5.5 Early years interventions and special educational needs diagnosis

A core task of early years interventions is prevention or moderation of the impact of disability. While children with SEN and disabled children are not identical groups, there is a substantial degree of overlap. To test the belief that pre-school attendance has particular benefits to children in disadvantaged circumstances – notably significant gains in cognitive, behavioural and social development – information for over 2,800 children attending 141 pre-school centres was selected from five regions across England and analysed. Centres were drawn from a range of types of pre-school providers – local authority day nurseries, integrated centres, playgroups, private day nurseries, nursery schools and nursery classes (Sammons *et al* 2003). At entry to pre-school, a third of children have been classified as being at risk of SEN diagnosis; on entry to primary school two years later, this drops to one fifth.

> *'Schools and nursery schools need to look at integration of difference and disability and how they can manage it in their environment. .. education about difference and disability needs to be expanded in the early curriculum through play.' (Mother)*

Children who had had no pre-school experience were more likely to be at risk of having SEN in terms of their cognitive development, even taking into account this group's higher levels of multiple disadvantages. Certain settings, notably integrated/combined centres, local authority day nurseries and playgroups, are more likely to have children 'at risk' of SEN on their roll. Due to the variable use of 'systems' for identifying children with SEN across the different types of pre-school, some children 'at risk' of SEN may go unidentified and, as a result, may miss the opportunity for early interventions in these forms of provision. It therefore appears that high-quality pre-school education, particularly delivered through nursery classes,

integrated centres and playgroups, can reduce the likelihood of the most disadvantaged children acquiring an SEN label in primary school.

5.6 Neonatal challenges

It has been recognised for over half a century that low birth weight (LBW) (less than 2,500 grams) is a major risk factor for developmental delay, cognitive deficits, behavioural `adjustment and poor academic performance (Marlow *et al* 2007). At the extreme edge of neonatal viability, the majority of babies born before 26 weeks gestation will not survive; of those that do, around half will have some form of disability with a quarter of resulting impairments being severe (Christie 2000). Some moderate gains have been reported through interventions in neonatal intensive care units (NICU), but no consistent links between strategies and outcomes have been identified (Symington and Pinelli 2006). Social disadvantage both increases the likelihood of LBW and compounds the negative impact when it occurs. Preventative strategies lie beyond the parameters of this review; however, the literature on neonatal intervention is extensive, though somewhat disappointing in terms of positive impacts.

A multi-site randomised controlled trial examined the impact on 985 LBW babies of an Infant Health Development Programme (IHDP), consisting of early childhood development and family support services, on child behavioural and other health problems (McCarton 1998). Interventions began on discharge from neonatal nursery. These consisted of weekly (bi-weekly from 12 months) home visits using curricula focused on social, cognitive and linguistic development, plus help for parents to manage self-identified problems. From 12 to 36 months, children attended a child development centre five days per week where the home-based programme was implemented by teaching staff. In addition, from 12 months, bi-monthly group meetings to offer advice and problem-solving were held with parents. Outcomes were assessed using the Behaviour and Child Behaviour checklists. While positive impacts were noted at 36 months compared to the control group – specifically improving children's competencies and mother–child relationships – these advantages were not retained at the five- and eight-year follow-up.

Relatively disappointing results have also been reported on compensatory interventions for pre-term babies in a Bristol-based randomised controlled trial on 309 infants. Babies showed only minor developmental benefits from Portage[6] and family-based support at 24 months (Avon Premature Infant Project 1998), and none when cognitive, behavioural and motor functions were measured at five years follow-up (Johnson *et al* 2005).

The Avon Premature Infant Project (APIP) is a randomised controlled trial in which the parents of 284 babies born at 33 weeks gestational age received a developmental education programme, a social support intervention, or standard

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[6] Portage is a home visiting educational service for pre-school children with additional support needs and their families.

care. The follow-up study reports outcomes at five years for 187 (66 per cent) of these children. Pre-term infants showed poorer cognitive performance than their term peers. There were no significant differences between pre-term groups indicating no effect of either intervention. Similarly, there was no significant effect of intervention on behavioural or motor outcomes. Further analyses, in which outcome data was adjusted for social factors, did not reveal any differences between the three pre-term groups or subgroups classified by a range of perinatal variables. The small advantage shown in the earlier study – at two years – was no longer detectable at five years, placing a question mark against the effectiveness of early intervention in enhancing cognitive, behavioural and motor function at five years for this group of children.

A meta-analysis of interventions between birth and 18 months for babies discharged from neonatal intensive care units found some limited benefits reported for motor function development, but the study results were highly varied and the size of the impacts could not be calculated (Blauw-Hospers and Hadders-Algra 2005).

5.7   Effect of early years interventions on parents

Parents as well as children are beneficiaries of family-centred early interventions. Most studies examining parental impacts rely on self-reports, often retrospectively. While few longitudinal studies located have controls, some are drawn from large samples and provide data on a lengthy follow-up period (Bailey et al 2005). At the end of three years' intervention, most families in this study, which numbered 2,586, described themselves as more competent and confident in their ability to support their child, work with professionals and gain access to support. Areas identified that needed improvement were:

- more specialised help for families of children with behaviour problems

- expanded efforts to help families gain access to community support

- more accessibility to early interventions for families from diverse cultures.

However, the worst outcomes were reported for parents of children from minority ethnic groups, children with health problems and children who were living with a single adult.

While these results are broadly positive, many studies have reported that family-centred early interventions benefit the most disadvantaged families less than other families. A study of children with cleft lip or palate and Down's syndrome, incorporating a control group (Pelchat *et al* 1999), reached similar conclusions, though over a shorter follow-up period of 12 months. Compared to a control group, parents reported being less threatened by their situation, more confident in receiving help, were less stressed and depressed and received more help from spouses.

6. Which early years interventions are most effective for particular groups of disabled children?

Key messages

- The important 'difference' in a successful approach may derive from one or more of a number of elements: technique, teaching style, environment or resource level. Differences between approaches, where they occur, are usually modest.

- Electronic communication media can deliver teaching packages and information in format- and audience-specific modes.

- Family-centred interventions that accommodate the reality of the child's environment and can be delivered with a minimal level of demands on parents work best.

- No single intervention for autistic spectrum disorders (ASD) has consistent advantages over others.

- The introduction of key worker services is associated with better family relationships with services, quicker access to benefits and reduced parental stress.

- The risk of social exclusion can be reduced by helping children communicate with their peers.

- Investment in new early years intervention approaches should be based on robust evidence that, compared to existing approaches, result in significant gains for children and families.

- The majority of positive findings derive from model programmes which may be disproportionately well staffed and resourced – the challenge remains to replicate these results in mainstream services.

This section is based on evidence from 21 studies. Eleven are from the UK, eight from the USA, one from Canada and one from Ireland.

There is a shortage of studies comparing one intervention type with another and, in addition, an inadequate amount of research that differentiates between different interventions with different impairment types or other differentiated groups. Some studies show advantages for children from a specific programme over another, though gains are often modest (Apache 2005; Hesketh *et al* 2007); others find gains to be largely equivalent (Smith *et al* 2004; Magiati *et al* 2007).

Services provided by the Early Support Pathfinders have been identified as a particular priority for specific groups, mainly those where there might be some delay

in identification of need or access to services, or where the birth to age three banding was incongruent with the nature of 'early' support. These are:

- people seeking asylum or recently arrived in the locality

- travellers

- children with late onset, or only recently diagnosed, difficulties

- children with acquired or regressive conditions and thus changing needs

- children with autistic spectrum disorders (ASD) who might not – because of the nature of the diagnostic criteria involved – be referred to a service until after their third birthday

- families with disabled children without multiple difficulties, but where families would continue to require ongoing support to age five and beyond

- 'statemented' children from birth to19 years.

(University of Manchester and University of Central Lancashire 2006 p 175)

While the evidence base currently under review does not address all these children, these priority groups indicate the areas where additional knowledge is needed.

6.1 Speech, language and communication needs (SLCN)

Children with significant problems in communicating often do not present for assessment and intervention until around 18 to 24 months. Their gross motor development has often been satisfactory, and therefore it is only when they do not learn to speak and share play that parents become concerned. As children have become mobile at this later stage, it is not possible to foster facial attention and exchange directly, as with infants. It must therefore be achieved indirectly, in shared and structured play contexts.

Speech, language and communication difficulties as a primary need are thought to affect between 5 and 7 per cent of the primary-age population. More generally, around 50 per cent of children in the most disadvantaged communities have speech and language skills significantly lower than those of other children of the same age (DCSF 2008a). Continuity of support is of particular importance where children have SLCN problems; unfortunately, due to staff turnover, parents frequently report having to forge new relationships with therapists (Audit Commission 2003). A robust evidence base on interventions for children with SLCN exists, which includes a number of high quality systematic reviews. A meta-analysis of 25 randomised controlled trials concluded that speech and language interventions with children up to age 16 was effective with phonological or vocabulary difficulties but there was less evidence of effectiveness for children with receptive language problems. Both professionals and trained parents are equally effective at delivering interventions, as are peers with normally developing language. Both group and individual interventions achieve similar results (Law *et al* 2003). Positive results were also

reported from a meta-analysis of relatively short group interventions carried out by health professionals (speech and occupational therapists) for children age 4 to 11 years, with the strongest evidence for phonologically-based speech sound interventions targeting specific speech processes (Forsyth *et al* 2007).

SLCN may also manifest as a secondary need – associated with other impairments such as cerebral palsy, autism or learning disabilities (Lee 2008). A review of effective interventions suggests that improvements can be achieved in speech, language and communication with primary-aged children through:

- school-based interventions aimed at changing approaches used by staff and children

- phonological awareness training – awareness of the sound structure of spoken words

- strategies for teaching receptive vocabulary, word-finding training and grammar

- developing narrative skills in children with delayed language, teaching story and grammar knowledge, and boosting story comprehension

- developing language repair skills and conversational skills

- intervention for children with pragmatic language impairment

- teaching reading comprehension, for children with language difficulties

- developing communication skills with children excluded or at risk of exclusion.

(Lee 2008 p 16)

Studies of early interventions for language difficulties have reported some advantages in developmental outcomes (Law *et al* 2001) when comparing I CAN Early Years Centres – a network of NGO-run centres providing support for children with speech and language difficulties – with routine NHS facilities, with results favouring the former. Ninety-one children with primary language difficulties – 58 in two I CAN centres and 33 in NHS provision – with a mean age of 40 months, who performed similarly at baseline, were compared before and after intervention (which varied between 6 to 10 weeks) on a variety of measures, both quantitative and qualitative. I CAN children made relatively greater improvements in productive vocabulary and language comprehension, adaptive and pro-social behaviour and were less disruptive than those attending NHS provision, though there was equivalence on some measures and parents were equally satisfied with both services. A cost-benefit analysis of the two forms of provision also provided some moderate advantages to the I CAN model, with the authors concluding that support provided by early years centres was both cost-efficient and relatively cheap, though the long-term benefits – and any possible saving made through early intervention – could not be calculated (Law *et al* 2006).

> **Validated practice example: NHS Eastern and Coastal Kent, East Kent Hospitals University Foundation Trust and Kent County Council**
>
> **Multi-agency interventions to promote young children's speech, language and communication needs**
>
> **What is it?** The I-CAN Early Talk programme was implemented through a targeted, multi-agency network and is aimed at children with severe speech, language and communication needs (SLCN).
>
> **What does it do?** The purpose of the programme is to enable children with SLCN to participate in everyday activities and attend their local primary school without the need for a place in a specialist unit.
>
> **Why is it different?** Short, individual therapeutic sessions carried out in isolation from the child's home and school life have limited effectiveness. The I-CAN programme is based on a joint approach, which empowers parents to be co-educators in the delivery of a programme in nursery, a Children's Centre or at home.
>
> **What has it achieved?** Home nurseries have increased their knowledge base on children with SLCN; 92 per cent of children in the programme were able to attend primary school; 70 per cent demonstrated a marked increase in their use of language; only 1 child in 12 required a statement of SEN, and high levels of satisfaction were recorded in feedback from parents.

Awareness of individual phonemes (one set of speech sounds that serve to distinguish one word from another) is related to the development of literacy and usually develops in the early school years. Speech and language therapy for children with speech disorders involves tasks that require a phonemic level of awareness. However, children typically attend for intervention at a pre-school, pre-literate stage. A UK study (Hesketh *et al* 2007) examined whether it was possible to teach phoneme awareness skills to pre-literate children. In a randomised controlled trial, 42 children with speech disorders, aged 48 to 54 months, were allocated to either a phonological awareness or a language stimulation programme. Significantly more children improved in the phonological awareness group than in the language stimulation group for three out of the four outcome measures, though for the two most advanced tasks only a small minority of children showed improvement. The authors concluded that children who have a certain level of cognitive adequacy may be helped by targeted intervention to improve their phoneme awareness skills. Other children, particularly those younger or cognitively less able, may make little or no change, even following an intensive period of intervention.

A robust study, quasi-experimental trial, compared two sets of children who had already been enrolled, non-randomly, into two different programmes for children with ASD (Magiati[7] *et al* 2007). The first group of 16 children received autism-specific

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[7] Early Intensive Behavioural Intervention is a highly structured approach to teaching younger children with Autistic Spectrum Disorders who present significant behavioural challenges.

nursery provision, the second group of 28 received Early Intensive Behavioural Interventions in a community-based setting. Both groups showed improvements in age equivalent scores on cognitive ability, language and play over baseline at 24-month follow-up, without any statistically significant advantage for either group. However, large differences in outcomes were noted in individual scores, with the best predictors of performance being intake IQ and level of language ability.

A second UK study comparing two approaches to the treatment of ASD – Portage and the Scheme to Promote Early Interactive Conversations (SPEIC[8]) – found some benefits to the latter, though gains were modest and not statistically significant (Smith *et al* 2004). As regards improving expressive language and participation in play, positive results were found for the 22 children in both groups, with non-statistically significant advantages for the SPEIC programme.

Teaching style may be an important factor associated with the benefits of programmes. A study which compared a highly directive teaching style with a style that facilitated – rather than mandated – activities for pre-school children with developmental delays (Apache 2005) showed clear advantages to the latter procedure, with improved motor skills resulting from the less directive approach.

6.2 Technical interventions

A small number of studies examined the impact of media-based formats in achieving positive outcomes for parents of disabled children. No study was found that compared different media-based approaches, or compared media-based formats to other methods of learning. One review (Zaidman-Zait and Jamieson 2007) examines the advantages and disadvantages of web-based information for parents of disabled children. Websites, the study suggests, could be used to supplement direct provision of early intervention services with teaching tips and could incorporate videos and exercises. An 'ask the expert' function could be a substitute resource for parents where professionals are not readily available.

Programmes that involve parents in developing online resources would be more likely to have better targeted information and support. Although the dangers of misinformation and information overload are present, the capacity of web-based knowledge to offer instant 24-hour support, to focus on parents with specific issues or problems, and to improve child health, parent–professional relationships and empowerment appears to greatly outweigh any risks.

> *'.. socially disadvantaged parents may not have access to a PC/internet/printer, so even though it reduces costs, it does not always reach parents.' .(Mother)*
>
> *'…the wide use of electronic information and teaching packages will not suit all families..' (Mother)*

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[8] SPEIC is a programme designed to help children to develop non-verbal communication skills through tone of voice3, expression and body posture.

All interventions require high levels of compliance and therefore must be accessible to all or most parents. A study of a video-based intervention (Sharry *et al* 2005) is notable as it achieved positive results for children, good feedback from parents, was carried out in ordinary settings and was accessible to all referrals. Although a small study with no control group, decreased parental stress and child-conduct problems were noted, post-intervention and gains were maintained at the five-month follow-up.

6.3   Rare conditions

A number of impairments affect very small numbers of children, but may do so in severe and distressing ways. The research base on effective interventions is often narrow and limited due to the small size of the population affected.

Rett syndrome is a neurodevelopmental disorder almost exclusively affecting girls, as affected male foetuses rarely survive to full term. Development is normal until age 6 to 18 months. As communication presents particular challenges for children with Rett syndrome, strategies that are integrated into ordinary parent–child activities, which also have a therapeutic value, are highly desirable. Although a small-scale study (Koppenhaver *et al* 2001), storybook reading accompanied by restraints to control gestures is a promising approach, which achieved increases in symbolic, non-verbal communication by all participants. While larger studies are needed to confirm these findings, positive results were achieved through a low technology intervention that was integrated into the normal lives of families.

Deaf-blindness, also known as multi-sensory impairment, affects three in every 10,000 children, with very large numbers of possible congenital or acquired causes. Deaf-blindness causes extreme developmental disadvantage, especially regarding environmental information, communication and social development. The majority of children with deaf-blindness will also have other physical disabilities or complicating medical conditions. A recent study reviewed the effectiveness of early intervention for deaf-blind children (Murdoch 2004). Only two specific interventions, Promoting Learning through Active Interaction (PLAI) and the Intervener Programme were identified; both were studies conducted in the USA and both reported positive outcomes through using in-home parent training. The review concluded that because of the low incidence of deaf-blindness, generic professionals are unlikely to have sufficient experience of multi-sensory impairment, and early interventionists need training in how to meet the needs of both the child and the family. While the benefits of early intervention for children with multi-sensory impairment have been accepted, further research is needed on the benefits of different intervention components for different children with different needs.

6.4   Autistic spectrum disorders (ASD)

ASD has become one of the most intensively researched fields of development disorder. Children with autistic spectrum problems typically have difficulties sharing activities with adults and peers and communicating with others during play. Children with communication problems may not present for assessment until aged 24 months.

Their motor development has often been satisfactory. It is only when speech and play appear abnormal that parents become concerned. Earlier studies have claimed considerable and sustained progress towards normal functioning using a variety of methodologies. Later work has failed to confirm this level of confidence.

Three recent studies add to our knowledge base: a relatively weak correlation study (Medhurst and Clay 2008) of the Thomas Outreach Project, an English early intervention scheme; a stronger but still limited trial using a wait-list control of an early intervention scheme – the EarlyBird programme – developed by the National Autistic Society (Shields and Simpson 2004); and a meta-analysis of studies (McConachie and Diggle 2006) which examined parent-facilitated early intervention for children with ASD. While positive results are reported in the latter two studies, limited data is reported by Medhurst and Clay, and the study population size (20 children) was small.

Developed by Hampshire County Council, the Thomas Outreach Project aims to enhance the development of children with ASD during their pre-school years and through the transition to mainstream primary education. Families using the Thomas Outreach Project typically receive seven to nine hours per week of direct intervention. The interventions offered focus on improving outcomes in relation to social interaction, language and communication and play.

Key success criteria identified by staff were the use of a clear routine, a visual schedule, consistent approaches, consistent expectations and the use of transition cues. The outcome most valued by parents was improved social interaction and communication.

EarlyBird (EB) is a three-month parent-training programme designed by the National Autistic Society (UK) for parents with children newly diagnosed with ASD. Since 1997, it has expanded from its original base at the EB centre in Yorkshire and is now licensed for use in other parts of the UK. The programme aims to build parent confidence, reduce stress levels and adapt natural parenting skills to the needs of their children (Shields and Simpson 2004). The EB evaluation was larger and more robust than that of the Thomas Outreach Project. Of particular note was the absence of difference between outcomes at the original base and outcomes at the sites where the programmes had been franchised. This could either indicate that treatment fidelity has been carefully maintained, or that differences in approach or intensity are not significant. While the programme offers no 'cure' for ASD, it does appear to help parents feel more positive about their children. Although the results need replicating with a randomised study design, positive support is offered by this study both for this intervention and the ability to franchise the methods more broadly.

The positive impacts of parent-implemented intervention for children with ASD emerge from a meta-analysis of the 12 studies that met the review inclusion criteria (McConachie and Diggle 2006). Outcomes for children included improved communication skills, and behaviour, and for parents improved knowledge about autism, teaching strategies, reduced stress and better communication with their children.

Similar reviews of parent education programmes for young children with behavioural problems have produced highly positive results; it is plausible that similar impacts may accrue when parents of children with ASD are taught specific skills. However, many of the included studies were undertaken as pilots and it is unclear whether the level of expertise required and the level of demand on parents can necessarily be replicated in all environments.

6.5 Children with complex needs

While definitions of 'complex need' vary, a feature of children who have been defined as having complex needs is that they typically receive services from a multitude of agencies. Estimates of numbers of children with complex needs vary considerably depending on the definition used; those planning services will need to be clear on which definition their assumptions are based.

Multi-agency services for children require collaboration and coordination. Lead professionals are expected to act as a single point of contact and to coordinate the actions of other agency personnel; in the case of services for children with severe disabilities or complex needs, key workers will act as lead professionals and will generally offer support to a level over and above that of a lead professional (CWDC 2009). While key worker strategies are relevant throughout the lifespan, the rapid biological, developmental and procedural changes that occur in the early years, as well as the diagnostic period, indicate that an effective key worker strategy is particularly relevant to this chronological period.

> *'Having a key worker and multiagency meetings would make all the difference rather than having to deal with so many different agencies and repeating oneself.' (Father)*
>
> *'Parents and carers want and need a "one stop shop" where they have a key worker that knows their child and their family. There needs to be more funding to facilitate this; better continuity of staff, and better training for parents and practitioners. (Mother)*
>
> *'While it is always good to talk about integrated services and a "multiple agency" approach co-ordinated by a key-worker… parents are becoming very cynical about this as key-workers seem to be ever-changing, if indeed they exist or are identified to the parent. I have been waiting 13 years to be told who our family's is.' (Mother)*

A recent review of literature and associated good practice (Cavet 2007) reported that:

- Where a key worker system is present the quality of life of families with disabled children is improved, including better access to benefits and support services, reduced levels of stress and greater empowerment.

- Elements of a key worker service most valued by families include regular contact, supportive relationships, a single point of contact and a family-centred, rather than a child-centred approach.

- Parents perceive effective practice as key workers recognising the families' strengths and representing the families' interests rather than those of employing agencies.

- Effective key working requires basic counselling and communication skills, the ability to work in partnership with parents and children, to advocate for their interests, to have specialist knowledge and to have respect for their expertise.

- Key workers must document unmet needs, encourage participation in service development and facilitate smooth interagency working.

Where key workers carry out more aspects of the key worker role, had appropriate amounts of contact with families, regular training, supervision and peer support, a dedicated service manager and a clear job description, then better outcomes resulted for families (Sloper *et al* 2006).

Validated practice example: Ealing Service for Children with Additional Needs (ESCAN)

Keyworking service for children with complex needs[9]

What is it? As one of the Early Support Pathfinders, Ealing sought to integrate health, education and social care services for children with complex needs up to age 5 years. Key workers were allocated to children receiving 3 or more specialist services in addition to a paediatrician and GP.

What does it do? Families have a named person to contact and someone who is proactive in their involvement. Keyworkers coordinate services and appointments, examine all the family's needs, make Family Service Plans, help families with the Early Support materials and monitor the outcomes.

Why is it different? All services for disabled children are co-located on a central site, there is an over arching information sharing agreement between services including the special schools/units and children's centres and a local website provides information on services, activities and support groups to both parents and professionals. This has enabled better joint working and has improved information sharing between professionals. Appointments for families are more easily coordinated.

What has it achieved? Up to 100 families are served at any time; evaluations report that parents are better supported, more knowledgeable, more involved in decision making and better informed. No re-referrals to the service have proved necessary and only four children in the past year have needed additional interventions by the social care team, demonstrating the preventative role of keyworking.

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[9] A short Case Study Video of this validated practice example is available on the C4EO website {SCIE to insert url}

Implications for policy and practice include the need for regular training, supervision and peer support for key workers and negotiated time and resources for them to carry out the role. These influence the extent to which key workers carry out all aspects of the key worker's role and their amount of contact with families, which in turn impacts on outcomes. Results also suggest that parent involvement is valuable, but it cannot overcome the disadvantages of key workers not carrying out all the aspects of the role.

6.6   Peer group interventions

Significant numbers of children, and particularly disabled children, have difficulty forming social relationships. Problems in establishing positive peer relationships can lead to an elevated risk of maladjustment in adolescence and adulthood. This risk particularly affects children with a range of developmental delays, including cognitive delays, behavioural problems, ASD and communication disorders. A range of effective interventions for improving peer interactions and social competence for pre-school children has been empirically validated, which depend on environmental design and both teacher- and peer-mediated interventions (Brown et al 2008). These interventions fall into three domains:

1. **Classroom interventions:** including developmentally appropriate practices, inclusive pre-school education, social competence curricula and strategies to encourage positive attitudes towards disability in non-disabled peers
2. **Naturalistic peer interaction interventions:** including unstructured or incidental teaching of social behaviour alongside a formal curriculum and activities to promote friendships
3. **Explicit social skills interventions:** more structured and intensive interventions than can be delivered routinely may be required. This will include linking pre-schoolers with serious social interaction difficulties with social responsive peers in teacher-designed activities and training social responsive peers as 'buddies' to help children in need of additional support.

(Brown *et al* 2008 p 144–153)

7. Which features of early years interventions are considered to be most effective by parents?

Key messages

- Mothers remain the primary carers of disabled children.

- Reduction of stress on the primary carer has been identified as the trigger for reduction of stress on the whole family.

- There is a high degree of consistency in the kinds of service features valued by parents: these include access to information, and coordination of services that meet the needs of the whole family.

- In general, parents value family-centred services delivered by reliable professionals employed by efficient, well-resourced and responsive agencies who have the skills and knowledge relevant to the child's impairment.

- Accessing services is easier when professionals are highly knowledgeable, impairments are clearly defined and diagnosis is made following birth or in infancy.

- Early intervention improves the mental health, relationships and emotional wellbeing of parents.

This section is based on 14 studies, eight of which are from the UK, three from the USA, and one each from Canada, Australia and the Netherlands.

Unlike impairment-specific interventions, there is a great deal of similarity in the results of studies which either focus on parental views on service effectiveness, or report on this issue as part of a broader investigation. However, while many studies have large numbers of respondents, almost all are convenience samples. It is likely that these studies are broadly representative of the whole population of parents of disabled children, but representation is a weakness of this study type.

7.1 Parents or mothers?

As early years interventions have become less child- and more family-centred, multiple perspectives on where the focus of work should lie, and what might constitute success, are required (Carpenter 2007). While early intervention is reported as having positive effects on the emotional wellbeing of both parents (Pelchat *et al* 1999; Davies 2005), the use of the term 'families' or 'parents' conceals the fact that the overwhelming numbers of primary carers of disabled children are mothers. Mothers also comprise the large majority of research subjects, an observation sometimes concealed by studies that use the term 'parents' in their title and abstract or fail to distinguish between results by gender (Webster *et al* 2004).

Studies that omit to record the gendered nature of care will also fail to expose the different impacts of early interventions on mothers and fathers.

Attention has also been drawn to the persistent professional dominance in early intervention design and its disproportionate impact on mothers, whose cooperation in family-based care will usually be essential to any care plan and who may be labelled 'good' or 'bad' depending on their capacity or willingness to cooperate (Leiter 2004). This caring labour may be seen as an extension of a mother's traditional role: activities such as lifting, feeding and dressing still take place, but may take more time and energy than usual. At other times, as the scope of care work increases, mothers may need to gain specialised therapeutic and medical knowledge. Because of the overlap between typical childcare and atypical healthcare, mothers' added healthcare work and its impacts can remain hidden.

Where studies consider gender as a variable, significant differences can emerge. Fathers, it is reported, find it more difficult than mothers to talk about their parenting role. Mothers are likely to find discussing their emotions helpful; conversely, fathers are more likely to use cognitive strategies (Pelchat *et al* 2003). A Dutch study of the perceived changes in wellbeing of parents (81 mothers, 67 fathers) whose children were enlisted in a therapeutic toddler class, reported that mothers – who were the primary care givers in every case – reported greater gains in wellbeing than fathers, who gained more insight than mothers into the abilities of their children. Variation in parental needs may drive these results, with mothers having a greater perceived need for support, and fathers a greater need for understanding (Hendriks *et al* 2000).

7.2   Service features valued by parents – UK and international studies

A highly consistent message about the services that parents most value emerges from studies which focus on this issue. The UK studies reviewed include views from a total of about 197 parents (one study only specified 'parents of 11 children'). Parents of children with ASD, who are blind, deaf, have cerebral palsy, motor disorders, spina bifida, Down's syndrome, muscular dystrophy, dyspraxia and unspecified developmental disorders are included. Services most valued are able to provide:

- support at time of diagnosis

- access to information and advice

- assessment that takes on board family views

- effective and stress-free service coordination

- an efficient and not over-prolonged statementing process

- a service that considers and meets the needs of the whole family

- targets and developmental milestones to work towards

- evidence of achievements

- rapid and obstacle-free access

- ideas and suggestions for activities

- a knowledge base on which parents can rely for informed treatment options

- help to enable parents, especially mothers, to enter or return to work

- skills to parents.

(King *et al* 1999; Li *et al* 2003; Robinshaw and Evans 2001; Jennings 2008; Slade *et al* 2009)

Validated practice example: City of York Council Educational Psychology Service:

Specialist Speech and Language Teaching Assistant Project

What is it? The Specialist Speech and Language Teaching Assistant Pilot Project delivers support in school settings to children with speech and communication problems.

What does it do? A full time teaching assistant, trained and supported by a speech and language therapist and an educational psychologist, work in two schools, offering both individual and group work to children in Foundation Stage and Year 1.

Why is it different? Children receive high quality interventions in a school setting rather than having to attend clinics. Close communication with both teachers and parents results in therapeutic strategies being followed up at home and in school.

What has it achieved? All children involved in the intervention showed improved speech, language and communication skills following the first ten months of intervention, specifically improved listening, vocabulary, narrative skills, articulation, confidence and progress in Early Years Foundation Stage learning goals. Feedback from parents replicated the quantitative data and noted an overall progress in language development following the intervention.

Parents express relatively high levels of satisfaction with services once they are being received. However, access problems may be acute, particularly so where professionals involved in diagnosis are insufficiently knowledgeable; diagnosis takes place later rather than earlier; and the type of impairment – especially in the case of psychological disorders – is less clear (Slade *et al* 2009). While the following are relevant to many parents, they feature particularly highly in the wish-lists of parents with autistic children:

- skilled interventions specific to the child's impairment, notably the management of challenging, especially obsessional behaviour, disrupted sleep patterns and communication

- a smooth transition from pre-school settings (Webster *et al* 2004)

An Australian action research study (Beamish and Bryer 1999) provided the only hierarchical list of key service features, the three most important being:

- staff sensitivity, commitment and accessibility

- educational and therapeutic programmes that fit the child and family needs

- ongoing assessment that uses different techniques appropriate to the individual child.

The Portage home-teaching model

The Portage home-teaching model was introduced into the UK over 30 years ago and now serves well over 5,000 pre-school children (Russell 2007). The central feature of Portage is the home-teaching process. On a weekly basis, home teachers identify new skills which parents would like their child to acquire. Once the home teacher and parents agree on a home-teaching plan, corresponding teaching strategies are then written down and demonstrated by the home teacher before being carried out by the parent.

> *"I think we need more Children's Centres with more organised activities for disabled children. I would also like to see my local authority host more holiday schemes." (Mother)*

Evaluations of Portage schemes have been criticised for not taking into account baseline measures and normal developmental progress. Advocates of Portage have defended the approach by pointing out the bespoke nature of the programme and the difficulty of standardising treatment models (Cameron 1997). Portage programmes have shifted focus since their introduction into the UK from a child-centred to a more family-centred model. This broader approach is reflected in the features of the service considered most useful by parents – a non-representative convenience sample of 161 (Russell 2007 p 681).

The most valuable features of Portage were described as:

- the child making progress through the setting of clear goals and using a 'small steps' approach to learning

- providing emotional and practical support for the family by responding to the individual needs of families and providing encouragement, information, advice and other opportunities, including contact with other families

- the qualities in the service delivery, including home-based support, regular contact, being user-friendly, qualities of the practitioner and their ability to work with families, a positive approach and coordinated service delivery.

8. Which factors or conditions are required for successful outcomes for disabled children, young people and their families?

Key messages

- Services that are successful at improving child–parent relationships may be more successful than services that focus on narrow child developmental goals.

- Successful outcomes for children are associated with family social capital – social disadvantage must be addressed alongside child developmental issues.

- Effective services improve parental responsiveness to children, which helps parents to see themselves as part of an overall strategy for improving their child's care.

This section is based on evidence from seven studies, four from the UK and three from the USA.

The extent to which individuals and families can cope is related to levels of education, income, informal support, social environment and the effectiveness of the services received. Services need to moderate difficulties in families caused by family structure, social disadvantage or parental impairment in order to maximise the developmental progress of the child (Guralnick 2005).

8.1 Developmental outcomes

The relationship between the characteristics and functioning of the child, its family and the likely developmental outcomes is summed up in Figure 1 (see opposite).

The overall message is relatively clear. Families low in social capital by virtue of illness, poor functioning, family structure, oppressive environments or poverty, especially where this is compounded by severe child impairment, will be less equipped to take advantage of support services. Successful outcomes will partly depend on services' capacity to compensate for these problems. Currently, the evidence suggests that the families richest in social capital benefit most from services. Individual teaching methods, while important, may be less crucial than service structure, resourcing and reliability.

Figure 1 **Factors influencing developmental outcomes for children**

Family characteristics

Personal characteristics of parents

* Mental health

* Intellectual ability

* Child rearing practice and attitudes

Financial resources

* Social supports ⟹ **Family patterns of interaction** ⟹ **Child**

* Marital relationships   * Quality of parent–child transactions   **developmental**

* Family, friends, community   * Family orchestrated child experiences   **outcomes**

Child temperament   * Family provided health and safety

⇑
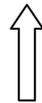
Child characteristics

* Potential stressors for families

   created by child disability

   or biological risk

* Information needs

* Interpersonal and family distress

* Resource needs

* Confidence threats

Source: Guralnick 2005 p 317

8.2 Professional or para-professional?

One key question for early years intervention services is the extent to which similar services requiring different levels of skill (and hence having different costs) can achieve the same result. A study of a para-professional home-visiting service compared outcomes for 88 families who received bi-monthly visits from trained staff who were also mothers of children with special needs, to 71 families who received a normal clinic service (Rosenberg *et al* 2002). Children in all families were less than 50 months old, had or were at risk of developmental disability and considered 'at-risk' due to environmental or care-giver situations. Outcome measures for children were enrolment in early intervention services, increased use of health services, less use of emergency services and reduced risk of maltreatment. Maternal measures were: improved quality of care-giving, increased safety of domestic environment and improved psycho-social functioning. Outcomes for children in the intervention group were the same as for those in the group who received the normal clinic service, though intervention group children were more likely to receive individual service plans. Mothers in the intervention group reported benefits on two measures: improved mental health status at one-year follow-up, and more appreciation of the helpfulness of the intervention. However, the majority of both child and maternal measures were similar in both groups.

The gains detected by this study are more associated with child–parent relationships than specific child developmental gains. These mixed results suggest that a focus on complex developmental programmes may deliver less direct benefit than non-directive parent advice schemes delivered by lay workers, which might improve parent – specifically maternal – self-esteem, confidence and coping skills. This study is an example of a well-received intervention that nonetheless failed to achieve better outcomes than a less intensive one. It suggests caution is needed in expecting impressive results from programmes that do not contain all the elements needed to effect significant change in challenging populations.

Some studies have explored what impact being asked to assume para-professional roles has on parents' identity. The effect on parents of assuming some professional duties may not be all-positive. While based on a small sample, one study has warned that a consequence of parents being enlisted in a para-professional role may be a future rather than a present orientation of parents towards their children and a perception of effective parenting based on professional values rather than that of 'normal' parents (Rix and Paige-Smith 2008).

8.3 Family factors

The evidence base consistently suggests that poorer outcomes are associated with levels of education, resources, positive networks, education, coping strategies and parental responsiveness. Poor coping is associated with lone parenthood, maternal mental health problems, low self-esteem and social isolation. These conditions

disproportionately affect carers, especially mothers, of disabled children, who bear most of the burden of childcare. Teaching programmes such as Portage are aimed at improving child development; it has also been suggested that these programmes can, and should, aim to decrease stress and increase maternal coping. Some families, notably lone mothers, employ poorer coping strategies, which are in turn a predictor of poorer mental health (Bright *et al* 1997). Similar factors and attributes predict both maternal and paternal involvement in services; however, paternal involvement depends much more heavily on financial security (Gavidia-Payne and Stoneman 2004).

8.4 Service factors

Early interventions that promote parental responsiveness to their children have significant impacts on children's developmental functioning, though there appears to be little variation between different instructional models – each appears to be equally successful (Mahoney *et al* 2004). Nonetheless, models which incorporate the improvement of parent–child interactions as a programme goal may be more effective at achieving child developmental outcomes than those that do not.

The evaluation of the Early Support (ES) Pathfinders project found a number of service features associated with success. The projects that were most successful at achieving well-embedded and sustainable provision had taken a service model rather than a service programme approach. A service model approach is concerned with philosophy, principles and implementing practice tools, whereas a service programme approach is driven by eligibility concerns. Other key features (Young *et al* 2008) included:

- a concern with philosophy and principles rather than just eligibility

- a vision of ES as a catalyst for change across children's services rather than a short-term project for a specific population

- a low level of complexity in service design and partnership arrangements.

The authors consider the outlook positive as long as specialist service provision for disabled children and their families is enabled to influence and be influenced by the integrated children's services agenda as a whole. They concluded that the philosophy of Early Support is an example of how a specialist provision can be a coherent component within children's services as long as mainstreaming occurs.

(p 232)

9. Conclusions and main messages

Key findings

- The overall verdict on early years interventions is positive, though excessively optimistic findings from small, poor-quality studies should be treated cautiously.

- The families who benefit most from early years interventions tend to be the best educated and wealthiest.

- Families with fewer resources are likely to benefit more from sensitive needs assessments.

Recommendations for commissioners and providers

- Ensure that early years services consider the needs of the whole family and are delivered in 'natural' surroundings, through a seamless and integrated interagency process.

- Develop services that are characterised by structure, intensity and duration so that gains made by children are built on and sustained.

- Favour programmes which the current evidence base indicates are most likely to result in positive child outcomes.

- Prioritise high-quality pre-school education which the evidence base suggests can reduce subsequent acquisition of an SEN label in primary school.

- Support parents by delivering family-centred early interventions that are sensitive to the environment and capacity of the child and their carers, with special attention to the needs of mothers.

- Be cautious about large-scale investment in new approaches unless there is clear evidence of improved gains of sufficient magnitude to justify the resources and time demanded.

- Use electronic communication media to deliver teaching packages and information to parents and children.

- Introduce comprehensive key worker services; these are associated with better family relationships, quicker access to financial benefits and reduced parental stress.

- Ensure that services address child–parent relationships as well as addressing specific child development goals.

- Integrate early years intervention for disabled children into an overall strategy for improvement in children's services.

- Both the child's development progress and the quality of the support received by parents are of equal importance.

Main evidence gaps

- Information on children from five to eight years

- Robust data on outcomes for parents or other family members

- Data on fathers

- UK empirical studies – these are emerging, but the database is still shallow

- Long-term outcome studies of early interventions, particularly those with a focus on disability rather than social disadvantage

This review has highlighted a number of key messages about 'what works' that could inform the development and delivery of services for disabled children and their families. The most effective early years services are characterised by structure, intensity, duration and lack of complexity, utilise evidence-based behavioural programmes and support whole families as well as addressing child developmental goals. While children from the most disadvantaged families can benefit the most from early years services, actual service usage is disproportionately biased towards more educated and advantaged families. Better targeting of more disadvantaged families is needed to reduce these inequalities. Some early years intervention programmes may make unrealistic demands on families; most frequently this means maternal demands. By delivering family-centred early interventions that are sensitive to the family's environment and capacity, the relationships between services and families may be improved and a more realistic intervention programme agreed and implemented. There is now an extensive evidence base that supports the introduction and maintenance of comprehensive key worker services. These services are associated with better family relationships, quicker access to benefits and reduced parental stress.

This review does not answer all the important questions associated with effective early years services for disabled children. Substantially more information is needed on children aged between 4 and 8 years. The evidence base reviewed focuses largely on pre-school children, with birth to three years old the chronological period most intensively studied. Furthermore, family studies are primarily concerned with mothers and relatively little data is available on fathers. Finally, there is an absence or insufficient quantity of material addressing a number of specific disorders, notably hearing and sight impairments, attention deficit hyperactivity disorder and some other impairment-specific disorders.

The Department for Children, Schools and Families suggests that success in achieving improved outcomes for children is best secured through improved integrated frontline delivery, processes, strategy and governance[10]. The need for whole, rather than partial and ad hoc system change was a theme in the strategic

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[10] For more information, see
www.dcsf.gov.uk/everychildmatters/about/aims/strategicoverview/strategicoverview/

and policy documents reviewed. Whole system change can only be achieved by coordinated action within and between domains, as illustrated in Figure 2.

Figure 2   Whole system change

Source: DCSF 2008b

Key effective strategies emerging from this review relate to the five layers of this 'onion' as follows.

Outcomes for children are young people are to be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic wellbeing (DfES 2003). Strategies include:

- introducing comprehensive key worker services which are associated with better family relationships, quicker access to financial benefits and reduced parental stress

- using electronic communication media to deliver teaching packages and information to parents and children.

Integrated frontline delivery requires the re-focusing of local children's services around the needs of children and families rather than around professional service boundaries. Strategies include:

- ensuring that services address child–parent relationships as well as addressing narrow child developmental goals

- supporting parents by delivering family-centred early interventions that are sensitive to the environment and capacity of the child and their family, with special attention to the needs of mothers.

Integrated processes, including the development of Children's Trusts, sharing of information between professionals and common assessment are essential to drive effective multi-agency working. Strategies include:

- developing services that are characterised by structure, intensity and duration so that gains made by children are built on and sustained

- favouring programmes which the current evidence base suggests are most likely to result in positive child outcomes.

Integrated strategy depends on a process of joint needs analysis, prioritisation, pooling of budgets, planning and commissioning. Strategies include:

- being cautious about large-scale investment in new approaches unless there is clear evidence of improved gains of sufficient magnitude to justify the resources and time allocated

- prioritising high-quality pre-school education which the evidence base suggests can reduce subsequent acquisition of an SEN label in primary school.

Interagency governance requires robust arrangements for interagency cooperation which set the framework for accountability in achieving whole system change. Strategies include:

- ensuring that early years services are delivered in 'natural' surroundings, that they address the family context and are delivered through a seamless and integrated interagency service

- integrating early years intervention for disabled children into an overall strategy for improvement in children's services.

Both the validated practice examples and the feedback from stakeholders largely support the main findings of the review. Integrated and responsive services were valued by parents and carers, especially those which involved:

- a full statutory–voluntary sector mix

- early and sympathetic diagnosis and intervention

- a 'whole' family approach

- partnership with parents

- simplicity rather than complexity

- aspirational features of services

- intensive and persistent interventions – as long as excessive demands were not made of carers, especially mothers.

There was some evidence that electronic communication and intervention models were received with less enthusiasm by parents and young people than by some professionals. Timing of diagnosis and a perception that professionals were reluctant to respond to parental concerns at developmental delay with sufficient alacrity were other points of ongoing dispute. The persistent difficulty many parents have in accessing inclusive day care – or any day care at all – was another notable problem, as was the more general issue of inadequate levels of provision, especially in relation to key workers and high staff turnover. However, the evidence base, which is relatively robust, does provide a number of clear messages and, with some exceptions, a positive account of the potential of effective early years interventions to make a significant difference to the lives of young disabled children and their families.

Data annexe

Key messages

- National datasets are available on the prevalence of disability (including by background characteristics such as age, gender and ethnicity) and also on the social and living circumstances of disabled children and their families. These datasets provide useful monitoring data that can be tracked over time, such as on the prevalence of disability.

- The disabled children's services national indicator (NI 54) measures parental experiences of health, education and social services provided to disabled children.

- At present, however, there is little information about the impact of early interventions on improvements in the wellbeing of disabled children and their families.

Introduction and availability of data

Currently, no survey is specifically designed to collect data on the whole population of disabled children. Some data is available at a national level about the prevalence of disability among children, though the most comprehensive population estimate (from the 2001 Census) (ONS 2001) is now dated. Data on the prevalence of disability by some of the demographic characteristics of children (such as age, gender and ethnicity) is also available, though the coverage is not comprehensive. Data in the *Annual schools' Census* records the primary and secondary special educational needs (SEN) of young people in the educational system. However, while some of these needs may relate to young people's disabilities, they are arguably not sufficient to provide a proxy measure of disability at a national level.

The range of data on the social and living circumstances of disabled children and their families is more limited than data on prevalence, but is available in a number of published datasets, including the *2001 Census* (ONS 2001), and the *Family resources survey* (DWP 2005). However, many of the sources of data on disabled children are limited by factors such as population coverage, in terms of the age of children, geography and their place of residence. Little data is available that is focused specifically on the birth to eight age group. Some datasets provide a breakdown of disability data by age, but this data tends to be aggregated in different ways, with the most common breakdown being for children from birth to four years, then 5 to 15 (or 17) years; some datasets aggregate all data for children into one group of children and young people under 18 years of age only.

Excluding data from specific cross-sectional or longitudinal research studies, there appears to be little publically available data on interventions (and the impact of those

interventions) for disabled young people and their families, or the services and support they receive. Existing data, therefore, provides few if any insights, as yet, into the extent to which early interventions improve the wellbeing of disabled children from birth to eight years.

The disabled children's services national indicator (NI 54) measures parental experiences of services provided to disabled children[11]. It is measured by a national sample survey, in which parents of disabled children complete a questionnaire asking for their views of three service sectors: health, education, and care and family support. The indicator is based on the core offer of *Aiming high for disabled children: better support for families* (HM Treasury and DfES 2007):

- good provision of information

- transparency in how levels of support are calculated

- integrated assessment

- participation and accessible feedback

- complaints procedures.

The five 'core offer' standards for each of the three service areas form fifteen sub-indicators, which are compiled into an overall score for NI54.

This survey is a recent data source. Data were first published in 2008–09, and have since been published for 2009–10. Before this survey, there was little publicly available data that detailed the services and support provided to disabled young people and their families, other than the overviews included in surveys such as the annual *Children in need census* (DCSF 2009b).

This data annexe presents further discussion about the data currently available on disabled children up to the age of eight. It provides:

- a summary of the search strategy for identifying data

- an overview of the nature and scope of the data that was found, with a brief commentary on the quality of this data, and any gaps that have been identified

- data charts on the prevalence of disability, the background characteristics of children with disabilities and service support received.

A summary table of the data sources of readily available, published data for disabled children at a national, regional and/or local authority level is presented in Appendix 4.

Data search strategy

There are a number of archival databases in the UK, such as the National Digital Archive of Datasets (NDAD) and the UK data archive, some of which have services that facilitate searching or access to macro- and micro-datasets (including ESDS International). Even so, searching for current and recently published data cannot yet

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[11] The definition of disability used is based on the DDA definition.

be conducted in the same way as searching for published research findings. Access to newly published data is not supported by comprehensive searchable databases in the same way that literature searches are supported.

Data for this annexe was obtained by a combination of search methods including obtaining online access to known Government publications, such as the *Statistical First Releases* from the Department for Children, Families and Schools (DCSF, now the Department for Education); access to data published by the Office of National Statistics, the Department of Health and other government departments; data published by the National Health Service and other national, regional and local bodies; and online searches following leads emerging from these publications, research funding council summaries and other literature searches. It should be noted that links to statistical sources that were live at the time of searching may not remain live after publication.

Nature and scope of the data

Two recent studies have contributed significantly to an awareness of the range and scope of data availability on disabled children and their families. Read *et al* (2007) identified a range of cross-sectional surveys, panel and longitudinal studies, and administrative data sources for health, education and children's social services, as well as what she called 'sentinel' condition data sources (such as the UK Collaborative Cerebral Palsy Register), that provide data on the prevalence of disability. Mooney *et al* (2008) provided a critical commentary on the nature of the data included in such datasets for the Department for Children, Schools and Families (now the Department for Education). In addition to these two source documents, we have identified a number of other surveys, research studies and administrative datasets that include some indication of the prevalence of disability among children and young people.

Although there appear to be a number of sources of data about the apparent prevalence of disability among children and young people at both national and local level, it is difficult to obtain an accurate estimate of the overall numbers of children and young people in England with disabilities. This is partly because of the wide variation in definitions of disability used by the collectors and collators of that data, and partly because of the ways in which data are collected: while national cross-sectional surveys provide estimates of prevalence, no single administrative dataset collects data specifically on childhood disability.

Read et al (2007) identified four main definitions of childhood disability used by data collectors:

1. Definitions derived from the Disability Discrimination Act (DDA), which includes children whose impairments and conditions result in significant difficulties with daily activities. These definitions are used by the Department for Work and Pensions for surveys such as the *Labour force survey (LFS)* (ONS 2005) and the *Family resources survey (FRS)* (DWP 2005), but are not

used by the Department for Children, Schools and Families (now the Department for Education) for the collection of data on special educational needs (SEN) and were not included in the 2001 Census.

2. Definitions based on limiting long-standing illness, disability or infirmity (LLSI), used in the *2001 Census* (ONS 2001) but with no sub-classification data (by specific disability).

3. Definitions based on long-standing illness, disability or infirmity (LSI), which can capture a wide range of health conditions of varying severity, but which do not give any indication of the extent of impairment.

4. Definitions based on specific impairments (such as visual impairment) or on specific support needs (such as SEN), which do not provide an overview of all disabled children.

A further issue for this data scoping study is raised by the purpose for which data is collected, which can limit the scope and extent of data collection, and/or its ability to be used for comparative or trend analysis:

- **Population census data**, while comprehensive (covering an estimated 96 per cent of the UK population), is infrequent (every 10 years) and uses LLSI without sub-classifications.

- **Department for Children, Schools and Families (now Department for Education) administrative data**, collected through the *Schools' Census*, is comprehensive in including all children and young people in compulsory education from Foundation Stage to Key Stage 4. Data on disability, however, is confined to a classification of primary and secondary need under the SEN variable. It is likely, therefore, that the census underestimates the prevalence of disability. Local authorities' administrative data on disability is collected as part of their statutory requirement under the Children Act 1989 (GB. Statutes 1989), and uses the definitions in that act. The voluntary nature of registration data and the different criteria applied for registration between local authorities means that the data is not a good indicator of prevalence, however. Similarly, until October 2008, the data collected for the *Children in need (CIN) census* (DCSF 2009b) provided an indication of the number of disabled children who received social care during the defined census week but did not cover all disabled children known to the social services or in the local authority area. The 2008/09 CIN census collection covers the period October 2008 to March 2009 while, from April 2009, the data collections will cover the entire financial year.

- **Cross-sectional surveys** (such as the *Family resources survey* or FRS) (DWP 2005) are generally seen as providing the best estimate of disability at any one time, but are often limited in terms of the amount of analysis that can be undertaken, because the data is not linked to the development stage of the child, because the sample size is too small, or because they include only children and

young people in particular family circumstances. Such surveys vary, too, in their definition of disability. While the *Labour force survey* (LFS) (ONS 2005) and the *FRS* are DDA-related (and also use LLSI and/or LSI), the Health survey for England (NHS 2010), the Survey of English housing (DCLG 2009) and the General Lifestyle survey (formerly known as the General household survey) (ONS 2010) are not, primarily using variations of LLSI or LSI or 'sentinel' data recording.

- **Longitudinal panel studies** (such as the Families and children's study (NCSR 2010), the British household panel survey (ISER 2010), the Avon longitudinal study of parents and children (University of Bristol 2010), and the Millennium cohort study (CLS 2010)) while able to track trends over time, may suffer from attrition and are not as good as cross-sectional surveys for providing information on prevalence. The same issues of defining disability definition apply to them as to the cross-sectional surveys.

- **Data collected by primary care trusts** (such as records of disability collected on Child Health Computer Systems, or through the General Practice Research Database) tend to be related to the codes from the *International classification of diseases 2007 (ICD 10)* (WHO 2007).

- **'Sentinel' data** can provide a reliable source of data on children with specific disabilities or known support needs, but registration can be voluntary (as in the case of the Register for Deaf and Hard of Hearing, for example); or dependant on family circumstances (such as the Family Fund Trust); or on reporting by paediatricians (the UK Collaborative Cerebral Palsy Register) or other non-familial source. It is not always clear, therefore, whether population coverage is comprehensive.

At this stage of the data scoping study, we have found little information about the impact of interventions. Published national datasets do not record such information and it is likely that the best source of such evidence in the future will be from targeted longitudinal studies and sentinel data.

Charts showing trends and regional data

Much of the data on children and young people with disabilities aggregates the data, combining data for ages 0 to 17 (such as the Register for Deaf and Hard of Hearing), or differentiating only between pre-school (from birth to four) and school-age populations (five to 15 or five to 17). Data on young people aged from birth to eight is, therefore, difficult to access from public or published datasets. The data on prevalence of disability of relevance to this particular review (which is limited to age eight) is therefore limited.

Data on prevalence of disability (by age, by sex and by ethnicity)

Data from the 2001 Population Census provides some indication of children aged from birth to eight with a limiting long-standing illness (LLSI) (see Figure 3), by age, by sex and by ethnicity, although the aggregations for each variable are different. The age and sex categories provide information on children aged from birth to two, three to four and five to seven; the ethnicity category aggregates data for children and young people up to age 15; while the category for household tenure is divided up to include children aged 0 to four and five to nine.

Figure 3 provides an overview of the percentage of the population of children under seven who were recorded as having a limiting long-standing illness in 2001 (LLSI). The data referred to the general health of the child over the 12 months prior to Census day (29 April 2001). In each age category, the proportion of male children reported as having an LLSI was greater than the proportion of female children with such an illness/disability. As Figure 4 indicates, the proportion of children with an LLSI was also highest, across all age groups, in socially rented accommodation (whether council-owned or other social ownership) and lowest in owner-occupied housing.

Figure 3   All children with a limiting long-standing illness (LLSI): Population Census 2001; by sex
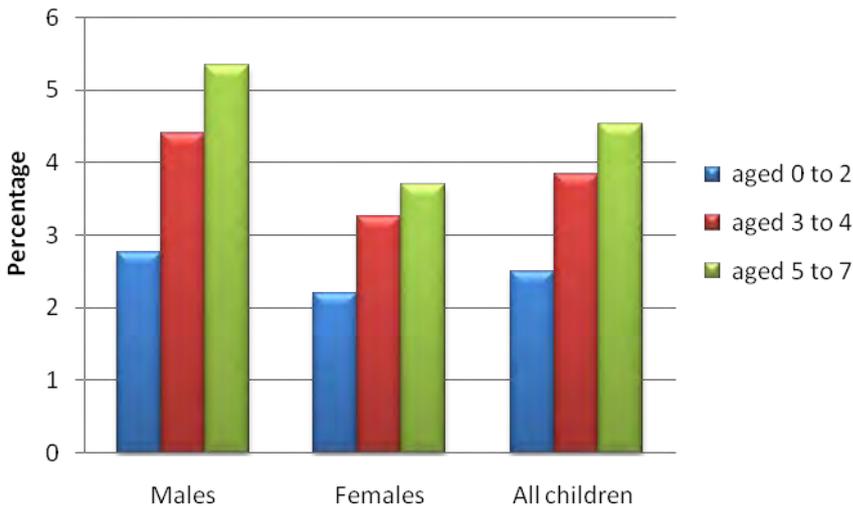
Source: ONS 2001

Figure 4   All children with a limiting long-standing illness (LLSI): Population Census 2001; by household tenure

Limiting long-term illness
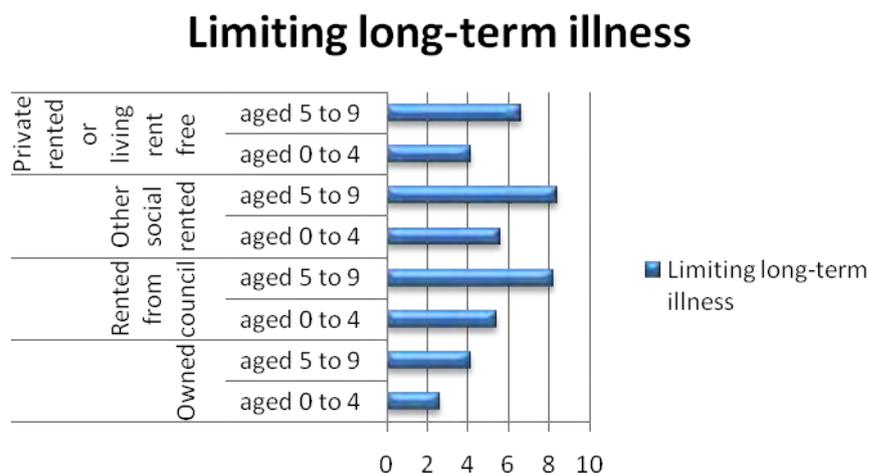
Source: ONS 2001

Data on prevalence of disability (children registered as blind)

There are issues around estimating disability amongst children and young people by reference to children registered as blind or with a visual impairment. There are concerns that data on children and young people officially registered as blind significantly underestimate the rate of visual impairment amongst the young population (Morris and Smith 2008). From audit data collected from Visual Impairment Services departments in 76 local authorities, representing 66 per cent of all of the children and young people educated in England, it was estimated that a total of 21,946 children and young people had a visual impairment. Of these, 4,108 were aged under five and 10,048 were aged five to 11. These figures are markedly higher than the numbers recorded in the Schools Census from the same year as having a visual impairment; 8,080 children and young people of school age in England were identified on the Pupil Level Annual School Census (PLASC) as having a visual impairment as their primary special educational need in 2007/08, while a further 940 were recorded as having multi-sensory impairment (DCSF 2008c).

Other official data on visual impairment (collected during the triennial review in 2008) recorded a total of 4,780 children and young people aged between 0 and 17 registered as blind (3.1 per cent of all those registered blind in England), with most of those (83 per cent) aged between five and 17. The largest numbers were in the North West, followed by Yorkshire and the Humber, London, the South East and the West Midlands. The lowest numbers of children registered blind in 2008 were in the North East (see Figure 5).

Figure 5   All children and young people registered as blind, year ending 31 March 2008: Government Office Regions
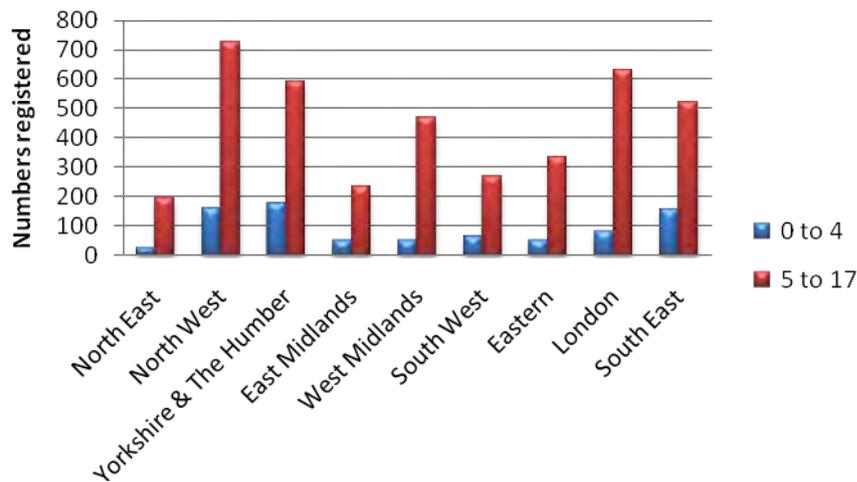
Source: NHS ICHSC 2008

Four per cent of all cases of people newly registered as blind per year are children (a total of 415 cases out of 10,230). As Figures 5, 6 and 7 indicate, there are marginally more cases of older children (those aged five to 17) appearing on the register in 2008, although, in that year, there was a difference across the regions. In the North East, North West, Yorkshire and the Humber, West Midlands, South West, Eastern and London region, more five- to 17-year-olds were registered than those of pre-school age, but in the East Midlands and the South East, the reverse was true.

Figure 6   Blind people registered as new cases by age group, during the year ending 31 March 2008: England and the regions
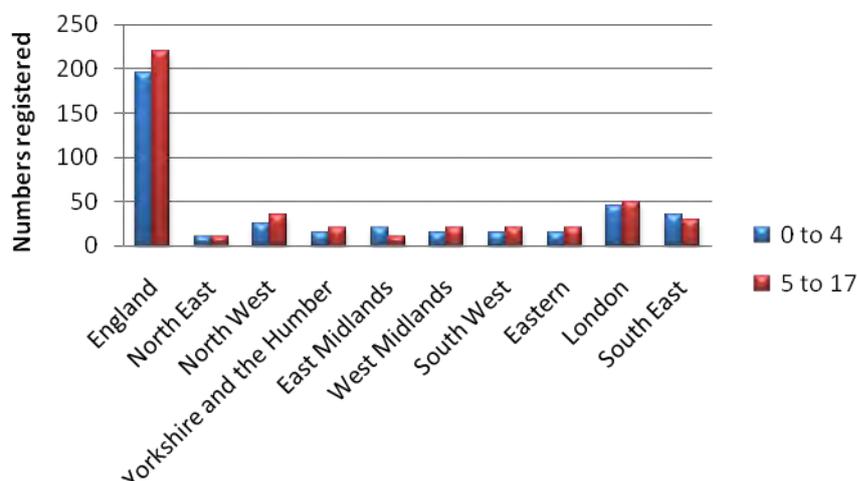
Source: NHS ICHSC 2008

Figure 7   Blind people registered as new cases by age group, during the year ending 31 March 2008: Government Office Regions only
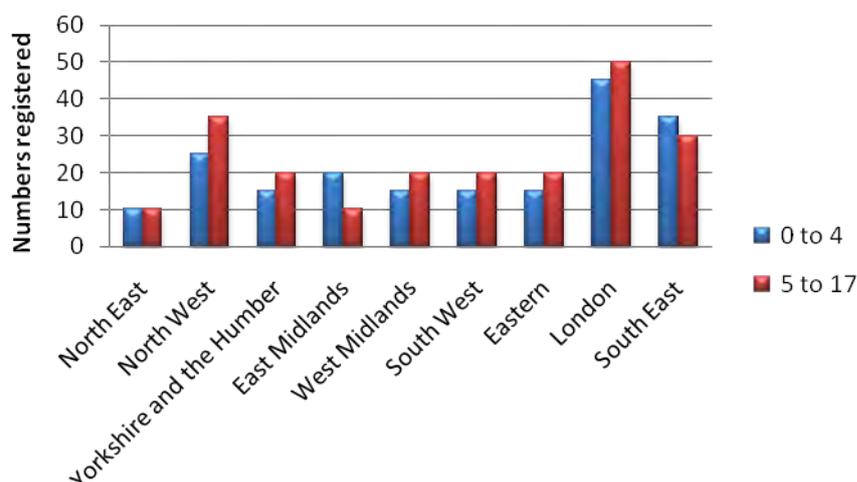
Source: NHS ICHSC 2008

Data on support provision and cost

Data on children with a disability in receipt of social care is collected during the annual *Children in need census* (DCSF 2009b). It should be noted that this Census is of children and families accessing a service in a single week and is not an

estimate of disability – or indeed of the number of disabled children accessing a service (for whatever reason) in a year.

A total of 9,700 disabled children from birth to eight in England received support during the week of the *Children in need census* in February 2005[12], with the numbers receiving support increasing with the age of the child and varying according to family circumstance. Less than one per cent of the children in families receiving support in this age range were aged less than one year of age, by comparison with four per cent of the Looked after children (LAC) in the same cohort. For children between the ages of three and six, the numbers receiving support in family settings was fairly constant, but rose for those from age six to age eight. Over 20 per cent of the disabled children obtaining support in family settings were aged seven to eight; 30 per cent of the disabled children in LAC settings were in the same age cohort. Figure 8 presents the numbers of disabled children, in family settings and in LAC settings, who received support during Census Week 2005.

Figure 8   Numbers of disabled children receiving support during a sample week in February 2005

Source: DfES 2006

The cost of providing such support appears greatest for those children who were looked after, with the cost for the youngest children (those aged under one) being highest (see Figure 9). There appeared to be less variation in cost for children living with their families, although younger girls seemed to attract more costs than male babies and toddlers.

Figure 9   Average cost per child receiving a service by age, sex and need code (disability)
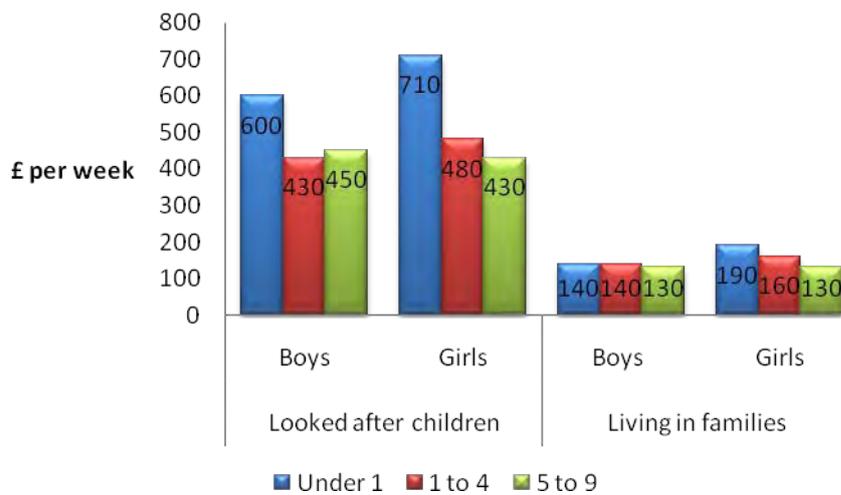
Source: DfES 2006

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Glossary of research terms

This glossary describes different types of study designs and defines some key concepts and terms you will come across when reading research. It is arranged alphabetically.

Action research

Action research is an iterative approach which normally takes place within a practice setting. Unlike models of research where data is collected, analysed and published when the project is complete, researchers in an action research model will interact with staff and users, feed back the results in stages and enable changes in direction, based on the findings, to be made while the project is still underway.

Bias

The deviation from the truth or reliability of results due to the way(s) in which the study is conducted.

Blinding

Refers to measures taken to disguise allocation to groups to avoid bias. In a single-blind study, participants are unaware of which group they have been assigned to, but the researcher does know (or vice versa). A double-blind study means that neither the researchers nor the participants are aware of the allocation to groups.

Case-control studies

Individuals with particular problems are 'matched' with similar people (control group) without the problem. The exposure of the two groups to possible causes is then compared. This can be used to investigate risk factors.

Case study

A case study refers to the in-depth investigation of a single subject or event. The most useful case studies highlight important issues that, while being from the perspective of only one person, can represent a commonly experienced problem.

Cohort studies

Cohort studies collect information about the same individuals at regular intervals over a period of time, which may vary from months to decades.

Confidence interval (CI)

A confidence interval is often used around percentages. For example, a newspaper might report that the average IQ of researchers is 99. If the 95% confidence interval is 80–120 this means that 95 per cent of researchers have an IQ of between 80 and 120.

Control group

A control group is used in order to try to establish whether any effect found in the intervention group was due to the intervention or would have occurred anyway. The control group is the comparison group that gets a different service/ intervention (or no service/ intervention) to the intervention group.

Critical appraisal

A systematic way of assessing a research study, and considering it in terms of validity, bias, results and relevance to your own work.

Cross-sectional surveys

A representative sample of people are surveyed at one point in time. These may be repeated on a regular basis to establish trends. Unlike cohort studies, the same respondents are not re-sampled.

Effectiveness

Describes the extent to which an intervention improves the outcome(s) (ie changes that happen as a result of the intervention) for those receiving it and the extent to which these benefits outweigh the harm (if any) caused by the intervention.

Ethnography

A qualitative research methodology that entails collecting and analysing data in a manner that considers the social and cultural settings of those involved.

Focus groups

The researcher facilitates and leads a group of individuals through a discussion around a specific topic. Focus groups can be more or less structured and the researcher may choose to be directive or take on a more observing role, depending on the objective of the research. A key feature is that participants are able to interact with each other.

Homogeneity

This term is used in systematic reviews to describe the extent results were similar to each other. If many studies show similar results, we can be more confident about the findings. Studies are said to be 'homogeneous' if their results do not vary more than

would be expected by chance. The opposite of homogeneity is heterogeneity, a measure of how study results differ.

Hypothesis

A statement to be tested through investigation or research. A hypothesis should be stated in a way that renders it capable of being proved true or false by the investigation methods proposed.

Intervention

A service, programme or policy intended to affect the welfare of individuals, families or communities.

Intervention group

The group that receives an intervention (service, medicine, treatment). (See also 'case-control studies' and 'randomised controlled trial'.)

Longitudinal study

The same data are collected at different time points over a period of time. Longitudinal studies may be cross-sectional (different respondents) or cohort (same respondents). A longitudinal study is used to measure long-term effects or changes.

Mean

An average obtained by taking the sum of all values and dividing it by the number of values.

Meta-analysis

A statistical technique that pools the results from several studies into one overall estimate of the effect of an intervention. (See also 'systematic review'.)

Narrative reviews

In contrast to systematic reviews, narrative reviews tend to be less methodically executed, often focusing on easily accessible research, such as that published in major journals. A potential problem with this approach is that authors may consciously or unconsciously refer to those studies that reflect their own biases.

Outcome

Changes or effects that happen as a result of an intervention. Outcomes may be for individuals, families, communities or organisations.

P-value (statistical significance)

Broadly, this refers to the probability that the results found by a study have occurred by chance rather than as a result of the intervention. A p-value of 5 per cent (0.05) indicates that there is a 5 per cent probability that the results occurred by chance. A p-value of less than 5 per cent is generally regarded as statistically significant. This does not necessarily mean that the results of the study are important socially and clinically.

Participant observation

A type of qualitative research in which the researchers participate in the social setting they are observing. Observation can be covert or non-covert. However, ethical issues arise with the use of covert observation.

Population surveys

A sample of the chosen population (or the whole population in the case of the decennial UK Census) is asked to provide responses to questions on the subject of interest. Population surveys can be used to measure the prevalence of problems.

Power

Sometimes referred to as 'statistical power', this word describes the likelihood that a sample is large enough to detect a statistically significant difference between a control and an intervention group, if such a difference actually exists. Power sampling can be used to calculate the required sample size.

'Pre-post' studies

Sometimes referred to as 'before and after' studies, this type of research design involves taking measurements at the beginning and end of an intervention (and sometimes at 'follow-up'). The same measurements are taken at time 1 (pre) and time 2 (post), to see if any changes have occurred after the period of intervention. Typically, standardised outcome measures are used, such as a depression scale or a quality of life inventory. Pre-post studies do not contain control groups. Those with control groups would be classified as quasi-experimental or experimental studies.

Purposeful (purposive) sampling

Choosing specific participants with particular characteristics, rather than being based on random selection. Methodologically, this is the least robust form of sampling.

Qualitative research

Concerned with the meanings people give to their experiences and how they make sense of the world. Often studies of people in their natural settings. A range of methods can be used including participant observation and non-participant observation, talking with people (interviews, focus groups) and reading what they

have written. Can be used to find out about social processes and what matters to people, how these vary in different circumstances, and why.

Quasi-experimental studies

These measure the difference between two groups, which are usually pre-existing populations, matched for similarity. One group receives a particular service; the other does not, or receives another type of service.

Randomised controlled trial (RCT)

An experiment in which individuals are randomly allocated either to receive an intervention (intervention group) or to receive no intervention or a different one, such as the standard service (control group). Both groups are measured at baseline and at the end of the intervention period, and are often followed up later. The outcomes of the two groups are then compared to determine the effectiveness of the intervention under investigation.

Reliability

This refers to the likelihood that the same results would be found if the study were repeated in the same way if carried out at different times by the same researcher, or by two different researchers.

Replicability

Researchers should provide sufficient information about a study so it can be replicated by others. The notion of replicability implies that research should be transparent to its readers.

Sample

A subset of cases selected from the population to be studied.

Sample size and power

Sample size is a crucial determinant of whether a difference will be detected if it really exists. Sometimes the number of participants in a study is chosen because the number 'seems appropriate', or because that is how many participants the study can afford to test or interview. However, the appropriate size for a particular study depends on the likely size of the effect you are trying to detect – eg the likely size of the odds ratio (OR), or the magnitude of the difference between two means. Where the effect is likely to be small, then larger study numbers are required.

Semi-structured interview

An interview where the researcher has a set of themes they want to discuss with a respondent, but they are not bound by these themes, and can investigate emerging

issues arising during the course of the interview. (See also 'structured interview' and 'unstructured interview'.)

Standard deviation (SD)

Measures how far results scatter or deviate from the mean. The smaller the standard deviation (in relation to the mean), the more similar the scores; the larger the standard deviation (in relation to the mean), the more spread out the scores.

Statistical significance (see also 'p-value')

Significance levels show you how likely it is that a result is due to chance. The most common level is 0.05. This means that the finding has a chance of 5% (0.05) or less of not being true.

Structured interview

An interview in which the same predetermined questions are asked to each participant. (See also 'semi-structured interview' and 'unstructured interview'.)

Survey

Surveys gather information via a questionnaire or structured interview at one time point to obtain responses from more than one person, which can then be quantified and subjected to statistical analysis.

Systematic review (SR)

A systematic review is a critical assessment and evaluation of existing research that addresses a specific question. SRs are transparent and explicit about the search terms used and range of sources searched. They aim to be exhaustive and comprehensive in the range of sources searched. When a systematic review pools data across studies to provide an estimate of the overall treatment/ intervention effect, it is referred to as a meta-analysis.

Triangulation

The use of more than one theory, method, data source or researcher in a research study to reinforce the trustworthiness of its findings.

Unstructured interview

An interview in which a researcher asks participants very general questions, enabling them to shape the interview in whichever way they see fit, without a predetermined plan for the flow of the conversation. (See also 'semi-structured interview' and 'structured interview'.)

Validity

Validity refers to the extent a study can be regarded as accurate and reliable. If the internal validity is high, the study has been designed and carried out in such a way as to avoid systematic bias – which means that it will give you a good estimate, for example, of the effectiveness of an intervention. External validity is also sometimes called transferability or generalisability, and refers to the extent to which you can generalise the findings from one study and apply them to other populations, settings and arrangements.

Variable

A principle factor of experimental studies is that one element is manipulated on purpose by the researcher to see whether it has any impact upon another measure. The element or factor that is being manipulated by researchers is known as the independent variable, whereas the change (or outcome) resulting from the implementation of the independent variable is the dependent variable.

Appendix 1: Research review methods

The review includes literature identified by a C4EO scoping study (Martin *et al* 2009) as being relevant to the review questions. The scoping study used systematic searching of key databases and other sources to identify literature which was then screened and coded (see Appendix 2). Apart from reference harvesting, no further searching for material other than that located by the scoping review was undertaken for this review.

The review team used a 'best evidence' approach to select literature of the greatest relevance and quality for the review. This entailed identifying:

- the items of greatest relevance to the review questions

- the items that came closest to providing an ideal design to answer the review questions

- the quality of the research methods, execution and reporting.

The team reviewed all priority items and summarised their findings in relation to the review questions. The reviewer also assessed the quality of the evidence in each case. In judging the quality of studies, the team was guided by principles established to assess quantitative research (Farrington *et al* 2002) and qualitative studies (Spencer *et al* 2003).

All items, both from the initial scoping review and from the reference harvest, were coded and entered into a database using the EPPI-Reviewer software managed through the EPPI-Centre at the Social Science Research Unit at the Institute of Education in London. This enables a record to be kept of judgements made on the eligibility or ineligibility of located texts, a summary of the study to be recorded and all items to be organised through a variety of fields including type of publication (book report, paper etc.), date, age range and author. Only items dated 1985 or more recently were included. Items lacking an abstract were excluded. The first sift for eligibility undertaken was based on abstracts only. The second sift was based on an examination of the full text, which resulted in the final choice of studies on which this review is based. In both phases, judgements on eligibility were made independently by two or more reviewers and a consensus agreed. Particular attention was given to items recommended by the Theme Advisory Group.

EPPI Reviewer 3.0 may be viewed at: http://eppi.ioe.ac.uk/eppireviewer/login.aspx

Appendix 2: Scoping study process

The first stage in the scoping study process was for the Theme Lead to set the key review questions and search parameters and agree them with the National Foundation for Educational Research (NFER) scoping team (see Appendix 1 for the full set of parameters). The list of databases and sources to be searched was also agreed with the Theme Lead. Sets of keywords were selected from the British Education Index (BEI) and were supplemented with free text phrases. The keywords comprised an age group set covering a range of terms describing children up to the age of eight; a set of terms relating to disability to ensure retrieval of documents pertaining specifically to disabled children; and a set of terms relating to early interventions. The keywords were adhered to as far as possible for all bibliographic databases, with closest alternatives selected where necessary. Web-based databases were searched using a more limited number of terms, enabling a simultaneous search across the three priority areas within the disability theme.

A list of websites considered relevant to the search was compiled by the NFER team and supplemented by key organisations identified in the National Children's Bureau (NCB) organisations database, the British Education Internet Resource Catalogue (BEIRC) and by others identified in the course of the bibliographic database searches. Current research was specifically searched for in the CERUKplus (education and children's services research) database, in the Research Register for Social Care and on the websites of key organisations. Members of the Theme Advisory Group (TAG) were invited to suggest relevant documents, networks and websites.

The next stage in the process was to carry out searching across the specified databases. The database and web searches were conducted by information specialists. Owing to the spread of database holdings across consortium member institutions, the NFER, the Social Care Institute for Excellence (SCIE) and the NCB; the information specialists worked in close consultation to ensure consistency. Initial screening was done at this stage to ensure that the results conformed to the search parameters. The records selected from the searches were then loaded into the EPPI-Reviewer database, duplicates were removed and missing abstracts sourced. The scoping team members used information from the abstract and/or the full document to assess the relevance of each piece of literature in addressing the key questions for the review. They also noted the characteristics of the text such as the type of literature, country of origin and relevance to the review questions. A 10 per cent sample was selected at random and checked for accuracy by another member of staff.

The numbers of items found by the initial search, and subsequently selected, can be found in the following table. The three columns represent:

- items found in the initial searches

- items selected for further consideration (that is those complying with the search parameters after the removal of duplicates)

- items considered relevant to the study by a researcher who had read the abstract and/or accessed the full document.

Table 1   Overview of searches

	Items found[1]	Items selected for consideration	Items identified as relevant to this study
Databases			
Applied Social Sciences Index and Abstracts (ASSIA)	11	11	
British Education Index (BEI)	54	21	9
ChildData	345	195	127
Cinahl Plus	12	12	6
Cochrane Library	71	67	18
Excerpta Medica (Embase)	43	42	19
Health Management Information Consortium (HMIC)	39	35	14
MEDLINE	57	52	24
PsycINFO	15	15	14

Internet databases/portals			
British Education Internet Resource Catalogue (BEIRC)	81	0	0
CERUKplus	86	9	6
Making Research Count	n/a	n/a	n/a
Research in Practice	7	0	0
Research Register for Social Care	12	0	0
Social Care Online	79	26	21
TAG recommendations (including texts and organisations)	70	70	45

[1] Where n/a is indicated, this is because these resources were browsed rather than searched.

Search strategy

This section provides information on the keywords and search strategy for each database and web source searched as part of the scoping study. The searches were conducted by information specialists at various organisation as follows:

- British Education Index (BEI), British Education Internet Resource Catalogue (BEIRC), CERUKplus, Making Research Count, Research in Practice, Research Register for Social Care and Social Care Online were searched at NFER

- Applied Social Sciences Index and Abstracts (ASSIA), Campbell Collaboration C2 Library, Cumulative Index to Nursing and Allied Health

Literature (CINAHL Plus), Cochrane Library, EMBASE, Health Management Information Consortium, MEDLINE and PsycINFO were searched at SCIE.

- ChildData was searched at the NCB.

All searches were limited to publication years 1985–2008, in English language only.

A brief description of each of the databases searched, together with the keywords used in the searches, are outlined below. The search strategy for each database reflects the differences in database structure and vocabulary.

The following conventions have been used: (ft) denotes that free-text search terms were used, * denotes a truncation of terms; and (+NT) denotes that narrower subject terms have been included (where available).

Applied Social Sciences Index and Abstracts (ASSIA)

(searched via CSA Illumina 20/10/08)

ASSIA is an index of articles from over 500 international English language social science journals.

```
#1    children (+NT)
#2    disability
#3    learning disabilities
#4    sensory impairment
#5    #2 or #3 or #4
#6    #1 and #5
#7    portage (ft)
#8    early support (ft)
#9    early intervention (ft)
#10   early intervention programmes
#11   #7 or #8 or #9 or #10
#12   #6 and #11
```

British Education Index (BEI)

(searched via Dialog 28/10/08)

BEI provides information on research, policy and practice in education and training in the UK. Sources include over 300 journals, mostly published in the UK, plus other material including reports, series and conference papers.

Children set

- #1   infants
- #2   under fives (ft)
- #3   children (+NT)

#4   preschool children
#5   young children
#6   nursery school pupils
#7   kindergarten children
#8   primary school pupils
#9   #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8

Disabled children set

#10   disabilities
#11   disabled children (ft)
#12   disabled adolescents (ft)
#13   disabled students (ft)
#14   disabled young people (ft)
#15   intellectual impairment (ft)
#16   learning disabilities
#17   learning difficulties (ft)
#18   learning disorders (ft)
#19   mental disorders
#20   mental retardation
#21   integrated working (ft)
#22   inclusion (ft)
#23   inclusive education (ft)
#24   #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23

Intervention set

#25   intervention
#26   early intervention (ft)
#27   early support (ft)
#28   childhood needs
#29   family problems
#30   family programmes
#31   family support
#32   portage
#33   #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32
#34   #9 and #24 and #33

British Education Internet Resource Catalogue (BEIRC)
(searched 21/10/08)

The British Education Internet Resource catalogue is a freely accessible database of
information about professionally evaluated and described internet sites which
support educational research, policy and practice.

#1   disabilities or learning disabilities or mental retardation

Campbell Collaboration C2 Library
(searched 14/10/08)

The Campbell Collaboration Library of Systematic Reviews contains systematic reviews and review protocols in the areas of education, criminal justice and social welfare. The Education and Social Welfare sections were browsed but no relevant records were found.

CERUKplus
(searched 30/10/08)

The CERUKplus database provides access to information about current and recently completed research, PhD level work and practitioner research in the field of education and children's services.

#1   disabled children

#2   early intervention programmes

ChildData
(search completed 28/10/08)

ChildData is the National Children's Bureau database, containing details of around 35,000 books, reports and journal articles about children and young people.

Children set
#1   infants
#2   under fives (ft)
#3   preschool children
#4   young children (ft)
#5   nursery school pupils (ft)
#6   kindergarten children (ft)
#7   primary school pupils (ft)
#8   primary school age
#9   under eights
#10   under twos
#11   #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10

Disabled children set

#12   disabilit*
#13   disabled children (ft)
#14   disabled adolescents (ft)
#15   disabled students
#16   disabled young people (ft)
#17   intellectual impairment (ft)
#18   learning disabilities (ft)
#19   learning difficulties
#20   learning disorders (ft)
#21   mental disorders
#21   mental retardation (ft)
#22   mental disability
#23   physical disability
#24   multiple disabilities
#25   inclusion
#26   inclusive education
#27   #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26

Intervention set

#28   intervention (ft)
#29   early intervention (ft)
#30   early support (ft)
#31   childhood needs (ft)
#32   family problems (ft)
#33   family programmes (ft)
#34   family support
#35   portage
#36   #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35
#37   #11 and #27 and #36

Cumulative Index to Nursing and Allied Health Literature (CINAHL Plus)

(searched via EBSCO Host 14/10/08)

CINAHL Plus provides indexing for 3,802 journals from the fields of nursing and allied health.

#1   child, disabled
#2   child development disorders (+NT) or child development disorders, pervasive (+NT)
#3   #1 or #2
#4   mental retardation (+NT)
#5   sensory impairment (ft)

#6   technology dependent (ft)
#7   #4 or #5 or #6
#8   child (+NT)
#9   #7 and #8
#10 #3 or #9
#11 early childhood intervention
#12 early intervention or early intervention (ft)
#13 early support (ft)
#14 portage (ft)
#15 #11 or #12 or #13 or #14
#16 #10 and #15

Cochrane Library

(searched via Wiley Interscience 14/10/08)

#1   disabled children (+NT)
#2   mental retardation (+NT)
#3   developmental disabilities (+NT)
#4   sensory impairment* (ft)
#5   #2 or #3 or #4
#6   child* (ft)
#7   #1 or (#5 and #6)
#8   early support (ft)
#9   early intervention (ft)
#10 portage (ft)
#11 #8 or #9 or #10
#12 #7 and #11

Excerpta Medica (EMBASE)
(searched via Ovid SP 14/10/08)

EMBASE is a major biomedical and pharmaceutical database. There is selective coverage for nursing, dentistry, veterinary medicine, psychology, and alternative medicine.

#1   disabled children (+NT)
#2   mental retardation (+NT)
#3   developmental disabilities (+NT)
#4   hearing disorders (+NT) or vision disorders (+NT) or sensation disorders (+NT) or sensory impairment (ft)
#5   child (+NT)
#6   #2 or #3 or #4
#7   #5 and #6
#8   #1 or #7

#9   portage (ft)
#10 early support (ft)
#11 early intervention (ft)
#12 early intervention (education)
#13 #9 or #10 or #11 or #12
#14 #8 and #13

Health Management Information Consortium (HMIC)

(searched via Ovid SP 14/10/08)

The Health Management Information Consortium (HMIC) database is a compilation of data from two sources, the Department of Health's Library and Information Services, and the King's Fund Information and Library Service. Topic coverage is on health services.

#1   learning disabilities (+NT)
#2   developmental disabilities (ft)
#3   sensory impairment
#4   technology dependent (ft)
#5   disabilities (+NT)
#6   #1 or #2 or #3 or #4 or #5
#7   children (+NT)
#8   #6 and #7
#9   early support (ft)
#10 early intervention (ft)
#11 portage services
#12 #9 or #10 or #11
#13 #8 and #12

Making Research Count

(browsed 27/10/08)

Making Research Count is a collaborative national research dissemination network based regionally in the social work departments of nine UK universities. The following documents available on the national Making Research Count website (www.uea.ac.uk/menu/acad_depts/swk/MRC_web/public_html/) were browsed for relevant items:

- *Research news* Summer 2008 (the first edition of this newsletter)
- Quality Protects Research (QPR) briefings (numbers 1 to 9)

- Every Child Matters (ECM) research and practice briefings (numbers 10 to 16).

MEDLINE

(searched via Ovid SP 14/10/08)

MEDLINE is the primary source of international literature on biomedicine and health care.

- #1   disabled children (+NT)
- #2   mental retardation (+NT)
- #3   developmental disabilities (+NT)
- #4   hearing disorders (+NT) or vision disorders (+NT) or sensation disorders (+NT) or sensory impairment (ft)
- #5   child (+NT)
- #6   #2 or #3 or #4
- #7   #5 and #6
- #8   #1 or #7
- #9   portage (ft)
- #10 early support (ft)
- #11 early intervention (ft)
- #12 early intervention (education)
- #13 #9 or #10 or #11 or #12
- #14 #8 and #13

PsycINFO (searched via Ovid SP 28/10/08)

PsycINFO contains more than 2.5 million records on psychological and behavioural science.

- #1   disabilities (+NT)
- #2   child (+NT)
- #3   early support
- #4   early intervention (+NT)
- #5   portage
- #6   #3 or #4 or #5
- #7   #1 and #2 and #6

Research in Practice
(searched and browsed 27/10/08)

Research in Practice is the largest children and families research implementation project in England and Wales. It is a department of the Dartington Hall Trust run in collaboration with the Association of Directors of Children's Services, the University

of Sheffield and a network of over 100 participating agencies in the UK. The EvidenceBank was searched as follows:

> #1 disability (topic filter)
> #2 early intervention (ft)
> #3 early support (ft)

Research Register for Social Care (RRSC)
(searched 27/10/08)

The RRSC provides access to information about ongoing and completed social care research that has been subject to independent ethical and scientific review.

> #1 disab* (ft) and early intervention
> #2 disab* (ft) and early support
> #3 children and disabled people
> #4 portage (ft)
> #5 team around the child (ft)

Social Care Online

(searched 21/10/08)

Social Care Online is the Social Care Institute for Excellence's database, covering an extensive range of information and research on all aspects of social care. Content is drawn from a range of sources including journal articles, websites, research reviews, legislation and government documents and service user knowledge.

> #1 disab* (ft) and early intervention
> #2 disab* (ft) and early support (ft)
> #3 children and disabled people and integrated services
> #4 children and disabled people and (joint working or multi-disciplinary services)
> #5 portage

Organisations

A list of key organisations was approved by the Theme Advisory Group (see following table). The list, which primarily included the group's specific recommendations, was supplemented by some additional organisations considered relevant by the NFER team. These additional organisations were identified in the National Children's Bureau (NCB) organisations database and through initial Google searches (See Table 2).

Table 2   List of organisations

Organisation	URL	Records selected
Aiming High for Disabled Children	www.everychildmatters.gov.uk/socialcare/ahdc/	1
Barnados	www.barnardos.org.uk	2
Cabinet Office (Prime Minister's Strategy Unit)	www.cabinetoffice.gov.uk/	1
CanChild (Canada)	www.canchild.ca/	3
Care Coordination Network UK	www.ccnuk.org.uk/metadot/index.pl	2
Champion Centre New Zealand	www.championcentre.org.nz/	1
Communication Trust	www.ican.org.uk/Communication%20Trust/Communication%20Trust.aspx	0
Council for Disabled Children (CDC)	www.ncb.org.uk/Page.asp?sve=785	1
Down Syndrome Education International	www.downsed.org	1

Early Support Programme	www.earlysupport.org.uk/	8
Every Disabled Child Matters	www.edcm.org.uk	1
I CAN	www.ican.org.uk	1
Incredible Years	www.incredibleyears.com/index.asp	1
Joseph Rowntree Foundation	www.jrf.org.uk	4
KIDS	www.kids.org.uk/	1
National Children's Deaf Society	www.ndcs.org.uk/	1
National Portage Association	www.portage.org.uk/	6
Norah Fry Research Centre (Bristol)	www.bristol.ac.uk/norahfry/	1
RNIB	www.rnib.org.uk	1
Sense	www.sense.org.uk/	2
Social Policy Research Unit (York)	www.york.ac.uk/inst/spru/	1
Sunfield	www.sunfield.org.uk/	0
Surestart	www.surestart.gov.uk/	1
Thomas Coram Research Unit (Institute of Education)	http://ioewebserver.ioe.ac.uk/ioe/cms/get.asp?cid=470	1
University of Newcastle (Helen McConachie)	www.ncl.ac.uk/ihs/people/profile/h.r.mcconachie	4

Key texts

The Theme Advisory Group provided a list of recommended texts which were located at the start of the searching process. These are listed in the search parameters (Appendix 1).

Appendix 3: Parameters document

(Priority 2.1)

1.C4EO Theme: Disability

2.Priority

2.1 Improving the wellbeing of disabled children (up to the age of eight) and their families through increasing the quality and range of early interventions.

3.Context for this priority

Interventions for disabled children can come too late in their age or developmental stage and this can compromise their current and long-term development and wellbeing. Similarly, with parents, early interventions can ensure families have the support structures in place which they need or are entitled to and which may prevent later crises (in terms of parental or family wellbeing) and heavier demands on (more specialist) services. Early interventions include support and services provided by a range of agencies and thus drive the need for multi-agency working and working with partners (for example housing). This priority is central to Aiming High for Disabled Children. It also links well with the forthcoming mainstreaming of the Early Support Programme.

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4. Main review questions to be addressed in this scoping study (no more than five; preferably fewer)

1. What is the evidence that early intervention for disabled children and their families actually leads to improvements in outcomes?

2. Which early interventions are most valued by parents?

Note: definition of EI: suggest focusing on generic support to the child and family, and leaving out specific medical interventions and therapies. Interventions for sleep and behaviour problems can also be excluded.

5. Which cross-cutting issues should be included? (Child poverty: equality and diversity; disability; workforce development; change management; leadership; learning organisations)?

Equality, inclusion, diversity, leadership, workforce development, change management, learning organisations and safeguarding.

Disability has a strong cultural dimension – this would need to be addressed. There is also an issue around specific impairments, we need to decide whether we are going to look at all disabled young children based on what definition, or specific groups which may be seen to require or benefit more from early intervention techniques.

Please specify the review questions for cross cutting issues in this scope

6. Definitions for any terms used in the review questions[1]

7. What will be the likely geographical scope of the searches?

(Work conducted in/including the following countries)

☐ **England only**

☐ **UK only**

☐ **Europe only**

☑ **All countries (English language)**

8. Age range for CYP:

0–8

9. Literature search dates

Start year

1985

10. Suggestions for key words to be used for searching the literature.

11. Suggestions for websites, databases, networks and experts to be searched or included as key sources.

- please start with the Early Support Programme headed by Liz Andrews who have already put much of this together

- Julie Jennings RNIB

- Sue Buckley Down Education Trust

- Barry Carpenter (Sunfield School)

- for 4 & 5 combined:

- Evaluation of Early Support programme (DCSF website). Person to contact – Alys Young, Univ. of Manchester

- Work on disabled children and Sure Start – Anne Pinney, independent researcher.

- Family-based approach and multi-agency working – work by CanChild (Canada) – www.canchild.ca; key workers and multi-agency working – SPRU and CCNUK

- Helen McConachie, University of Newcastle (early intervention and ASD)

- Early Support – Liz Andrews

- White Hill Centre – XX

- National Portage Assoc. XX

- SENSE- Eileen Boothroyd

- Communication Trust XX

- Incredible Years – Judy Hutchins

- Avon Premature Infant Project

- Phoenix Centre, Bromley – Helen Norris

- Star Centre

- National Deaf Children's Society

- I CAN

[Please look at international models eg Champion Centre, NZ, roll-out of portage in

Spain etc

Early Support Databank

Prime Minister's Policy Unit (information on children's trusts and what makes a difference to outcomes for disabled children).

DATABASES: ASSIA; BEI; BEIRC; CINAHL; CERUKplus; ChildData; MEDLINE; PsycINFO; Cochrane, CENTRAL/ SPECTR/ C2RIPE (Campbell collaboration), HMIC and EMBASE.

Appendix 4: NI Indicators and key data sources

Table 1   National indicators and data sources, by Every Child Matters outcome

National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)
Demographics		Population census (2001)	UK, regional and local authority	Every 10 years	2001	1801	www.nomisweb.co.uk/home/census2001.asp Trend data available
Demographics		People registered as blind/partially sighted, NHS Information Centre (2008)	National, regional and local authority Data available on children aged 0–4 and 5–17	Every three years (2009 data collection moved forward a year)	2008	1982	http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/people-registered-as-blind-and-partially-sighted-2008-england Trend data available
National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)

Demographics		National Statistics/DH: *People registered as deaf or hard of hearing* (March 2007)	National, regional and local authority Data based on 0 to 17-year-olds	Every three years	2007	1989	www.ic.nhs.uk/webfiles/publications/Registdeaf2007/2006-07%20Deaf.pdf Trend data available
Demographics		NFER/RNIB survey of local authority visual impairment services	National (100 English local authorities and/or consortia) Data available on children aged 0–23 months, 24–35 months and 36–59 months	Ad hoc (1995, 2002, 2007)	2007	1995	http://www.rnib.org.uk/aboutus/Research/reports/edemp/Pages/edemp.aspx Trend data not available
Demographics		General LiFestyle Survey (GLF)	Great Britain only Data available on children aged 0–4 and 5–17	Annual	2008	1971	http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=5756 Trend data available (from General Household Survey)

National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)
Demographics		DWP: Family resources survey	Great Britain and Northern Ireland, and regional data	Annual	2007/08	1992	http://research.dwp.gov.uk/asd/frs/2007_08/frs_2007_08_report.pdf Trend data available
Be healthy							
NI54	Services for disabled children	DCSF: Parental experiences of services provided to disabled children	National, regional, local authority and PCT Sample survey data on parental experiences of services for children and young people aged 0–19	Annual	2009/10	2008/09	http://www.dcsf.gov.uk/rsgateway/DB/STR/d000902/index.shtml Trend data will be available in the future

National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)
NI54	Services for disabled children	DfES: Children in need census	National, regional and local authority Data based on children under 18, including unborn children.	Annual between 2000–2005)	2005	February 2000	http://www.dcsf.gov.uk/rsgateway/DB/VOL/v000647/index.shtml Trend data available.
NI54	Services for disabled children	BMRB: Social research childcare and early years providers surveys: children's centres (2008)	National data only	Biannual 2001–2005; Annual 2006–2008.	2008	2001	http://www.dcsf.gov.uk/research/data/uploadfiles/DCSF-RR164(R).pdf Trend data likely
National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)

National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)
NI54	Services for disabled children	Health of Children and Young People	UK	N/A	N/A - derived from various data sources	N/A-derived from various data sources	www.statistics.gov.uk/cci/nugget.asp?id=795 www.statistics.gov.uk/Children/downloads/disability.pdf Trend data available.
NI54	Services for disabled children	Health Survey for England	England only	Annual	2008	1991	http://www.ic.nhs.uk/statistics-and-data-collections/health-and-lifestyles-related-surveys/health-survey-for-england Trend data available
Stay safe							

NI69	Children who experience bullying	Youth Cohort Study and Longitudinal Study of Young People in England	National	Annual	2008	2004 (for LYSPE), and 1985 for YCS	www.dcsf.gov.uk/rsgateway/ DB/SBU/b000795/index.sht ml http://www.dcsf.gov.uk/rsgat eway/DB/SBU/b000850/inde x.shtml Trend data available
National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)
Enjoy and achieve							
NI72	Achievement of at least 78 points across the Early Years Foundation Stage with at least six in each of the scales in Personal,	DCSF: Foundation stage profile	National, regional and local authority	Annual	2008/09	2003/4	http://www.dcsf.gov.uk/rsgat eway/DB/SFR/s000879/inde x.shtml Secondary analysis required to explore attainment of students with SEN/a disability Trend analysis may be possible for some years. However, the data

National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)
	Social and Emotional Development (PSED) and Communication, Language and Learning (CLL)						collection changed in 2006/07, so data are not comparable for all years.
NI92	Narrowing the gap between the lowest achieving 20% in the Early Years Foundation Stage Profile and the rest	Foundation Stage Profile	National, regional and local authority	Annual	2008/09	2003/4	http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000879/index.shtml Secondary analysis required to explore attainment of students with SEN/a disability Trend analysis may be possible for some years. However, the data collection changed in 2006/07, so data are not comparable for all years.

National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)
Additional indicators – early years		DCSF: Early Years Foundation Stage Profile attainment by pupil characteristics, in England (2008/09)	National, regional and local authority	Annual	2008/09	2006/07	http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000911/index.shtml Trend data available
NI104	The SEN/non-SEN gap – achieving Key Stage 2 English and maths threshold	DCSF: Key Stage 2 attainment by pupil characteristics, in England (2008/09)	National, regional and local authority	Annual	2008/09	2005/06	http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000889/index.shtml Trend data available

National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)
NI105	The SEN/non-SEN gap – achieving 5 A*–C GCSEs including English and maths	DCSF: GCSE attainment by pupil characteristics, in England (2008/09)	National, regional and local authority	Annual	2008/09	2005/06	http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000900/index.shtml Trend data available
Additional indicators – SEN		DCSF: Special educational needs in England (January 2009) Pupil Level Annual School Census (PLASC) and the SEN2 survey	National only	Annual	2009	1984/5	http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000852/index.shtml Trend data available

National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)
Positive contribution							
NI110	Young people's participation in positive activities	Health of children and young people	UK	N/A	N/A-derived from various data sources	N/A - derived from various data sources	www.statistics.gov.uk/Children/downloads/disability.pdf www.statistics.gov.uk/cci/nugget.asp?id=795 Trend data available
NI110	Young people's participation in positive activities	Youth cohort study and longitudinal study of young people in England	National	Annual	2008	2004	http://www.dcsf.gov.uk/rsgateway/DB/SBU/b000795/index.shtml www.dcsf.gov.uk/rsgateway/DB/SFR/s000760/index.shtml http://www.dcsf.gov.uk/rsgateway/DB/SBU/b000850/index.shtml

National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)
							Trend data available
NI 110	Young people's participation in positive activities	Taking part: the national survey of culture, leisure and sport: headline findings from the 2008/09 Taking Part child survey	Sample survey, England only

2,622 interviews | Annual | 2008/09 | 2005 | http://www.culture.gov.uk/reference_library/publications/6409.aspx

Trend data not available for 5–10 year olds as first year of collection, but may be available for 11–15 year olds. |

NI 110	Young people's participation in positive activities	PE and Sport Survey 2008/09	School census (99.8 per cent of all schools in England)	Annual	2008/09	2003/04	http://www.teachernet.gov.uk/_doc/14380/DCSF-RR168.pdf Trend data available
NI 110	Young people's participation in positive activities	TellUs4	Sample survey: national and local authority	Annual	2009	2007	http://www.tellussurvey.org.uk/Default.aspx Trend data not available
National indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)
Economic wellbeing							
NI116	Proportion of children in poverty	DWP: Family resources survey (2005)	Great Britain and Northern Ireland, and regional data	Annual	2007/08	1979	http://research.dwp.gov.uk/asd/frs/2007_08/frs_2007_08_report.pdf Trend data available
NI117	16–18-year-olds who are not in education, employment or training	Youth cohort study and longitudinal study of young people in England	National	Annual	2008	2004	http://www.dcsf.gov.uk/rsgateway/DB/SBU/b000795/index.shtml http://www.dcsf.gov.uk/rsgateway/DB/SBU/b000850/inde

| | (NEET) | | | | | x.shtml |
| | | | | | | Trend data may be available |

Appendix 5: Validated local practice assessment criteria

A small group of sectors specialists assess all the practice examples sent in to C4EO from the sector. The group use the following criteria to assess each example.

- **Adequacy of the information supplied.** Is there enough to apply the validation process? If not, and if the practice has potential, NFER will request more information; we will try to do this at screening stage.

- **Strength of the rationale**. Was the intervention/practice fit for purpose and based upon a clear and sound rationale? Was it based on prior and good quality evidence of need and what works in similar contexts?

- **Sufficiency of impact and outcome evidence**. Is there sufficient external and/or internal evaluation evidence that the practice/intervention has made a difference and led to improved outcomes? Are there good practitioner, service user and other stakeholder views? Do others implementing the same or similar practice or strategy changes or interventions report similar findings?

- **Evidence of what has/has not worked and why**. Is there some good guidance here which will be useful to others? What are the golden threads for what works? What barriers and ways of overcoming these have been documented?

- **Actual or potential for replication or transfer to other contexts and settings.** What evidence is there that the practice has already been successfully transferred to different settings, or has the potential for replication? Which elements are especially transferable? What elements are non-negotiable, and which are open to adaptation to suit other contexts? What do people need to put in place to transfer the practice, without substantial loss of effect?

Twenty two practices examples of relevancy to this review had been submitted at the time of writing. The review authors have only included the four examples that the validation panel assessed as being strongly supported by practice experience and evidence.

Strongly supported practice examples are fairly mature and well tried out interventions and practice for which there is convincing outcome data. The practice will have been applied to different settings or have been strongly developed within more limited contexts.

All the practice examples featured within the review, and those submitted and validated since the review was written, are available at the C4EO site.

Appendix 6: Stakeholder data

Parents and Carers

Overall, out of the Parents and Carers Panel, 19 parents have a child with a disability. This is made up of 4 fathers and 15 mothers. Fifteen of these responded to the early interventions and positive activities reviews and nine responded to the diverse needs review. They gave feedback on the reviews either by email or at meetings.

Children and young people

A total of 10 young people took part in two focus groups carried out by the Council for Disabled Children (CDC). Four disabled young people aged from 15 to 17 years were consulted by the National Children's Bureau (NCB) via questionnaires and interview feedback. Two of the young people had a Black or minority ethnic (BME) background.

Service providers

One hundred and seventy delegates attended the C4EO disabled children knowledge workshops (this figure excludes presenters and C4EO and partners).

The breakdown is as follows:

Category	Number of Delegates
LA Children's Services (Excl Sure Start)	122
Health	23
3rd Sector	14
Councillors/Lead Members	0
Sure Start Centres	0
DCSF/Government Offices	7
Misc	2
Parents and Carers	2
Total	170

JUNE 2010   **C4EODKR1**

Improving the wellbeing of disabled children through early years interventions (age 0–8)

This review aims to draw out the key 'what works?' messages on improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities. It addresses four questions, which were set by the C4EO Theme Advisory Group (TAG), a group of experts in disability policy, research and practice.

Centre for Excellence and Outcomes in Children and Young People's Services (C4EO)
8 Wakley Street
London
EC1V 7QE
Tel 020 7843 6358
www.c4eo.org.uk

117