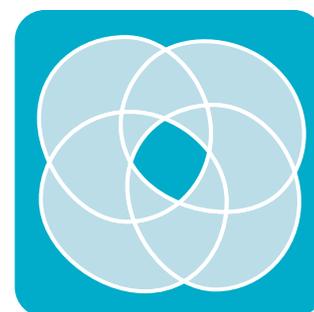


Early Support

Helping every child succeed

Professional guidance



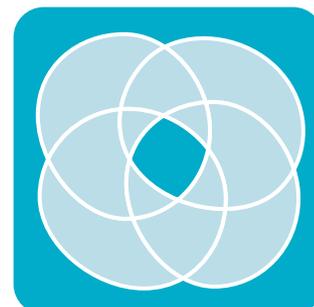


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'Through the forthcoming National Service Framework for Children, and the implementation of Every Child Matters, we will ensure the principles established by the Early Support Pilot Programme become integral to practice nationally.'

Removing Barriers to Achievement: The Government's Strategy for SEN
(2004)



Introduction

The *National Service Framework for Children* emphasises that young children who are disabled or who have complex health needs should receive co-ordinated, high quality child and family-centred services which are based on assessed needs, promote social inclusion and which, wherever possible, enable families to live ordinary lives. This guidance explains what is involved in achieving this. It builds on existing good practice and what families with disabled children say would improve the way that professionals work with them in the early years.

It can be used by anyone working with families with children who have special educational needs or disabilities in the first three years of life. It is likely to be of most use to people who work with this population on a regular basis, but should also be of interest to anyone working for health, education or social services or in a Children's Centre, Sure Start programme or early years or childcare setting with very young children.

The guidance is designed to help people who are doing an important and sometimes difficult job, supporting families, babies and children.

It explains how:

- the principles set out in *Together from the Start* can be applied flexibly in many different organisational settings
- the *Early Support* materials can help on an everyday basis at operational level
- initiatives that are driven 'bottom up' by families and the professionals working with them must be supported by multi-agency planning at strategic level.

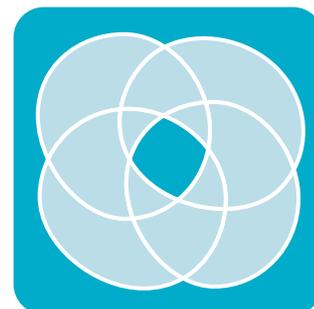
Why is professional guidance needed?

The [Early Support](#) initiative works in partnership with health, education and social services, service users and organisations in the voluntary sector to improve things in areas where family-centred multi-agency support for young children and their families is not yet well developed. Although practice in some areas is good, in general, change is overdue.

'Research on the needs of families with disabled children has produced consistent findings from studies covering different time periods, different areas of the country and different populations. The message from these studies is that substantial numbers of families report a 'constant battle' to find out about what services are available and about the role of different agencies and different professionals; to get professionals to understand their situation and their needs; to obtain recognition of their own knowledge of their child; to negotiate delays and bureaucracy. A major reason for the problems families face with services is the multiplicity of agencies and professionals involved with families of disabled children, the lack of co-ordination between different agencies and the burden on the family in terms of multiple contacts.'

Sloper P et al (1999)

'My son doesn't receive a co-ordinated package of therapies. Many 'experts' see him and deal with their part of him and then send him back to me for reassembly.'



Implementing *Together from the Start*

Summary

This section reviews *Together from the Start* and explains how it underpins the **Early Support** initiative and materials.

Background

In May 2003 the Department for Education and Skills and the Department of Health published *Together from the Start – practical guidance for professionals working with disabled children (birth to third birthday) and their families*.

Guidance addressing the particular service needs of families with very young deaf children identified by newborn hearing screening was published at the same time.

This guidance should be read alongside *Together from the Start*, the key document driving the implementation of service change through the **Early Support** initiative.

Where to find out more

If you have not already read *Together from the Start* or *Developing early intervention/support services for deaf children and their families* ring DfES Publications on 0845 602 2260 to order a copy.

Together from the Start and all the **Early Support** materials can be viewed and downloaded from the **Early Support** website at www.espp.org.uk

What does *Together from the Start* say?

Together from the Start recognises that where children have special needs or disabilities, it is important that these are identified at an early stage and that identification leads directly to early intervention and support for

families and children. It emphasises that early intervention strengthens the ability of families to provide effective support for their children and improves outcomes for the whole family.

The document identifies six priorities for service development:

- better initial assessment of need
- better co-ordination of multi-agency support for families
- better information and access for families
- improved professional knowledge and skills
- service review as a means to service development
- partnership across agencies and geographical boundaries.

Extract from *Together from the Start*

Together from the Start identifies the following key barriers to effective service delivery and partnership working with families:

- a lack of sensitivity at the time of diagnosis
- inconsistent patterns of service provision
- lack of co-ordination between multiple service providers
- exclusion from some mainstream and community services and facilities.

It reports the consistent experience of families and professionals that the following factors have a positive impact on service development and provision:

- earlier diagnosis and a joined-up approach to assessment
- effective co-ordination of service provision that incorporates the sharing of information
- the use of Family Held Records



continued...

- provision of a key worker who can act as a gateway multi-disciplinary support
- effective communication between professionals
- emotional support.

Together from the Start also emphasises the importance of [Family Service Plans](#) as a focus for joint planning, review and decision-making about priorities and service provision.

What kind of service provision does *Together from the Start* recommend?

Together from the Start recommends flexible, family-centred support that is:

- competent
- compassionate
- comprehensive
- continuous
- well co-ordinated
- culturally sensitive.

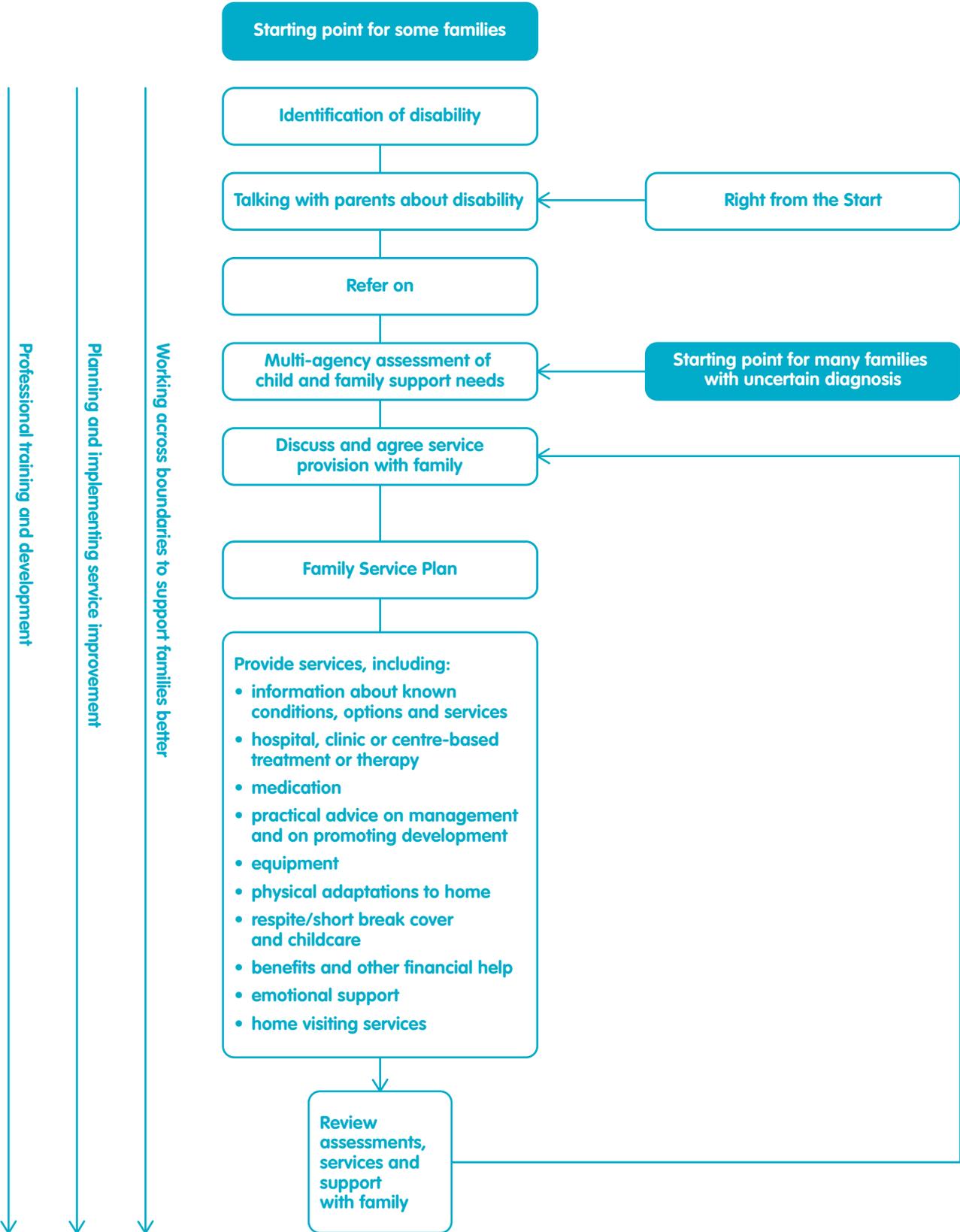
It says that families should experience 'intervention' as a linked series of events that is responsive to family need and which follows up identification of impairment or disability quickly with information and practical help. Action should be triggered at the point it becomes clear that a baby or young child has a condition which has a high probability of resulting in developmental delay or is already experiencing significant developmental impairment or delay. It emphasises that difficulty achieving a definite diagnosis should not prevent the provision of services and support where there is a clear need for support to be provided.

A diagram summarising key elements of service provision for families described by *Together from the Start* is presented on page 9. The material is presented as a flow diagram which progresses down the page as time

passes through assessment, joint discussion and planning to the provision of services and support. The review loop on the right is critical. It embeds an expectation of periodic joint review of the child's situation and support arrangements with families kept at the heart of decision-making. Key service level processes that run alongside direct work with families are identified on the left.

The flow diagram describes service provision for a very diverse population of children and families. Where conditions are identified in the early days of life, the model is robust enough to support professional practice through a three-year period. Where the identification of need in a child emerges over time and with less clarity, it emphasises the importance of joint discussion and planning from the point that a need for support is recognised. The interaction of information and practical help in empowering families to help their child is emphasised.

Model for support: *Together from the Start*





Early Support and the Early Support materials

Summary

This section explains how the **Early Support** initiative is implementing *Together from the Start* and introduces the **Early Support** materials.

'We see the effective dissemination of ESPP materials not as a stand alone task, but as an essential element in a package of measures aimed at identifying and supporting families much earlier on and improving co-ordination in planning and service delivery.'

Early Support Pathfinder

Early Support – phased implementation of *Together from the Start*

Early Support is a Government programme involving the Department for Education and Skills, Sure Start and the Department of Health. The purpose of the programme is to improve the delivery of services to disabled children under three and their families. **Early Support** promotes service development in partnership with health, education and social services, service users and organisations in the voluntary sector.

Early Support facilitates the phased implementation of *Together from the Start* across England. In 2002/03 it supported 27 initiatives developing aspects of service provision. In 2003/04 the programme worked in partnership with nine Pathfinder areas, encouraging them to:

- improve services, supported by funding and a multi-agency development plan
- use prototype **Early Support** materials with families and suggest improvements
- feed back experience about what is involved in implementing systemic change across agencies for very young disabled children and their families at local level.

From September 2004, [Early Support](#) will be funding and working with a community of 45 programme partners across England. See Appendix 1 for more details.

From the perspective of professionals, the [Early Support Pilot Programme](#) (ESPP) supports the implementation of change at operational and strategic planning levels with funding, training and materials.

From the perspective of families, ESPP:

- directly empowers parents with information
- provides families and professionals with practical tools to facilitate better multi-agency working
- helps professionals to help parents help their child.

The Early Support materials

[Early Support](#) has developed a flexible array of materials to support service development. The different components interact with one another and work best when used alongside one another. The materials comprise:

- This [Early Support Professional Guidance](#)
- An [Early Support Family Pack](#) and a set of [Information for parents](#) booklets
- An [Early Support Service Audit Tool](#)
- An [Early Support Monitoring Protocol for Deaf Babies and Children](#)

Read more about all the materials that are available at www.espp.org.uk and in Appendix 2

The introduction of these standard materials across the country will:

- make it easier for families to get hold of the information they need
- improve professional knowledge and understanding
- put materials into the hands of professionals across health, education and social services which directly support the work they do with families
- encourage better co-ordination of services via keyworking (or 'care co-ordination') and home visiting services



- improve the consistency and quality of support available to families in different parts of the country.

All the [Early Support](#) materials have been developed in active partnership with families and with those who work directly with families. A particular characteristic of programme activity in 2003/04 has been partnership working with a range of voluntary organisations representing a service user perspective in addition to the nine ESPP Pathfinder areas.

It is intended that the materials will be reviewed in 2006 when they have been in use for two years.

How the Early Support materials build on *Together from the Start*

All of the material produced by ESPP directly supports service providers in the work they undertake with families. They are equally relevant for people working for health, education, social services or for a voluntary organisation:

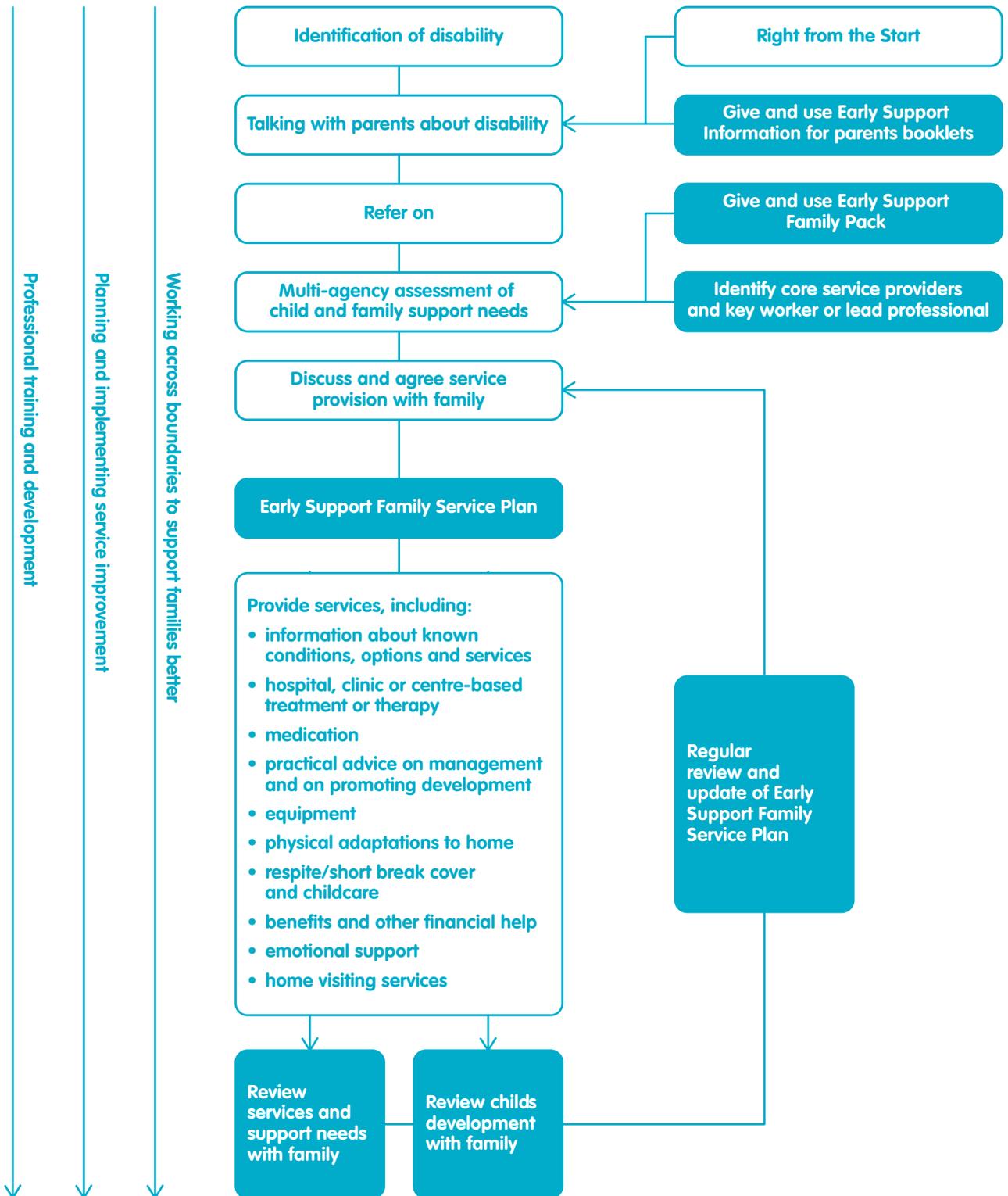
- The [Early Support Family Pack](#) provides information about how services operate and about where to look for help. Professionals can use and revisit this information bank with families as joint understanding of a child's situation and need grows over time. The [Family File](#) from the pack is a standard Family Held Record. It directly supports better co-ordinated joint action where more than one agency is working with a family. The [Family Service Plan](#) in the [Family File](#) provides the means to put into practice the recommendations made in *Together from the Start* about joint planning which keeps families at the heart of decision-making processes. All the material in the [Early Support Family Pack](#) is of direct, practical use to any professional working in a key worker or care co-ordination role.
- The [Information for parents](#) booklets provide standard information about particular conditions or disabilities. They can help professionals to respond to family need for information about the particular factors or conditions that are relevant for a child in the early days following a diagnosis.

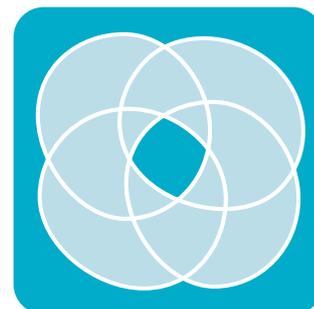
- The [Early Support Service Audit Tool](#) provides a means to carry forward the recommendations set out in *Together from the Start* about service review and strategic planning for multi-agency service development and change.
- The [Early Support Monitoring Protocol for Deaf Babies and Children](#) helps families with very young deaf children track development and it informs the discussions about emerging language and communication which go on between professionals and families over time.
- This [Early Support Professional Guidance](#) explains how to use all the other materials to put the principles set out in *Together from the Start* into practice.

The relationship of the [Early Support](#) materials to stages in the model for service provision suggested by *Together from the Start* is elaborated on in the following diagram. Better keyworking or care co-ordination is at the heart of the service development for the families discussed here and so it is also highlighted.

Read more about how the Early Support materials and Family Service Plans help key workers or lead professionals to do their job in **Keyworking, key workers and care co-ordination** and **Making and reviewing joint plans**

Model for support: Early Support building on *Together from the Start*





About this guidance

Summary

This section explains how the [Early Support Professional Guidance](#) is organised and how it is designed to be used.

Each section of this guidance expands on a key theme from *Together from the Start* and explains how the [Early Support](#) materials can be used to support professional practice and improve the information and support available to families.

In most sections, general information is complemented by examples of multi-agency service provision or initiatives to bring about service change. Additional case study material is available online at www.espp.org.uk

The guidance should not be read in isolation. The other [Early Support](#) materials interact directly with this text. Each section explains how the materials can be used to improve service delivery and begins with:

- a flow diagram representing the vision for service provision set out by *Together from the Start* to orientate readers, with red marks indicating the aspects of service provision that are addressed
- references to key policy documents, positioning material within broader policy initiatives
- a list of [Early Support](#) materials which should be read alongside the section
- [Early Support Service Audit Tool](#) standards and indicators that relate to the aspects of service provision covered.

A note about terminology

The guidance has been written for wide and flexible use across a range of organisational structures provided by health, education and social services and voluntary agencies. Particular professional groups are rarely identified – the emphasis is more on service functions that empower families to support their child.

The material is relevant for a long list of professional groups who work with young disabled children and their families on a regular basis, including:

- paediatricians
- social workers
- teachers
- health visitors
- speech and language therapists
- portage workers
- physiotherapists
- educational psychologists
- occupational therapists.

A note about presentation

Extracts from *Together from the Start* and other professional guidance materials are boxed throughout the text for easy reference.

Quotations from parents of young children are also presented consistently so that they can be easily recognised. Wherever text *appears in green italics like this* it means a parent or family member said it. Refer to the back of the publication for an additional note about quotations from families.

Working in partnership with families

Before moving on to the detailed material contained in the sections that follow, it is good to review the general principles for working with families set out in *Together from the Start*. These principles are reflected in all the **Early Support** materials and continue to steer the development of the **Early Support Pilot Programme** as a whole.

Early Support goes beyond the concept of partnership with parents. The starting point is respect for the daily reality of family life for parents who are raising young children in a situation which presents them with



repeated, unusual and unpredictable challenges and which is often highly emotionally charged. Improved service provision means joint decision-making, the right information at the right time and enough continuity of support to enable parents to take decisions and initiate positive action to help their child.

Extract from *Together from the Start*

Key principles for working with families include:

Rights and responsibilities

Parents have rights and responsibilities in relation to the development and care of their child. Professionals have a duty to acknowledge and understand the unique role and relationship each parent has with their child.

Respect

Parents have unique knowledge about their child. They have the right to be respected as the primary carers of their child.

Informed choice

Parents have the right to be provided with unbiased, accurate and up-to-date information in order to be able to make informed and appropriate choices for their child.

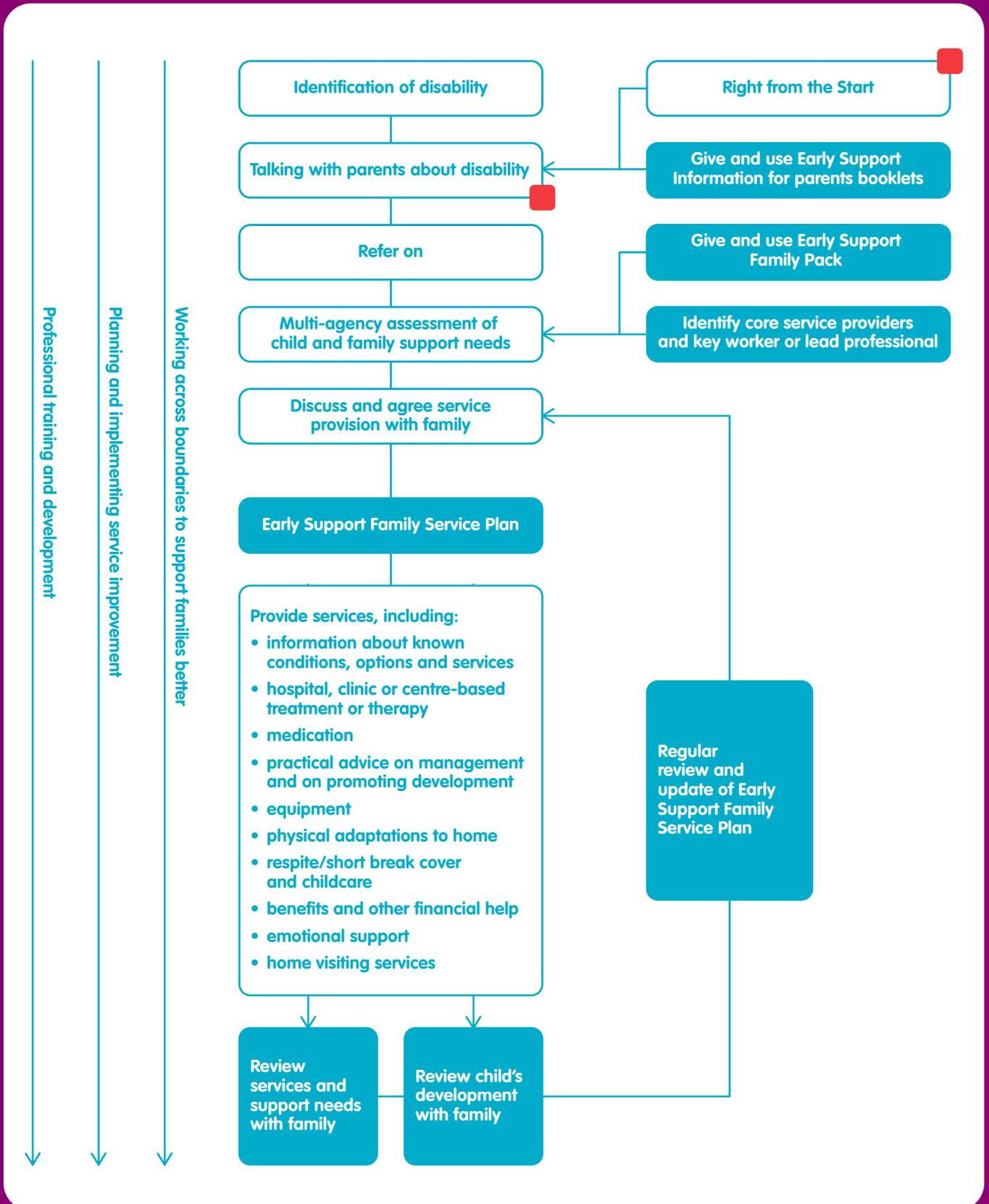
Individuality

There are many common issues for parents of disabled children, but no two families are the same or have identical needs. Families can be diverse in terms of their experience, resources and expectations as well as their cultural, religious and linguistic influences.

Equality

Optimum support for a disabled child will only occur when parents are considered to be valued and equal partners alongside the range of professionals working with them and with their child.

1 Right from the Start: talking with families about disability



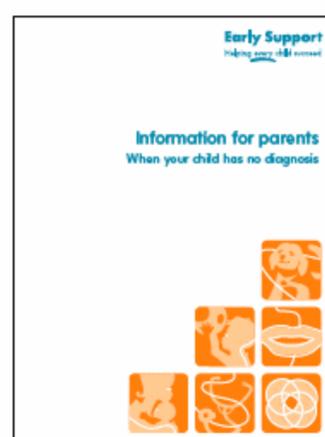
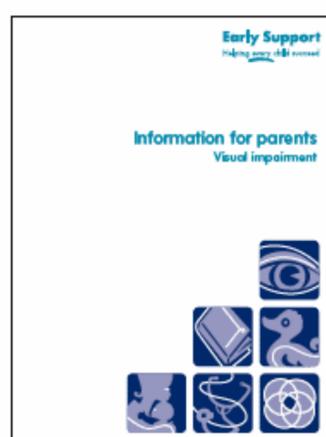
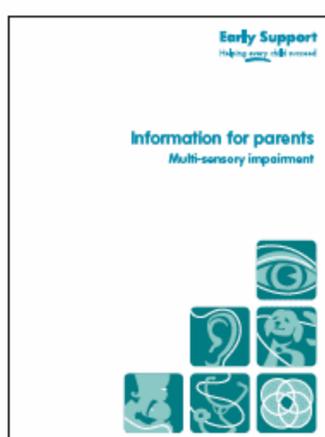
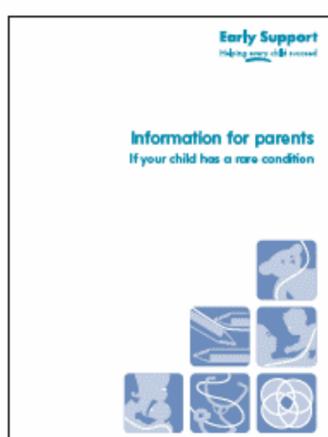
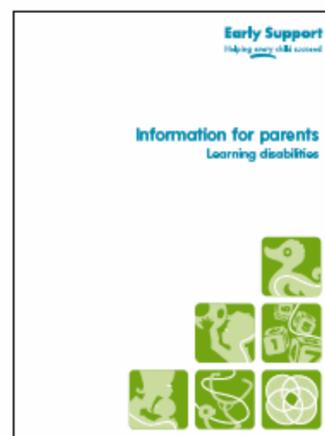
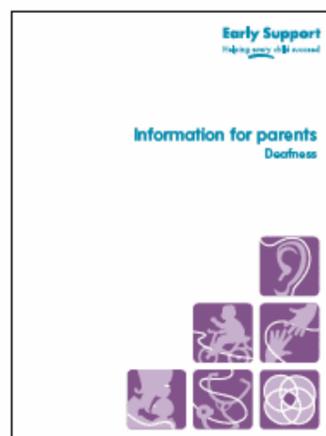
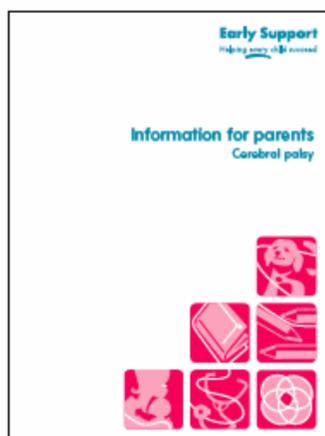
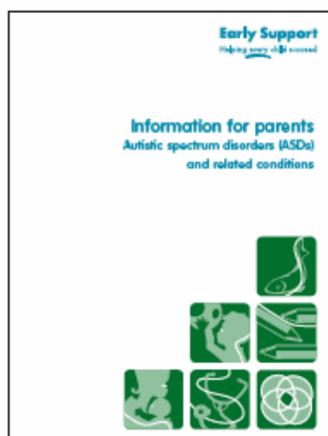
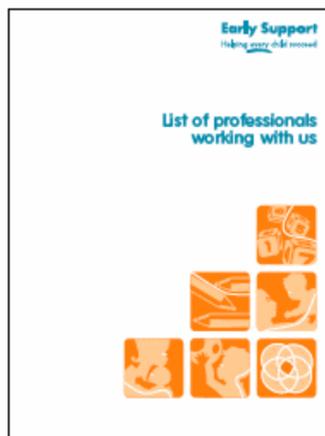
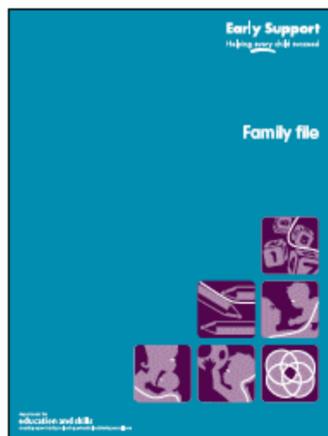
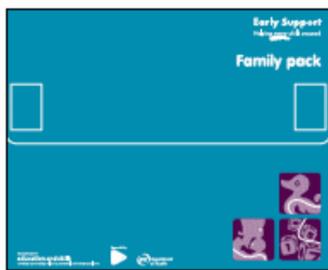
'All new parents face a steep learning curve. For parents of children born with special needs, there are even more unknowns and a bewildering array of services to negotiate. Repeated assessments and form-filling, telling the same story time and again, ferrying their child from service to service, all add to the pressure on parents.'

Removing Barriers to Achievement: The Government's Strategy for SEN
(2004)

Early Support Service Audit Tool

Standard B2: Referral, identification and initial assessment

Policies and practices regarding identification and 'communicating the news' are in place and are monitored and reviewed regularly for their sensitivity and effectiveness. Agencies work together to maximise effectiveness and minimise stress to families around the time of identification of a disability, health condition or need.





Right from the Start: talking with families about disability

Summary

This section explores how professionals can communicate clearly with families and be supportive at the time parents discover an impairment, condition or disability has been identified in their child.

'I think that conveying difficult news to parents is just as much an art form as doing an operation – and it's just as important to be self-critical.'

Professor Sir David Hall

It's not easy to tell parents that all is not well with their child, particularly when the news is unexpected.

Where a condition or abnormality is detected at or very soon after birth, there are particular sensitivities. For other families, the point of recognition or 'diagnosis' comes much later and may follow a long period of uncertainty during which the child's development has triggered concern. Whenever the moment of realisation arrives, handling early conversations with parents about a child well supports families in responding positively to their child and their child's situation and in adjusting to a new situation.

Whether there is an established existing relationship, or news is shared at the first meeting, this is likely to be one of the most significant pieces of information parents ever receive.

It is often helpful to see sharing concerns with parents as a process, rather than a single event. Before, during and after this process, it is important to be aware of the messages communicated both verbally and non-verbally to parents. Parent's experience at this time can have a huge impact on them and their child's future. It may also influence:

- how parents share news with friends and other family members

continued...

- parent's ability to respond to their new situation
- future working relationships with professionals
- parents' expectations of their child.

Working with families affected by a disability or health condition from pregnancy to pre-school

Contact a Family (2004)

Many paediatricians and other health professionals working on a daily basis with families in hospital settings may feel that all this is obvious and already central to their practice. Good practice is certainly already established in many places. However, it is important to remember that the *NHS Executive Guide to Good Practice: Child Health in the Community* reported in 1996 that:

'Despite publication of research and recommendations on good practice, this remains a subject of dissatisfaction to a significant number of families.'

Where bad news is delivered brutally, in passing, or in a situation where parents are left waiting for long periods of time on their own in a busy corridor, without information or support to make sense of the diagnosis, resentment can be strong, and it undermines confidence in the professional support services that families are likely to need most.

'We asked if we could speak to a paediatrician because we wanted to know what the implications were. We waited for about two hours. And a doctor came in and said "You realise your child has Down's Syndrome?" We said "Yes" and waited for an explanation. She said "Fine" and walked out the door.'



When we were told at the hospital it was by this young house doctor. He just came marching into the ward, didn't take me into a side ward or anything and said "Yes, your daughter has Rett Syndrome, she will have epilepsy, sclerosis" and reeled off all the worst things. Didn't say she could have it or she will have it and I just walked out of the hospital thinking "What on earth is going to happen?"

Sharing information in neonatal units

Where a condition or abnormality is detected at or very soon after birth, there are obvious and particular sensitivities.

- Encourage parents to have physical contact with their baby.
- Be positive. Comments such as 'Isn't she beautiful...' or 'How well you hold her...' can facilitate parents' relationships with their baby.
- Welcome visits from family members.
- Encourage parents to be present at the initial newborn examination.
- Summarise complex discussions in the notes and share with parents.
- Ask if and when parents would like up-to-date medical information on the baby's condition and details of support groups, where appropriate.
- Offer information on parent group meetings, if these are arranged in the unit.
- Liaise with the health visitor or specialist nurse and invite them into the unit prior to discharge.
- Establish efficient communication and offer written contact details of relevant health professionals.

Working with families affected by a disability or health condition from pregnancy to pre-school

Contact a Family (2004)

The Right from the Start Template

The Right from the Start initiative, co-ordinated by Scope and steered by a working group bringing together professionals, parents of disabled people, disabled people and voluntary organisations, provides a clear framework to support good practice. The *Right from the Start Template* is a working document designed to help professionals develop the policies, procedures and training programmes needed to ensure that more families receive a better service at what is likely to be a very stressful and emotional time in their lives. It is reproduced here in full.

Right from the Start Template

Key principles

Valuing the child

- All children are unique – it is vital that professionals see the child first and their condition/disability second.
- The child's name should be used at all times.
- Keep discussion about the child positive and avoid making predictions.
- Whenever possible keep the baby or the child with the parents when sharing the findings and diagnosis.
- If it is not appropriate for the baby or child to be present, remember to communicate in a way that shows respect for the child.

Respect parents and families

- Support and empower parents.
- Treat all parent's concerns seriously.
- Listen to parents and share information sensitively and honestly.
- Use plain and understandable language and give explanations to build parents' confidence.
- Acknowledge and respect cultural difference.



continued...

- Give opportunities to ask questions and check parents' understanding of their situation.
- Avoid giving negative non-verbal messages before concerns have been shared with parents.

Good Practice Framework

Preparation

- Allocate time for individual and team preparation prior to specific interviews/consultations.
- Families and their circumstances vary enormously, so professional teams need to share their knowledge of the family in order that the news is shared sensitively and effectively.

Who should be present?

- Evidence shows that parents, wherever possible, prefer to hear the news together and always in private.
- It may be appropriate for another family member or friend to be there in support of one or both parents.
- If it is unavoidable that a parent is alone, a member of the team should be present to support the parent during and after sharing the news.
- When an unaccompanied parent has heard the news alone, arrangements should be made to inform the other parent and close family members as soon as possible.
- The number of staff involved should be kept to a minimum, ideally the person responsible for sharing the news and one additional team member known to the family.
- If an interpreter is required, care should be taken in their selection and on no account should a family member be expected to undertake this role.

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Tuning into the parents: effective communication

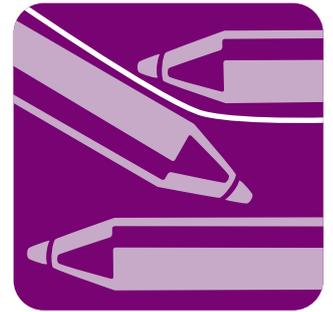
- Parents' reactions vary enormously and cannot be predicted.
- Professionals need to be well prepared and confident to share the news, while flexible enough to respond to parents' needs.
- Time and space should be available for parents to reflect on the news and meet again with a member of the team if they wish.

Next steps: practical help and information

- A record of the initial discussion should be made available to parents and their general practitioner. This could be in written or audio formats, but always in the parents' first language.
- Contact details should be provided at the initial meeting and parents should be encouraged to ask further questions as they arise.
- An early follow-up appointment should be arranged at the end of the initial meeting.
- Written information should be provided at an early stage about:
 - the child's condition
 - statutory and voluntary services
 - practical and emotional support.
- Support should be offered to parents to enable them to share the news with other family members and friends.
- Parents should be made aware of their right to seek other professional opinions.
- Early contact should be established between hospital-based and community services.

Support for professionals

- Acknowledge and address personal and professional development needs.



continued...

- Ensure staff participate in training, clinical supervision and continuous professional development.
- Promote inter-professional practice, mutual support and sharing of good practice.
- Give opportunities for de-briefing for all team members following meetings with parents.
- Identify, acknowledge and seek to address inequalities between professionals and parents.
- Promote an ethos of continuous quality improvement and auditing of practice.

Where to find out more

If you would like to know more about the Right from the Start initiative and training opportunities go to www.rightfromthestart.org.uk

Supporting families when English is not the language of the home

Where a family does not share the language of the professionals working with them it is important that professionals take responsibility for ensuring that early information about a child's condition or disability is communicated clearly and that it is understood. Important discussions should always be supported by an interpreter and wherever appropriate, families should leave with some written information about what will happen next in their preferred language. Where British Sign Language is the language of the home, the same rules apply and early discussions between families and professionals should be supported by a sign interpreter.

Sharing information and informing attitudes and expectations

'The most important thing that happens when a child is born with disabilities is that a child is born. The most important thing that happens when a couple become parents of a child with disabilities is that the couple become parents.'

Wills (1994)

'I think that the most significant thing that happened to me when I had my son was that my paediatrician was positive and the thing that he said to me that made me think more than anything was that he said "You have a lovely baby boy" first.'

The way in which a child's situation is first discussed with a family influences expectations for their child and their attitude towards disability more generally. Key points for professionals are:

- to value the child first and to talk about the child's condition or disability second
- wherever possible, to speak positively about the child's condition, the future and disability generally.

When children have life-threatening or life-limiting conditions, clearly other rules apply. However, in other cases, it is important to recognise that negative attitudes towards disability in general and 'medical model' language in particular can have an important and negative impact. Professionals who regularly speak with families in the early days of discovering a condition or disability should receive Disability Awareness Training to raise awareness of these issues and to check that their presentation, body language and words do not convey tragedy where no tragedy has occurred.

First steps

Revealing information to families is rarely a one off event. For most families, early discussions about their child begin a process of finding out more about the child's situation that may take some time. Early



experiences directly influence the confidence families feel in the services which are available to support them. It is therefore important to present 'diagnosis' as a process or joint journey and to bear in mind what research indicates families look for in the early days. Important points are summarised below.

Parents of children with multiple or complex disabilities report the following needs during the early days of adjusting to the news of disability in their child:

- for emotional support
- for information about the child's condition
- for information about services to avoid missed opportunities and unnecessary 'gaps' or delays in getting what is available and needed
- to be able to access what is available and not 'battle' with systems
- for support to be well co-ordinated to avoid an unmanageable range of appointments, poor flow of information, unnecessary duplication of assessment procedures and confused aims
- to address the 'whole picture' embracing the child's condition, treatment and progress and the wider family situation and welfare.

Adapted from:

Parents' support needs: the views of parents of children with complex needs (2001)

Limbrick-Spencer G

How the Early Support materials help

The [Early Support Information for parents](#) booklets are designed to help professionals meet the information needs of families in the early days following identification of a particular condition. Each publication has

been developed in consultation with families and reflects what they say it would have been useful to know. The material:

- sets out the nature and characteristic impact of a particular condition
- passes on practical advice from other families
- identifies voluntary organisations and other sources of information which may be particularly relevant.

The following titles are currently available in this series:

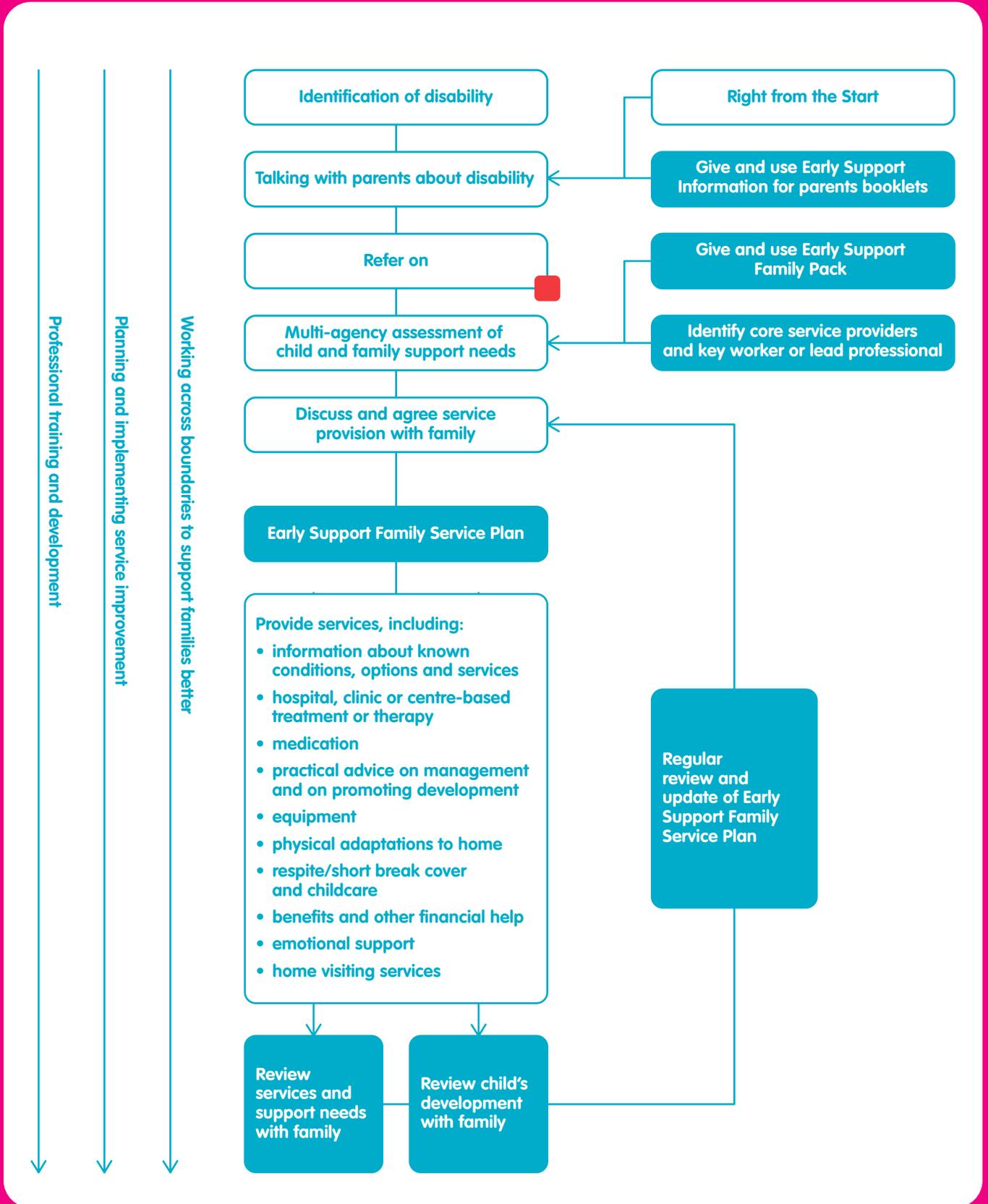
- *Autistic spectrum disorders*
- *Cerebral palsy*
- *Deafness*
- *Down's syndrome*
- *If your child has a rare condition*
- *Learning disabilities*
- *Multi-sensory impairment*
- *Speech and language difficulties*
- *Visual impairment*

Where it is clear that a child and family have support needs, but there is no clear 'diagnosis', families may find the remaining title in the series, *When your child has no diagnosis*, useful.

Details of how to get hold of copies of these booklets are given at the back of this [Professional Guidance](#).

Where families are meeting many different health professionals within a short time as part of the initial investigation of their child's condition, paediatricians and others may also wish to consider using the [List of professionals working with us](#) template from the [Family File](#) in the [Early Support Family Pack](#) as a convenient means of recording the names of members of staff for families.

2 Referring on



'Parents often experienced long delays in diagnosis, during which they were sometimes referred from one professional to another, with no single case file to record all the information about their child. If there was no proper inter-agency referral system in place, parents were obliged to go round different professionals themselves, telling the story of their child's condition over and over again.'

Let me be me

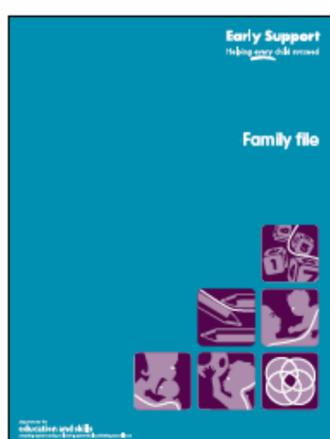
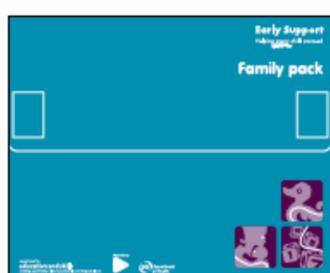
Audit Commission (2003)

Early Support Service Audit Tool

Standard B1: Referral, identification and initial assessment

There are clear and agreed policies and practices for referral, ie for making all relevant services easily and quickly available to families. These include integrated referral procedures with a single point of entry and a multi-agency referral panel, wherever possible.

See also **Standard B6: Referral, identification and initial assessment**





Referring on

Summary

This section underlines the importance of referring families on to colleagues and to other agencies promptly:

- **in the early days, as parents and the professionals working with them try to find out more about a child's situation**
- **as diagnosis, or an initial assessment of service need triggers referral to medical, therapeutic, educational and other services.**

Initial identification of disability or service need should move forward as quickly as possible and lead directly to action. Action in this context means providing:

- information
- medical, educational or therapeutic intervention
- practical help.

Recognition of factors in a child which influence or limit development can occur at many different times and in many different ways within the first three years of life.

However, the early stages of recognising a disability are always best understood as the first links in a clear chain of events. Assessment should lead to a better understanding of a child and family's need for support or services and an agreed plan outlining what different agencies will provide. Plans should record where services, therapies or other kinds of support will be provided.

Wherever possible, families at the end of an initial period of assessment should receive:

- a clear understanding of what will happen next and the timeframe within which things are likely to happen

Read more about this in **Making and reviewing joint plans**

- the name and contact details of a professional they can speak to if they have questions
- prompt referral on to the agencies they need to be in contact with
- information about the nature and characteristic impact of their child's disability
- contact details for any relevant voluntary organisations or other agencies that may be able to help.

Prompt referral on to other agencies is critical. Smooth transition from assessment of need into action is facilitated where professionals have agreed referral protocols or 'pathways' in advance of particular cases, particularly where the support of a number of different services is likely to be required.

Practical example

Integrated care pathway for children born with cleft lip and/or palate, Herefordshire

This initiative brings together:

- A guide to treatment with guide times for use by professionals across NHS PCTs working in special care baby units (SCBU), paediatric departments, ear nose and throat departments (ENT), audiology services, orthodontist oral departments and speech and language therapy services.
- Record notes for consultant paediatricians and checklists for audiology services and speech and language therapy services to record when steps on the agreed pathway have been actioned and when results from any assessments have been passed on to other professionals/agencies that need them.
- Information for families about cleft lip and palate, including a flow chart outlining the likely pattern of surgical intervention and follow-up support



- Additional pages for the child's personal child health record (PCHR or 'Red Book') recording key points from discussions with the family and tracking milestones on the agreed care pathway across the home health visiting service, ENT, orthodontist service, audiology service and speech and language therapy service.

All professionals are required to enter their name and contact details the first time they make an entry on the documentation so an up-to-date record of who is working with the child and family is always available.

The entry for speech and language therapy held by the family looks like this:

	Comments	Done?	Date	Signature
Contact will be made with you within the first month to give you information and contact details for a local speech and language therapist				
10–12 months Home visit to discuss your baby's speech and language development				
You will receive a report about this home visit and any further reports written about your child will also be sent to you				
1–3 years The speech and language therapist will arrange home visits as necessary to offer support and advice				
Following the 3 Year Cleft Palate Clinic, you will be referred to the speech and language therapist at your local community clinic. You will then receive a clinic appointment and advice/support/treatment as necessary				

continued...

	Comments	Done?	Date	Signature
If your child is under the care of the speech and language therapist when they start school, then advice and information will be given to teaching and support staff about how to help your child in school (you will be asked for your consent first)				
When your child's speech and language therapy treatment is completed, he/she will be discharged from speech and language therapy and this will be discussed with you				

Practical example

Referral paths for children with early identified deafness

Referral protocols between health, education and social services for babies with early identified, permanent deafness are currently under consideration in many areas, as new screening procedures are introduced which lower the average age of identification of deafness from 20 months to 3 months.

Relative to other populations, families with deaf children receive early and unambiguous information about the nature of their child's situation, although an estimated 35% of this population have another disability or learning difficulty which may be more difficult to diagnose.

Health services identify deafness, but ongoing information, support and practical advice in the home is provided through a partnership of health, education and social services, with education often playing a central role. Good multi-agency working, supported by clear protocols specifying the nature of the information to be passed on are needed to secure prompt referral on from one service to another and to establish ongoing collaboration. Quality standards are clearly defined and have been available for some years. They say:



- *Early Years support and education services must be informed of confirmation of deafness within one working day.*
- *The family must be contacted within one day and visited within two days.*
The National Deaf Children's Society (2000)

In 2002/03, new joint protocols were developed across audiology departments at Norfolk and Norwich University Hospital NHS Trust (Central & North Norfolk), Queen Elizabeth Hospital (West Norfolk) and James Paget Healthcare NHS Trust (East Norfolk) and with education services. The aim was to ensure that families with a deaf child across a large, rural county experience a similar, joint approach from a range of agencies following identification of deafness.

An initiative in North East London lead by LB Barking and Dagenham developed protocols for use across a number of different PCTs and local education authorities. The paperwork takes into account variations in local practice at operational level, but aims for consistency across a wide area. The protocols were developed by health, education and social services in partnership with families/service users. They now form part of a 'training pack' issued to anyone coming into contact with families with deaf children identified by newborn hearing screening. The pack has been endorsed by senior managers across all participating areas.

Both these initiatives put families as service users at the heart of planning for multi-agency service development and were funded in 2002/03 by [Early Support](#).

Explaining patterns of referral to families

In addition to agreeing protocols, it is important to explain the pattern and likely timeframe for action to families. This is particularly important where indications of learning difficulties or disability emerge over time and the process of assessment starts later or takes longer.

'I believed that the paediatrician had a lot more power than they did. So when the paediatrician said, "I've written to the education department and told them to do a statement", I thought "A doctor has told the education department to do a statement, that means it's going to happen. I had no idea that a doctor had no power or authority over the education department. All she was doing was asking the education department to put our name down on a list. Nothing happened.'

'I had to go through two or three different professionals. Some won't refer, some will, and you just have to keep asking for a second opinion when you can. We got a referral from somebody that I would never have expected to be able to refer. It was a clinical psychologist in the end, who was basically helping us with diet. She was the one that referred us to occupational therapy when no one else would refer us there. Mind blowing really.'

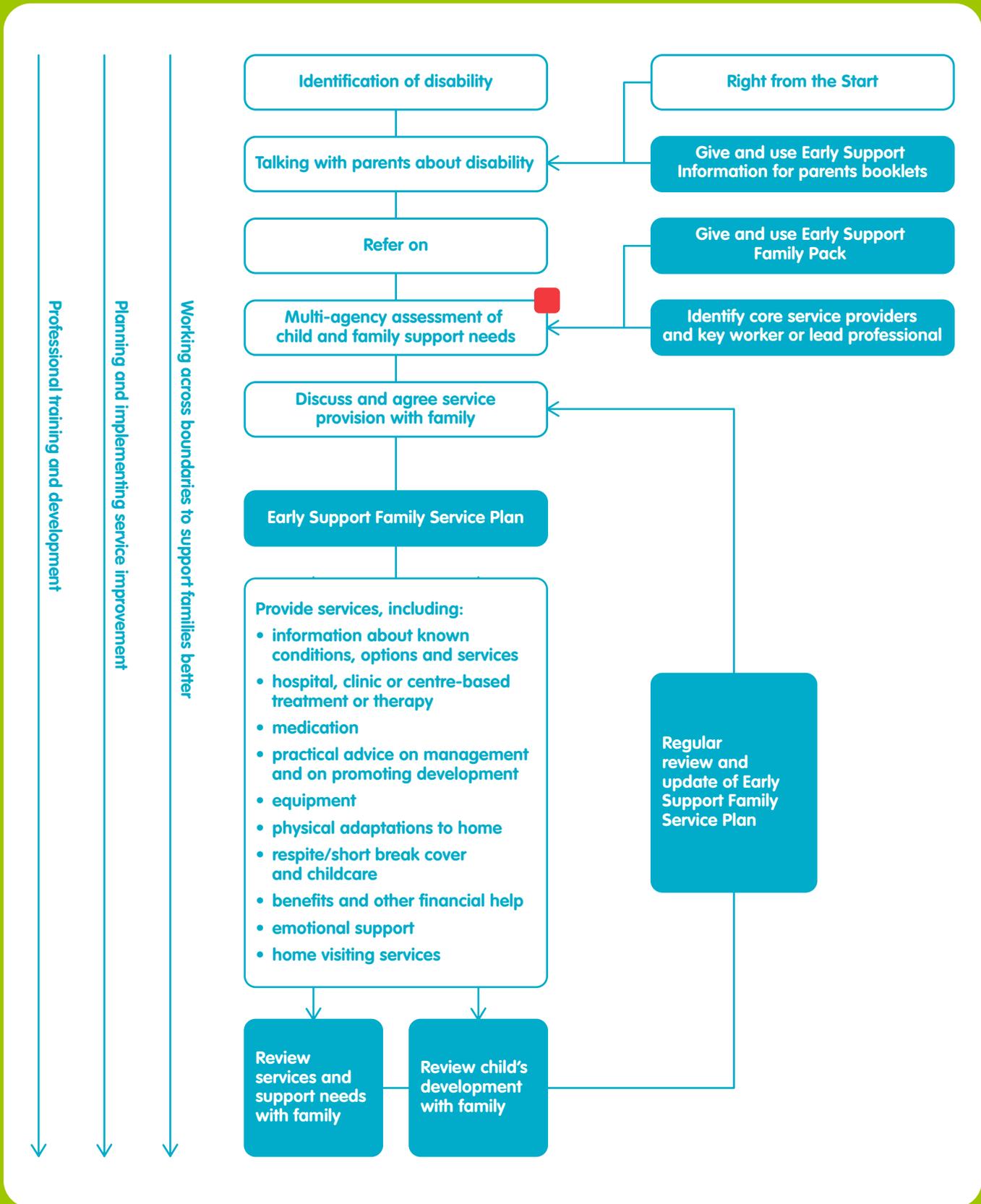
How the Early Support materials help

When there is uncertainty about whether a condition is present or permanent and where the level of family service need is low, families are unlikely to find the materials in the [Early Support Family Pack](#) helpful.

However, where there is clear evidence of service need and/or where the process of initial assessment takes a long time, the materials in the [Early Support Family Pack](#) and [Family File](#) can help.

Read more about this in [Finding out what children and families need](#)

3 Finding out what children and families need



The National Service Framework for children wants to see health, education and social care services organised around the needs of children and their families, with co-ordinated multi-agency assessments leading to prompt, convenient, responsive and high quality multi-agency interventions which maximise the child's ability to reach their full potential.

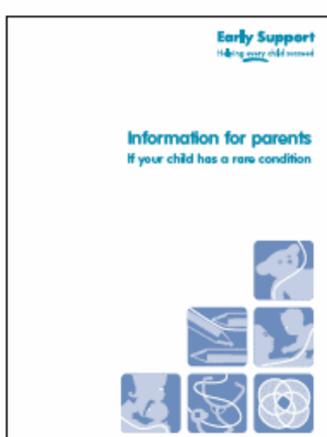
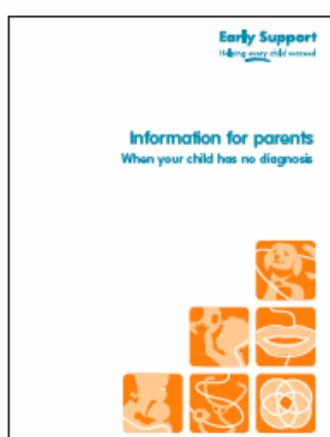
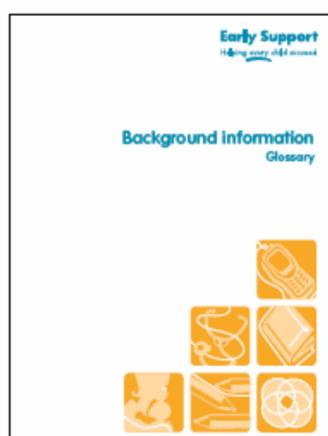
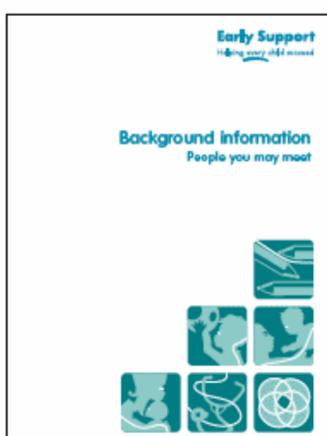
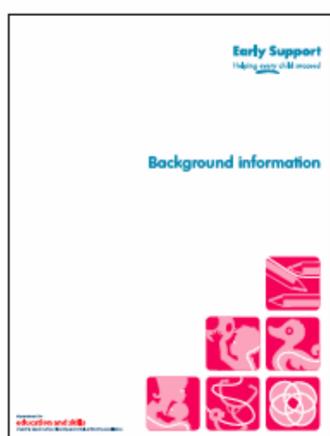
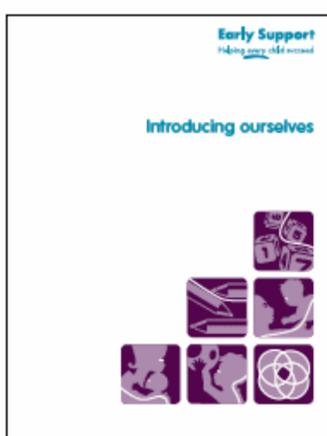
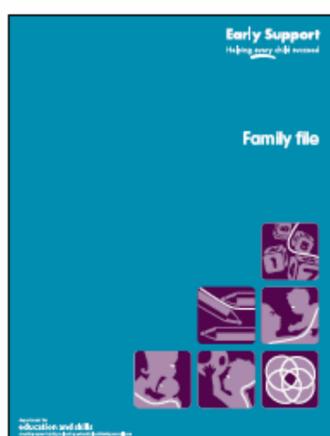
Early Support Service Audit Tool

Indicator C2: d) Ongoing support

Practitioners from different agencies carry out joint assessments wherever this will support:

- more efficient and effective monitoring and gaining of evidence
- shared understanding of child and family need
- effective use of family time
- family confidence and understanding.

See also **Standard B3: Referral, identification and initial assessment**





Finding out what children and families need

Summary

This section explores how initial multi-agency assessment of service need can be made more responsive to families and explains how some of the materials in the **Early Support Family Pack** can help.

'Assessment that is about empowering and enabling the family to progress, to remain together, to find solutions and not blocks. This is the assessment that families value.'

Carpenter (1997)

'I remember when I didn't know where to turn and there seemed to be a brick wall between me and the professionals. I had people saying "Sorry, I can't help, you need to contact this person". Then they would say "No, you need someone else". I found this very annoying. Then, when you did get the right person, you have to wait six months for an appointment.'

Extract from *Together from the Start*

Where assessment arrangements are duplicated and service provision fragmented, the normal routines of family life with a young child may be severely disrupted by multiple appointments outside the home and a string of unconnected visits to the home by professionals representing different agencies. Families may be left with the feeling that the right hand does not know what the left hand is doing and:

- experience additional stress in an already difficult situation
- waste time attending appointments at different times which might have been scheduled for the same day
- develop a negative or confrontational attitude towards professionals

continued...

- incur unnecessary travel costs
- incur unnecessary childcare costs, where there are siblings to consider
- receive conflicting information and advice
- be obliged to retell the story of their child's life (including the bits that are particularly painful to them) each time they meet a new professional
- be left to put together for themselves information received from different agencies where one aspect of their child's need has been assessed and considered in isolation.

Effective, joint multi-agency assessment in the early years means:

- co-ordinating action, particularly where different aspects of a child's situation need to be assessed by different people
- responding to a family's need to get reliable information as quickly as possible and learn from more than one perspective at a time
- ensuring that initial assessment leads to action and prompt provision of information and practical help.

Identification of disability, diagnosis and the provision of services

The population of children with disabilities under three is very diverse and the need for information, therapy, equipment and services also falls across a wide range.

The model of service provision presented on the flow chart at the beginning of this section assumes a clear starting point – when a syndrome, significant impairment or disability has been identified. For many families, the process is not so simple. The need for support emerges later and over a longer period of time, signalled by general developmental delay, a slow start with learning

Read what families are reading about this in the Early Support Information for parents booklet **When your child has no diagnosis**



to communicate, or increasingly unusual behaviour patterns. For some families, getting to the start point on the flow diagram, when the nature of a child's difficulty is recognised is a long, uncertain and frustrating process.

The trigger for practical help and therapy is a clear child and/or family need for support, which may, or may not, be accompanied by a 'diagnosis'. Families require:

- prompt response to indications of factors in the child which should be investigated
- discussion of the child's situation which brings together as many different perspectives on the child's situation as possible
- a diagnostic process which builds up a cumulative picture of the nature, severity and range of conditions or impairments involved and identifies relevant conditions whenever possible
- an initial assessment of need which reviews everything that is known about the child and family situation so far, and considers it as a whole
- discussion and agreement on what will happen next with clear information about who will make contact and what help will be given.

Extract from *Together from the Start*

Assessment should begin as soon as possible when a developmental delay or disability is suspected; fast track arrangements may be necessary to ensure timely support.

Assessment should:

- identify the health and other needs of the child
- promote understanding and agreement about the potential developmental implications of the condition so that effective educational, behavioural, physical or communication strategies can be put in place to promote development and be delivered in a location appropriate to the child

continued...

- address the needs of the child in the family context so that the family is empowered and feels confident to provide for the learning and care needs of their child at the same time as feeling that their own needs and those of their other children are also being addressed.

What well co-ordinated initial assessment looks like

Co-ordination becomes important when many different assessments are needed to establish the nature of a child's disability/disabilities and to identify the services required. Co-ordination is helped from the service user's point of view when families:

- have the opportunity to discuss their child with more than one professional at a time – particularly where there is the opportunity to hear professionals who have assessed different aspects of a child's situation discussing things with one another
- are not asked to attend multiple hospital appointments on different days where this is avoidable
- have a clear idea of the process and timeframe for assessment and some understanding of what might happen next.

When processes are well managed, there is the added advantage of achieving 'buy in' by the range of services or professional disciplines that the family may need from the start. Joint planning for service delivery with families is easier to achieve where a range of professionals, disciplines or agencies have been involved at the time when relevant factors are first identified in a baby or young child and a range of agencies have been consulted as part of the initial discussion of service need.

Integrating statutory assessment processes

Social services departments are required to follow the guidance in the *Framework for the Assessment of Children in Need and their Families*. The



framework is a multi-dimensional tool to ensure that the child and family's needs are seen from the perspectives of the child's development, the families' needs and capacities as well as environmental factors, like housing. Specific practice guidance about the use of the Assessment Framework with families with disabled children has been produced which suggests how additional assessment can be built onto the model.

In the second and third years of life, a few families may also experience a more formal assessment process led by education services, where LEAs are considering issuing a Statement of Special Educational Needs.

The general principle should be that wherever possible, statutory processes use and build on whatever is already known about the child and family, including any relevant documentation, in order to reduce demand on families. In practical terms, this means that where an 'initial' and/or 'core' assessment has already been made by social workers, the findings from that assessment should inform early joint discussion between the family and services and the development of a [Family Service Plan](#). In these circumstances, the [Family Service Plan](#) should contain a summary of the assessment within a broader multi-agency discussion of priorities.

Where social services engage with a family after a [Family Service Plan](#) has been agreed, the plan provides an obvious starting point for any necessary further assessments. Parents will be reassured by seeing the document they have agreed with other agencies being used in these circumstances – indeed, it would be natural for them to ask why it is not part of the process, when it is available.

This discussion is written at a time when the implications of the common assessment framework and integrated inspection framework for children's services signalled in the Government Green Paper *Every Child Matters* are still being developed. Look for more information at www.espp.org.uk as time goes by.

Read more about this in [Making and reviewing joint plans](#)

To find out what families are reading, look at the [Social services](#) section in the [Background Information File](#) in the [Early Support Family Pack](#)

Where to find out more

Key background documents to this discussion are:

Framework for the Assessment of Children in Need and their Families

Department of Health, Department for Education and Employment and the Home Office (2000)

Assessing Children in Need and their Families: Practice Guidance

Chapter 3: Assessing the needs of disabled children and their families
Department of Health (2000)

SEN Code of Practice

Department for Education and Employment (2001)

Joint assessment

Joint multi-agency assessment is facilitated but not necessarily delivered by service structures which co-locate personnel representing different disciplines and who may be employed by a range of statutory agencies. However, flexible arrangements for joint appointments, joint home visits and co-operative working can achieve the same effect, as the four examples which follow illustrate.

Joint assessment should never mean that families are confronted by a large panel of professionals at vulnerable times. It should mean that they have confidence that:

- all relevant people and agencies have been consulted
- if it would be helpful to consult with a number of different professionals, this can happen
- the process of assessment by a number of different people is moving forward as quickly as possible.

Where a child and family have clear severe or complex support needs, the early identification of a key worker or alternative care co-ordination system facilitates joint working and more seamless working from the perspective of the service user.



Practical example

Co-ordinated multi-agency initial assessment of need by flexible arrangement

White Lodge is an independent agency which facilitates joint multi-agency initial assessment of need for young disabled children with complex or multiple disabilities. The service is provided by flexible arrangement and enables staff from different statutory agencies to work alongside each other using White Lodge as a neutral, but appropriately equipped base. In effect, agencies 'pool' their staff resources by seconding members of staff into a multi-agency team located in the centre on an occasional basis.

Each professional remains accountable to their 'parent' organisation, but they are required to work within a joint protocol that was developed and ratified by a management board, made up of senior managers from participating agencies and organisations. The Director of White Lodge functions as operational manager.

Practical example

Assessment by statutory services located in one place

The Phoenix Centre in Bromley has a well-established track record of co-locating health, education and social service personnel and of joint working with older children, although they observe that 'co-location of a range of services and different professional groupings does not necessarily mean joint working or joined-up thinking on provision of services'. The centre was funded in 2002/03 and again as an ESPP Pathfinder to extend joint, multi-agency assessment and support to children under three and their families.

In 2002/03 Bromley established a forum where professionals from different agencies could come together to consider and agree a set of processes and protocols for working with disabled children with profound and complex needs under three. The consistent involvement of a core group of parents emphasising the service user perspective was critical, providing a constant reminder of the benefits of early intervention and the need to 'think multi-agency' and 'think family friendly'.

Shared processes and protocols for identifying, referring, supporting and monitoring children with complex needs requiring multi-agency input were piloted by five paediatricians in the area and the new system is now operational for families with very young children with profound and complex needs across Bromley.

This work builds on an existing multi-agency assessment panel for older children and a key objective is to secure early, well-targeted referral on to appropriate support services.

Practical example

Taking multi-agency assessment out to families

In 2002/03, ESPP funded SENSE, to provide parent-led, multi-agency assessment across two regions.

Deafblindness is a low incidence disability which is usually identified very early and which requires specialist input from qualified and experienced professionals from a number of different agencies. This initiative brought together flexible, itinerant groups of professionals competent to bring a range of perspectives to multi-agency assessment, who worked with families in many different places and with their local service providers.

The assessment teams brought together around the needs of particular children and families included:

- teachers holding qualifications to work with hearing impaired, visually impaired and multi-sensory impaired children
- portage workers
- social workers
- audiological scientists
- physiotherapists
- speech and language therapists.

Some multi-agency assessments took place at centres where professionals were based; some were undertaken in family homes. For each of the 10



families involved, the outcome was an early, holistic profile of their child's strengths and difficulties, taking account of the interaction between multiple factors. Families also had the opportunity to observe strategies to support development modelled directly with their child.

This flexible intervention, organised over much larger areas than local service providers are normally in a position to plan for, achieved the objective of bridging the gap between discussions with health professionals, which parents experienced as 'helpful blocks of input followed by long periods without any input'.

Practical example

Joint assessment and referral on for children with visual impairment

In 2002/03 RNIB with health and education services from Cambridgeshire were funded by ESPP to develop a written protocol based on the experience of setting up new joint working arrangements in Peterborough, Wisbech and Kings Lynn. In 2003/04, two services have been set up in different places on the same model, using the protocol as guidance.

Previously, the community paediatrician, a specialist teacher working with visually impaired children and orthoptist, all assessed children, working separately. The paediatrician usually saw the child first and then referred to the specialist teacher, who made a home visit. Meanwhile, the child would attend a hospital eye clinic, usually more than once.

Communication was time consuming and parents reported long waits at the hospital before being seen, so that the child was tired, hungry and stressed – all factors which can affect visual functioning.

Families with children of pre-school age now attend a monthly joint clinic provided by a paediatrician, a specialist teacher and an orthoptist working together. Families can:

- benefit from the knowledge professionals have about child development and paediatric eye conditions
- experience skilled measurement of visual acuity, squint and nystagmus

- get information about the nature and impact of visual impairment
- hear about the importance of early stimulation and how to promote development
- get information about what will happen next
- leave with written information naming any condition(s) identified
- plan how ongoing support will be provided with a number of different professionals at the same time and agree dates for next contacts.

Leadership of the clinic by a paediatric consultant ensures the service is embedded firmly within mainstream services for children with disabilities. The advantages are obvious – time efficiencies, a process which moves forward more quickly for families and better communication all round. However, the most significant factor in terms of cost effectiveness is the improved quality of assessment achieved by bringing a range of perspectives together in a place where the child feels comfortable and can be observed in a 'play' situation. Referral on to the education service, which characteristically provides ongoing support in the home, is also seamless.

How the Early Support Family Pack can help

Multi-agency assessment of need can be facilitated as soon as it is clear that there is ongoing need for support, by early introduction of the [Early Support Family Pack](#) and use of the [Family File](#). These materials can be particularly effective when used by someone like a health visitor who may be assuming care co-ordination responsibility in the early days, before a key worker is identified.

The [Introducing ourselves](#) section in the [Family File](#) encourages families to write down anything they would want a professional meeting their family for the first time through the assessment process to know. Where initial assessment goes on for some time and involves many different people, it can be a powerful means to prevent families having to repeat their child's case history over and over again (including the most painful bits) to different people.



The [Current records](#) section in the [Family File](#) provides an easy means for families to keep relevant paperwork to hand as they move from department to department and from professional to professional. Where individuals involved in the assessment process give paper copies of what is known so far with names for any conditions identified, the file held by families provides an effective safety net complementing more formal paper systems that are in use. It also reduces pressure on families to remember information they have received when upset and helps where families are asked what someone else has said.

The [List of professionals working with us](#) section of the [Family File](#) asks professionals who are part of a complicated assessment process to log in with their name and contact details so that families can be confident that they have remembered the names of consultants and other people they meet correctly. From a professional point of view, scanning this page as assessment moves forward provides a quick overview of which agencies or clinical department are already involved.

All of these materials will be changed where families go on to use the [Family File](#) over time and for many families, early introduction of the [Early Support Family Support Pack](#) may not be appropriate. However, where families are meeting many different professionals as part of an initial assessment/diagnosis process that leads into support from a number of different agencies, the [Family File](#) helps to co-ordinate activity from the start.

Where initial assessment leads to clear identification of medical and other conditions or disabilities, families will benefit from receiving relevant copies of the [Early Support Information for parents](#) booklets as soon as possible. To read more about these materials see [Right from the Start: talking with families about disability](#) on page 21. Where assessment does not lead to clear identification of a condition, families are likely to find the booklet [When your child has no diagnosis](#) particularly helpful.

Assessing child need and family need

Initial assessment procedures, particularly in hospital and other clinical settings often focus on the child's situation, achieving a reliable diagnosis

and taking action to address known difficulties. However, supporting parents and families is also an important component element within a holistic response to meeting the needs of children. Where the needs of parents are not identified or ignored, the family's ability to provide support can be critically compromised.

'The people I came into contact with in the early months were only interested in my child, they never asked how I felt. I remember feeling totally exhausted mentally – having to accept one bombshell after another.'

'If someone had asked me how I felt, instead of concentrating solely on my daughter's problems, I believe it would have released the stress that built up and led to severe depression six to seven months later.'

'No one noticed that I didn't sleep for five weeks in the hospital.'

Extract from *Together from the Start*

Where services are **well co-ordinated**, families participate in the development of a cumulative understanding of their child's needs and receive:

- useful input from professionals meeting the family for the first time
- release from the responsibility of rehearsing the child's history from the beginning with each new individual they meet
- relevant information from a number of different perspectives
- reassurance that needs are recognised and taken seriously by different agencies
- input on particular aspects of their child's development which takes note of other relevant factors in the situation
- consistent messages
- a focus on their child's abilities as well as impairments



continued...

- well co-ordinated practical help
- continuity of care.

We found that this helped – to be in a group with everyone giving their opinion and finding the best way to proceed.'

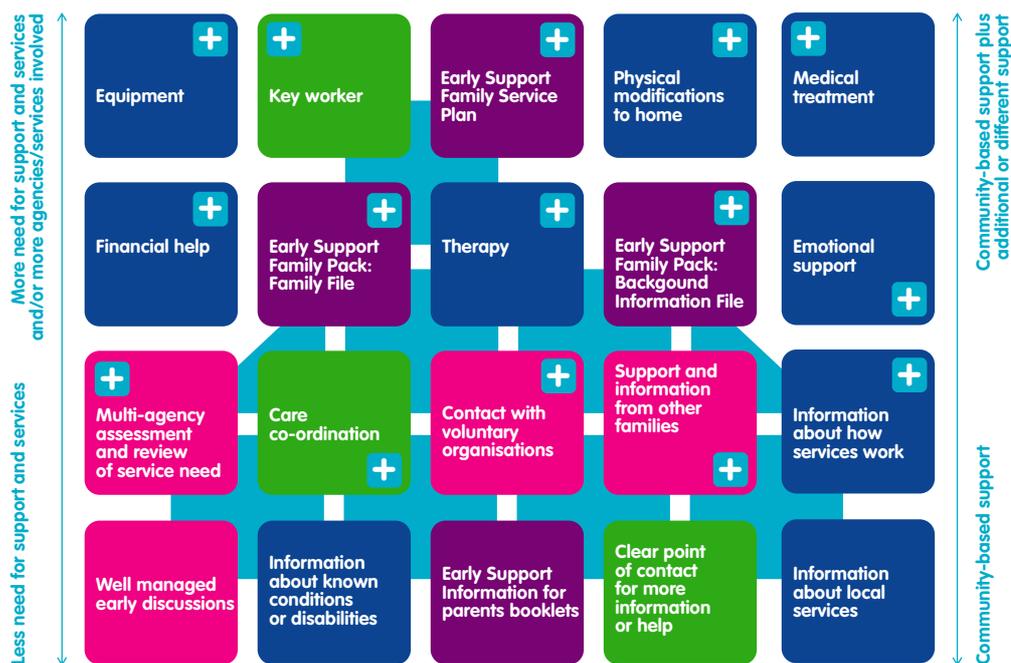
Assessing the level and type of need

The diagram on page 56 illustrates the range of services a family may need and indicates how the **Early Support** materials interact with elements of support provided by community-based services and more specialised agencies. Elements of support are deliberately not tied to particular service providers.

The continuum marked down the left-hand side highlights that families and children differ widely in the level of support they require and that some families are supported by many different agencies, while others are not.

All families with young children are supported by community-based health, education and social services. The continuum on the right highlights that the more multiple or severe the challenges faced by a child, the more likely the family are to need support services that are additional to or different from 'universal' services.

The diagram represents a pile of bricks, which can be combined flexibly with one another.



All children with an identified condition or learning difficulty require the elements of support identified on the bottom row of bricks. For example, early discussions with families about disability always need to be sensitively managed and parents usually want early and easy access to information about any particular conditions that have been identified.

The more severe or multiple the conditions identified in a child, the more likely the child and family are to need a combination of bricks in addition to this basic minimum. Any brick in the pile can be combined with others in flexible ways. The greater the number of elements of support involved, the more deliberate and well co-ordinated intervention has to be to meet the needs of service users. For example, where families are using a number of services, but not very regularly, some care co-ordination may be required, but this could be achieved informally by the professional who is in most regular contact with the family. Families who need more of the bricks towards the top of the pile and who are regular, multiple users of services provided by different agencies, need a key worker or identified lead professional.

Read more about this in [Keyworking, key workers and care co-ordination](#)



On this diagram, the elements of early intervention (medical treatment, therapy, financial support, equipment and physical modifications to the home and information) are marked in blue. Mechanisms to ensure that support is well co-ordinated are marked in green.

The [Early Support](#) materials are marked in purple and are placed near to the elements of support that they facilitate. For example, the [Family File](#) in the [Early Support Family Pack](#) helps with care co-ordination and multi-agency assessment and review of service need. It also actively supports key workers in their role of co-ordinating support for families. It therefore appears close to these bricks on the diagram. The [Early Support Information for parents](#) booklets provide the information about known conditions that families often look for in the early days and so these two bricks appear next to one another.

The diagram is intended to illustrate in a simple way that:

- the more severe child and family need, the more support families require
- the greater the number of services involved, the more likely it is that families will need active co-ordination of support via key worker services or another mechanism
- only a combination of support elements that is flexible and well co-ordinated can be responsive to family need, which falls across a wide continuum.

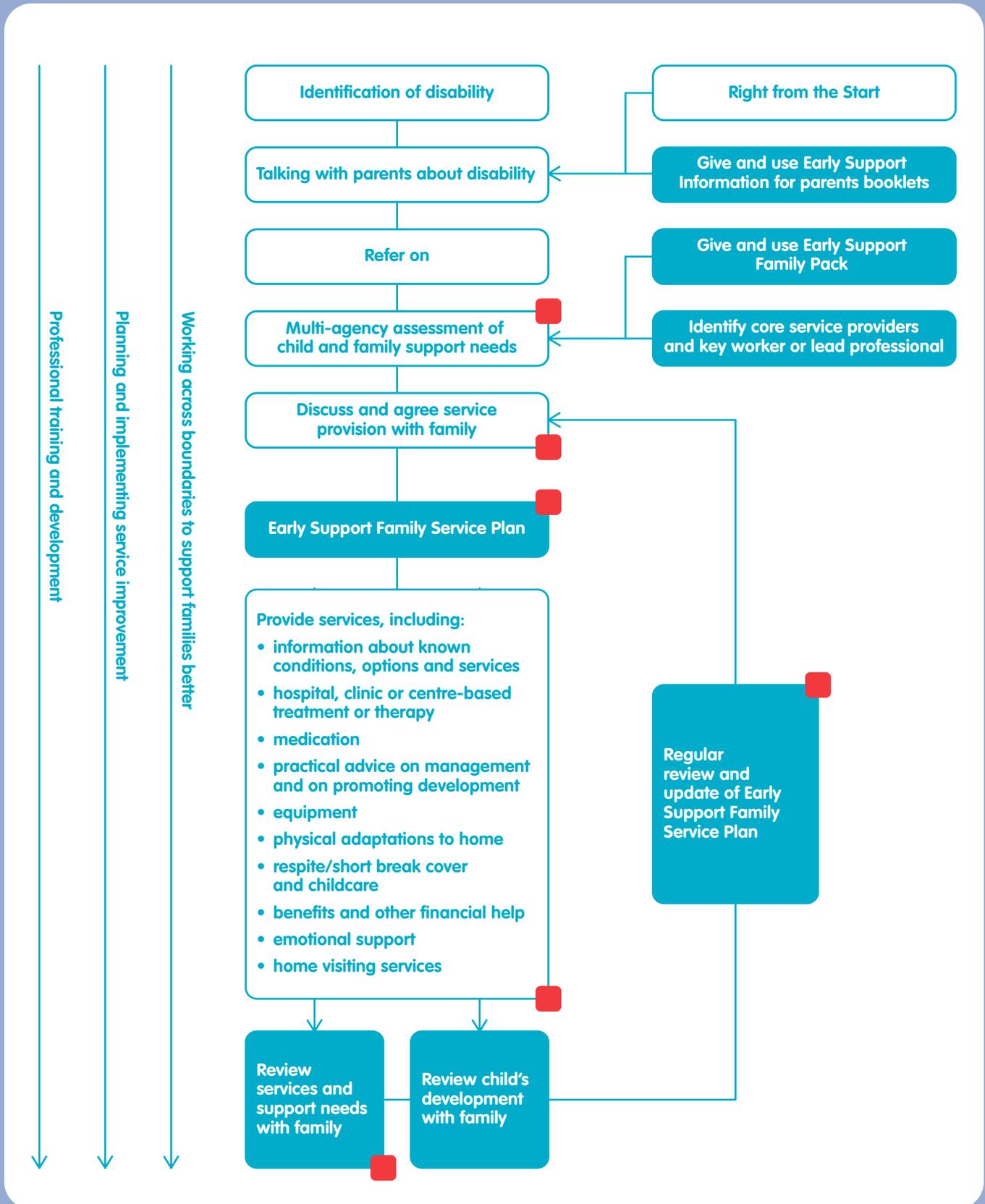
'The assessment of a disabled child must address the needs of the parent carers. Recognising the needs of parent carers is a core component in agreeing services which will promote the welfare of the disabled child.'

Assessing children in need and their families: practice guidance

Section 3.6

DoH (2000)

4 Sharing information about families



'Children with multiple needs may be subject to multiple assessments by different people, each collecting similar information but using different professional terms and categories. The core information does not follow the child. This is not only an inefficient use of resources, but also alienating for the child and family who have to tell the same story to several professionals but may receive little practical help as a result.'

Every Child Matters

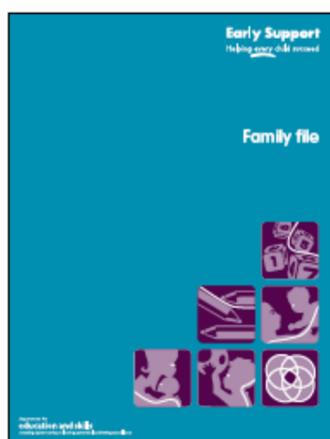
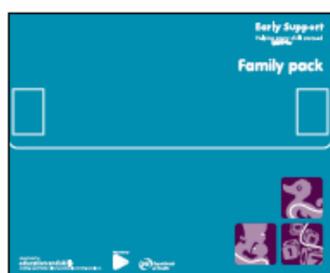
Government Green Paper
(September 2003)

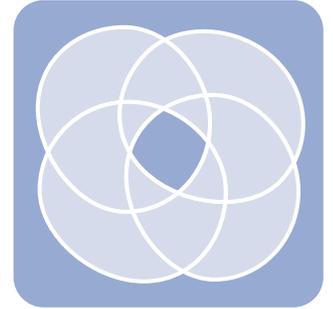
Early Support Service Audit Tool

Indicator A2: i) Leadership, management and organisation

There is a reliable multi-agency database, nationally compatible, that includes a process for regularly updating information. This has transparent systems and safeguards for access.

See also **Indicator D1: n) Providing and sharing information**





Sharing information about families

Summary

This section:

- considers the contribution that sharing information about a family and child can make to better co-ordination of service delivery
- discusses how simple paper systems can complement the wider integration of electronic systems
- explains how the **Family File** in the **Early Support Family Pack** can help.

'I don't think that the different disciplines like working with each other. I think they say they do and they communicate, but they're still very possessive of their role and not wanting to let go of things or not wanting to give.'

Extract from *Together from the Start*

However service delivery is structured, it is essential to have flexible and efficient arrangements to share information about the child and family between all the professionals and agencies involved. Without this, the opportunity to build a cumulative picture of the child's abilities and needs over time is lost and parents are left with the responsibility of bringing every new professional they meet up to speed and up to date.

Sharing information about families

The ability to share information about a family and child is an essential pre-requisite to the joint and holistic review and co-ordination of services and support. However, it is also a complex issue, involving on one hand, paper and electronic systems, and on the other trust between individuals coming from different professional backgrounds and cultures who may make different assumptions about client confidentiality.

Where families and children use services provided by more than one agency, the co-ordination of services depends on efficient and reliable systems to support communication between teams and individual professionals. The challenge is to enable those who 'need to know' to get hold of information easily, while restricting access to confidential material appropriately.

A simple and reliable mechanism to secure and record family consent for information about their child to be shared is therefore essential to any initiative to integrate data systems held by different agencies better – regardless of whether the information held is in paper or electronic format.

Sharing information in advance of meeting families

Any first contact between a family and an individual or service trying to help is likely to be more useful from the family's point of view if the person they are meeting for the first time:

- knows the child's name, some 'history' and what has been found out about the child's situation so far
- is aware of other agencies currently working with the family, including voluntary organisations and parent support groups
- can locate copies of any relevant paperwork quickly
- is aware that English is not the language of the home and has set up interpreter support ahead of the meeting
- knows any important facts about the family or family decisions about the child which parents have indicated they would like other people to be aware of
- knows what assessments have already been completed.



Without this sort of information, it is difficult to avoid:

- asking stupid and sometimes intrusive questions
- wasting time collecting information that has already been collected by someone else
- repeating assessments that do not need to be repeated
- spending time which could be better spent in other ways looking for bits of paper or trying to find out who else is working with the family
- burdening families with telling their story over and over again to strangers
- making families take responsibility for passing on information at what may be a very stressful time.

Effective communication, which respects the requirements of the Data Protection Act, is important at all levels. At operational level, a simple list of all the agencies currently in contact with a family facilitates day-to-day working. At the strategic level, initiatives to bring together information on electronic databases held independently by different statutory agencies have come high up the agenda for all local authorities in the short and medium term as a result of the Government Green Paper *Every Child Matters*.

This discussion about shared information systems therefore sits within a dynamic and much broader context within which ISA (Information Sharing and Assessment) initiatives are developing and local authorities are being required to integrate children's services. While these developments have been strongly influenced by Child Protection issues, they will impact directly on services for disabled children, as the following extracts from *Every Child Matters* indicate.

Extract from *Every Child Matters*

By the end of September 2003 local authorities should:

- audit current practice including the identification of information-sharing protocols, assessment processes, strategies for securing the engagement of stakeholders and mechanisms for ensuring that children in need of support receive appropriate services at the earliest opportunity. The audit should cover arrangements within the local authority, between the local authority and other statutory agencies and between the local authority and voluntary sector agencies.
- ensure that all agencies understand the legal framework that enables them to share information.

By the end of March 2004 local authorities should:

- be able to demonstrate that more effective information sharing between health, education and social care is improving services for children who display one or more risk factors
- have protocols in place for information sharing covering health services, education services and social care; and in development for all other agencies providing services to children and young people
- publish guidance on obtaining and documenting consent (including information leaflets for children, young people and their families and consent forms).

This section reports two initiatives to establish a common electronic database for professionals from a range of agencies, which highlight some of the issues involved. The case study material should be regarded as work in progress, unfolding within a much bigger agenda for change. It then moves on to explore how simple paper systems can make a difference and explains how the [Early Support](#) materials can help.



Practical example

Sunderland: Bringing Information Together In One Place

The initiative to bring together information about young disabled children and their families held on different electronic databases is central to larger initiatives to improve care co-ordination for this population. Consultation with parents revealed they were often asked to repeat the same information to each new professional they met and that some professionals didn't appear to know what the others were doing.

The aim was to enable professionals approaching the family for the first time to arrive better prepared so that they are able to ask more pertinent questions and carry out any additional assessment procedures more effectively. The model is a single system which allows professionals with the necessary security clearance to log on to the system, input an identification code for new referrals and gain immediate access to:

- a list of professionals and agencies already working with the family
- information about the level of involvement by other statutory agencies
- a list of assessments already completed
- basic information about the child's diagnosis and disability
- address, date of birth etc for use on any new paperwork.

The work was supported by a multi-agency steering group made up of managers from each participating statutory agency.

Key issues to date have been the:

- complexity, range and separateness of electronic systems used by different agencies
- fact that each of the statutory services have been upgrading their system and training staff, but at different rates and with different levels of investment

- need to negotiate an agreement between agencies on which information could and could not be shared and a consent form for families to authorise the sharing of information
- limited access to ICT equipment in the workplace experienced by some professionals who are potential users of the system.

'One of the biggest surprises was that defining the specification for the system was relatively straightforward, as representatives from all agencies quickly agreed the most valuable dataset to be recorded. Much more complex has been the inter-agency negotiation which needed to take place to agree links between systems, levels of security clearance, data protection requirements and the consent form for families. A key lesson learnt is to allow plenty of time for this negotiation to take place.'

This development work was funded by [Early Support](#) in 2002/03.

Practical example

Bristol: Piloting An Early Years Child Support Register

Data on 40 children under three has now been entered on a pilot version of a new database which was developed in 2003, following wide scale consultation with local stakeholders, including 100 written responses to questionnaires and five focus groups.

The registration form for the database asks for basic information about the child (including the NHS identifying number), the family, first language and religion, the nature of a child's disability and the name and contact number for a 'lead professional'. The database makes this information available to all professionals with appropriate security clearance. It also enables information to be sorted by age, disability, postcode and lead professional, which supports planning for service development across agencies and prepares early years and childcare services for any children of pre-school age entering the education system who have special educational needs.



None of the families approached have refused consent and experience demonstrates that the registration form takes 5–10 minutes to complete. Nevertheless, one PCT has been reluctant to participate because they fear families will not want to register and that the additional workload involved for health visitors is significant. While education and social services see registration forms from community-based health practitioners as a safety mechanism to ensure that early years services are aware of all the children who are likely to need support, health believes that signalling that a child may need support is a 'diagnosis of disability that it is not a health visitor's responsibility to make'.

Family Held Records

A Family Held Record is a collection of papers, kept by the family, which they take with them to hospital appointments, clinics, Early Years and childcare or Sure Start settings – in fact, anywhere they are likely to meet professionals or representatives of voluntary organisations that provide services for their child. Family Held Records are called by different names in different places. The [Family File](#) from the [Early Support Family Pack](#) is a Family Held Record.

At heart, files of this type bring together current results of medical and other assessments with copies of any relevant correspondence in which the child's condition or disability is discussed. A list of professionals and agencies working with the child and family is often also included. Other elements have been added to this basic minimum in different places to provide a range of models.

Family Held Records provide a simple safety net to support any other information systems which operate locally (for example, the passage of patient notes between hospital departments and clinics). They also facilitate information exchange between statutory agencies and ensure that:

- families hold copies of relevant paperwork and control who they show the material to

- paperwork is at hand to support discussions with a range of professionals
- anyone meeting the child and the family for the first time has timely access to information about:
 - the child’s development, their strengths and weaknesses
 - any known conditions or disabilities
 - clinical or surgical interventions to date and the results of any tests
 - the agencies or services already in contact with the family.

Practical example

Somerset Service Co-ordination Project

The Somerset Service Co-ordination Project has successfully used a Family Held Record to support service users for some time. Although the names are different, many of the sections in their ‘hand-held record’ map directly onto parts of the [Family File](#) from the [Early Support Family Pack](#).

The cover of their file explains to users that:

‘The purpose of this hand-held record is to build on the existing Personal Child Health Record and to provide a single place to hold all the information that you receive about the health, education and welfare of your child.’

Inside the file:

The [Somerset Service Co-ordination List](#) includes all the professionals involved with the child, including the ‘service co-ordinator’ (or key worker) and provides a place for a standard, brief history sheet which some families choose to fill out as a convenient means of sharing key information about their child. This is also the place that the family puts the ‘contract’ agreed with their service co-ordinator.

There is a section in which to put current action plans agreed between the co-ordination team and the family and a section in which families are encouraged to note down any questions and concerns they would like to discuss.



At the back, there is information about the Somerset Childrens' Information Service and a list of local services and agencies with telephone contact numbers.

How the Early Support materials help

The [Family File](#) in the [Early Support Family Pack](#) is a standard Family Held Record designed to be used across England. It has been developed in consultation with families and can be taken by them to hospital appointments, clinics, Early Years and Childcare settings – anywhere they are likely to want to talk with service providers about their child.

The material comprises some standard templates to be filled out by families or by families with the support of professionals and some empty sections into which papers can be inserted.

Where professionals help families to fill out the sections they wish to use, it ensures that:

- parents and carers control the information about their family they choose to make public
- families do not have to repeat their story to every new professional they meet – they produce one short statement about their child which can be updated over time
- anyone making a first contact with the family can see at a glance the range of services already being used
- relevant paperwork is at hand when it is needed to support discussion between the family and statutory or voluntary agencies.

The section headings are:

- [Introducing ourselves](#) (standard template)
- [List of professionals working with us](#) (standard template)
- [Record of professional contacts](#) (standard template)
- [Family Service Plan](#) (standard template)

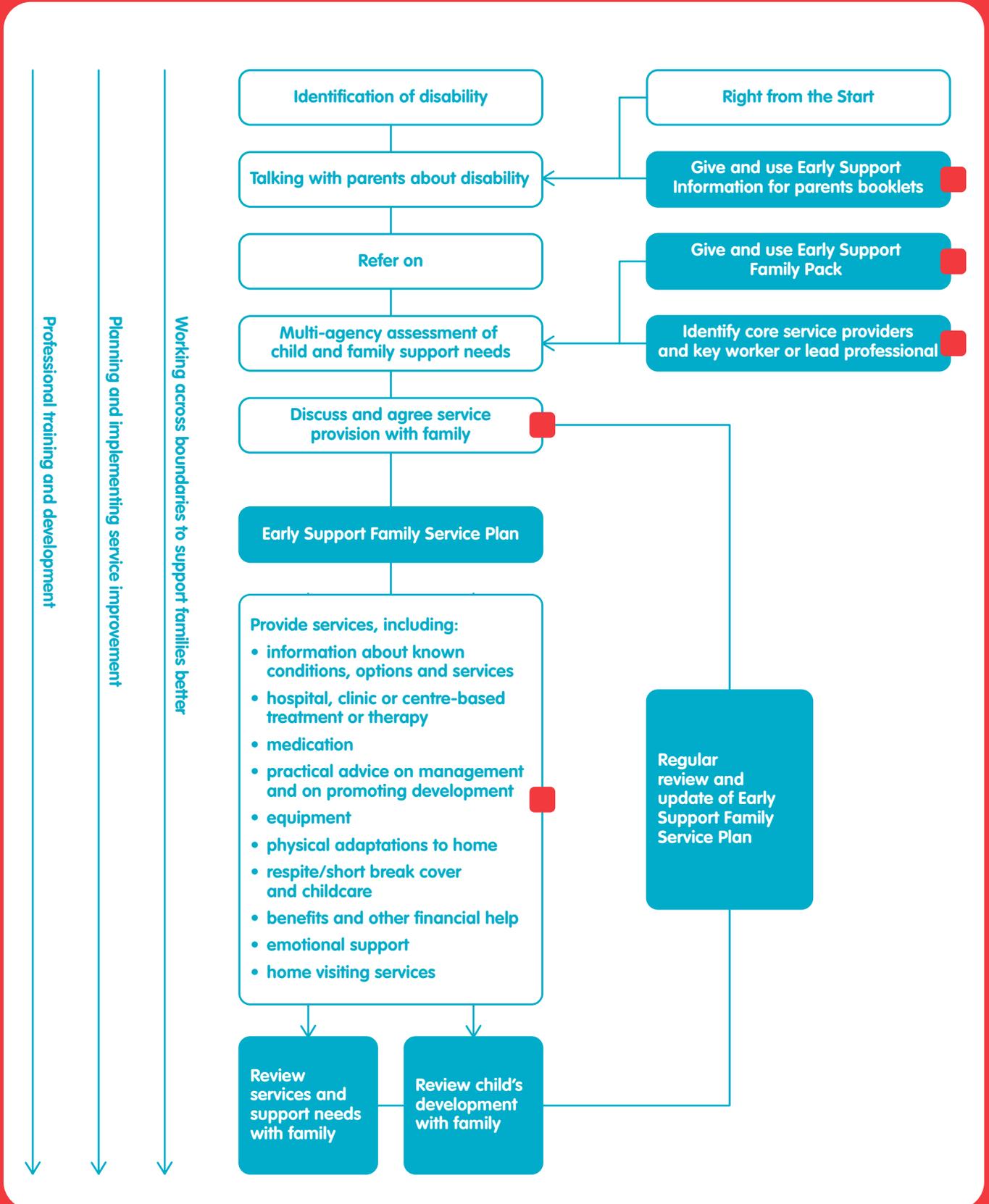
- [What our child can do now](#) (empty section to be filled in by parents if they wish)
- [Current records](#) (empty section to be filled in by parents if they wish)
- [Local organisations and contacts](#) (empty section for local information to be supplied by professionals working with the family).

The easiest way to understand the function of different sections in the [Family File](#) is to look in [How to use this pack](#), the introductory guide for parents using the [Early Support Family Pack](#). This publication includes completed examples of [Introducing ourselves](#) and a [Family Service Plan](#), for information.

Read more about [Introducing ourselves](#) in [Finding out what children and families need](#)

Read more about [Family Service Plans](#) in [Making and reviewing joint plans](#)

5 Making sure families have the information they need



Key principle for services for disabled children

- Service users know what services are available and how to get them and can access services and information via key workers or single points of access.

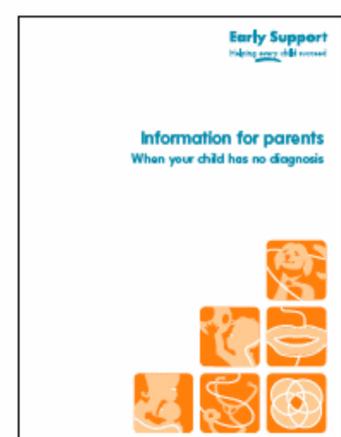
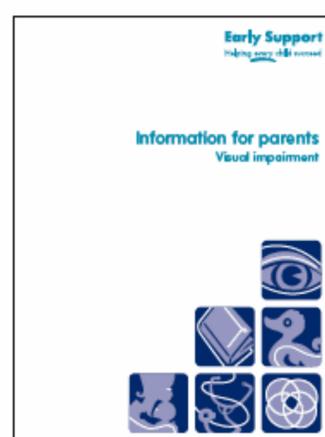
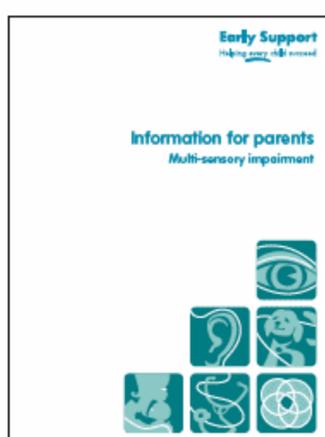
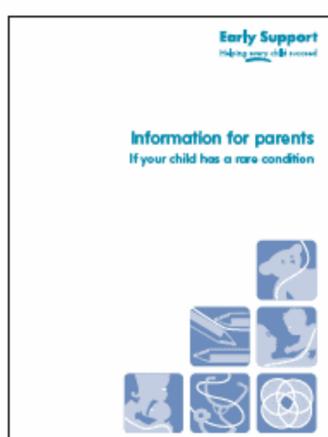
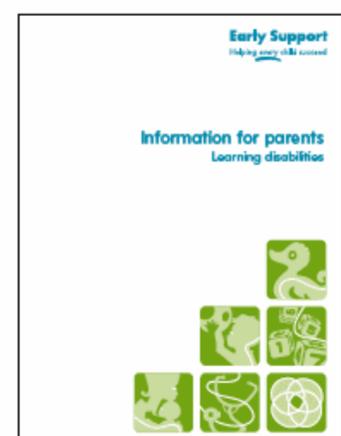
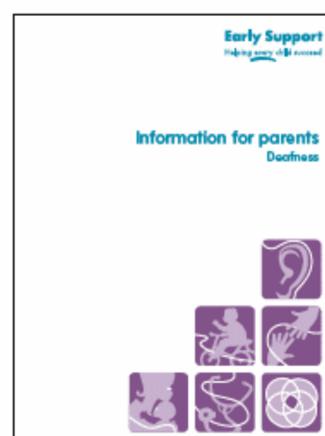
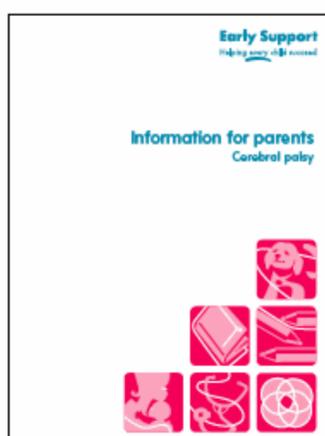
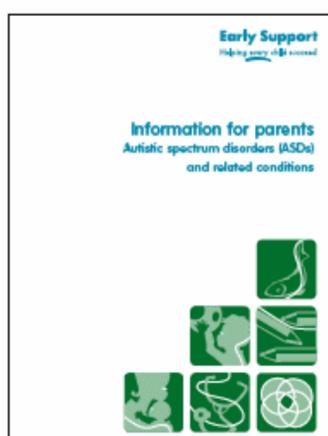
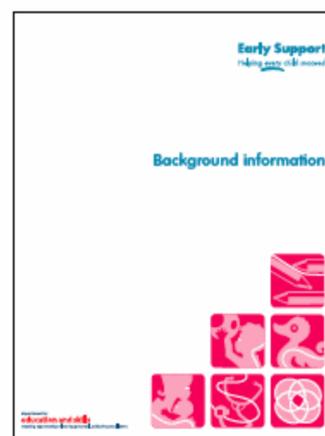
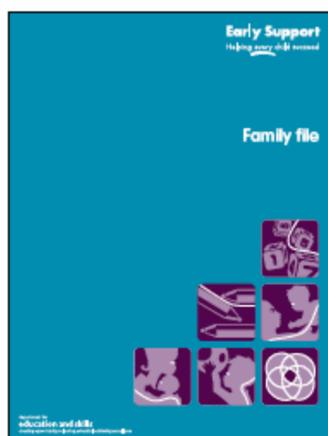
Services for disabled children: a review of services for disabled children and their families

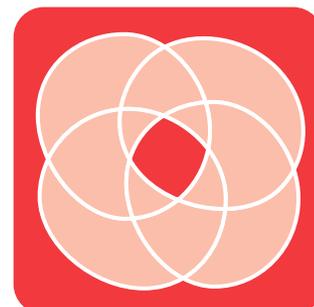
Audit Commission (2003)

Early Support Service Audit Tool

Standard D1: Providing and sharing information

Effective mechanisms are in place to ensure the co-ordination and appropriate exchange of information with families and other agencies about services, disabilities, interventions and therapies, child and family issues. Systems take account of and are responsive to family diversity and need and enable families to contribute their information.





Making sure families have the information they need

Summary

This section:

- lists the information that families need
- explains how the Early Support materials help professionals provide the right information at the right time
- explains how ongoing support to understand and apply information is a critical factor in determining how useful information is to service users.

Access issues are discussed in the context of keyworking and continuity of support.

'Even families with a diagnosis frequently experienced difficulties with finding out what services were available and what services and benefits they were entitled to, as information was not available from a single place or individual.'

Let me be me

Audit Commission (2003)

What kind of information do families need?

'Guides providing general background information, especially explanations and definitions of services, professionals' roles and acronyms used, were viewed as extremely useful as it was felt that all too often knowledge of this information was taken for granted or presumed.'

Mitchell & Sloper (2000)

Families say they need three main types of information:

- information about any particular conditions or disabilities relevant for their child
- information about local services with names and contact details

- general information about how services work, about the language which is used and about where to find out more.

There is clear good practice in some places and in relation to some aspects of information giving. It is also obvious that families who find their way to relevant voluntary organisations often find them valuable sources of information and support.

However, families too often report that they hear about Disabled Living Allowance (DLA) by chance, or that they had trouble finding accessible, up-to-date information about a particular condition identified in their child. Where more than one approach towards encouraging development is possible, some families also report finding it hard to get hold of unbiased information about the options available to help them make informed decisions. The Early Support materials have been specifically developed to ensure that the information needs of families are met more consistently across the country.

How do the Early Support materials help?

Information need	Where to find relevant material
Information about any particular conditions or disabilities	Early Support Information for parents booklets
Information about local services	Family File in the Early Support Family Pack section for Local services
Information about how services work, about the language which is used and about where to find out more	Background Information File in the Early Support Family Pack

The [Early Support Information for parents](#) booklets provide standard [information about particular conditions or disabilities](#). Professionals can give them to families and use them to explain particular factors or conditions in children. These materials are likely to be most useful to families in the early days following diagnosis. They:

Read more about these materials in [Right from the Start: talking with families about disability](#)



- set out the nature and characteristic impact of a particular condition
- pass on practical advice from other families
- identify voluntary organisations and other sources of information which may be particularly useful.

The [Family File](#) in the [Early Support Family Pack](#) contains an empty section for those working with families to insert [information about local services](#), with contact names and numbers. Where a printed guide is already available, it can be used here. Where printed material is not available, typed information sheets can be hole-punched and inserted. Families particularly value formats which introduce 'special' services, local voluntary organisations and groups where they can meet other families in the context of 'universal services'.

Some families who do not use the [Early Support Family Pack](#) and therefore do not have a [Family File](#), will also need standard information about local services.

The material in the [Background Information File](#) in the [Early Support Family Pack](#) is organised under the following headings:

- Introduction
- People you may meet
- Childcare
- Financial help
- Education
- Health services
- Social services
- Statutory Assessment – Education
- Glossary
- Useful contacts and organisations

As the section headings suggest, the file provides:

- information about how services work
- support to understand some of the language that families hear being used
- clear signposts on to other sources of information.

All these materials are freely available to families via the Early Support website (www.espp.org.uk) and as print versions. However, they most effectively meet the information needs of families when they are:

- provided by professionals who are already known to the family
- supported by ongoing discussion over time.

All the Early Support materials have been written in consultation with families or organisations working directly with families and conform to recommended best practice in terms of presentation of material for families with disabled children.

Where to find out more

To find out what families who are information users say about the format and physical presentation of information materials, read:

User-friendly information for families with disabled children

Mitchell W & Sloper P

Joseph Rowntree Foundation (2000)

Using the Early Support materials

The [Early Support Information for parents](#) booklets and the [Background Information File](#) in the [Early Support Family Pack](#) are free standing and can be used by families whether or not they receive regular support from professionals. They will meet the needs of a range of users who may:

- wish to read them through from start to finish at one sitting
- dip in and out



- come back to revisit the material on many occasions over a period of time.

The materials can be easily integrated into existing practice with families. They work in flexible combination with one another and add to whatever is already being provided. Information can be revisited and reinterpreted many times at different stages of the unfolding journey of discovery that parents make in the first three years of their child's life. They help structure support, ensure that nothing is missed out and provide a firm platform to support discussions between professionals and families.

It is important that standard materials have been developed and are used because families who move from one part of the country to another will be reassured by the fact that professionals use the same material in different places and it is easier to provide continuity of support where this is the case.

Supporting the use of information – personal contact and continuity of care

The most important feature of the Early Support information materials is that they are designed to be used by those working regularly with families, over time. They:

- underpin developing relationships
- support continuity of care
- actively promote better and more consistent early intervention across the country.

'Future models of good information-giving practice should be premised on three separate but interwoven elements: parents should receive in-depth booklets describing a range of services and support, alongside shorter guides providing essential local information, while being supported by locally based key workers or facilitators.'

Mitchell & Sloper (2000)

The paper materials are simply tools. Positive impact depends on the person who introduces them to families and the manner in which they are presented. 'The person who comes with the pack' is the essential, invisible ingredient in the mix.

It is particularly important that the [Early Support Family Pack](#) is not simply passed to families – it should be introduced and explained at the time it is given, using the [How to use this pack](#) booklet. It is most powerful when it is then used as an essential, standard background element supporting regular contact with families.

It is the particular responsibility of key workers to check the information that families have received and to encourage and pace discussion, so obviously these materials directly help them to do their job. However, everyone involved with a family has responsibility in this area and should be familiar with the materials and expect families to ask questions about what they have read. Where a key worker service is not available, the materials described above can be used by anyone working with the family, but more thought needs to be given to exactly how and when the [Early Support Family Pack](#) is introduced into the home. Those who are in most regular contact with a family are the ones who are most likely to use the materials.

Some families are proactive and well placed to use any information that comes into their hands. However, an important aspect of the work most professionals do with families is to help parents understand and use the information they receive by:

- applying general information to a particular situation and a particular child
- helping families translate advice into action
- interpreting and reinterpreting information as more is discovered about the child's situation.

Read more about this in [Keyworking, key workers and care co-ordination](#)



In other words, the process of using information materials is a dynamic one, which unfolds gradually. It is not about ensuring the pack is delivered to families only to then leave them to get on with it.

Meeting the information needs of all families – access issues

Keyworking and continuity of support become more important where families experience significant difficulty accessing and using information in paper format and in written English. Issues of access sometimes also relate to format – for example, when parents have a visual impairment.

The general principle is that families should receive the information they need in a format and language that makes it accessible to them. Deaf parents who use British Sign Language (BSL), for example, need the support of interpreters just as much as families where a spoken language other than English is the language of the home.

However, issues of access are more complicated than this. The discussion of information is more likely to be facilitated when families and the person working with them share a culture, as well as a language. Understanding is also positively encouraged where continuity of support is provided to complement meetings at which new information about the child or condition has to be exchanged in situations where there is time pressure.

The key mechanism for supporting access to information promoted by the Early Support initiative for all families is the introduction or extension of home visiting, key worker or lead professional services to provide families with some continuity of support. Where families use a language other than English, this can be achieved by English-speaking staff with the consistent support of an interpreter, or by the active recruitment, training and provision of key workers who share the language and culture of the home.

Where to find out more

If you would like to find out more about improving access to services, look at:

Section 1.5 of *Let me be me*, the Audit Commission handbook for managers and staff working with disabled children and their parents, which is called *Meeting the needs of a culturally diverse population*.

Providing language support for those who need it is also an important part of providing accessible, quality services. Good services:

- offer and provide interpreting at assessments and reviews for all families whose first language is not English, in the appropriate dialect
- offer translation of all key documents into the relevant language, where users have difficulty reading English, especially letters concerning assessments, diagnoses and service entitlement
- use plain, jargon-free English in meetings where there is no interpreter present, offering to repeat and explain in other terms or to postpone the meeting until an interpreter is available.

Let me be me

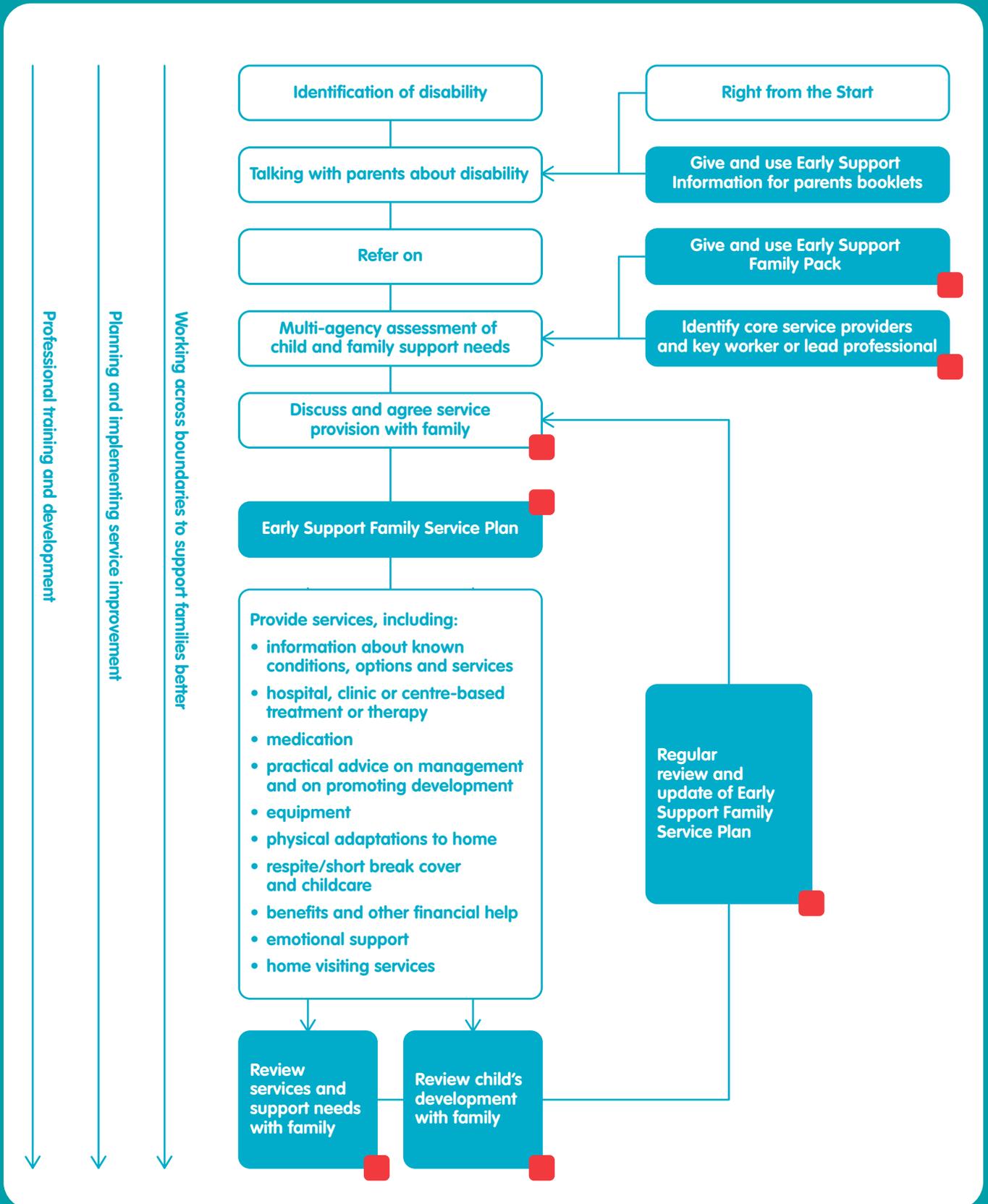
Audit Commission (2003)

In 2002/03, ESPP funded the development of information materials about deafness in video format for Syhletti-speaking parents in Tower Hamlets and the introduction of support workers who shared the language and culture of families in another area.

From September 2004, a number of ESPP funded partners are supporting access to information for particular populations – for example, refugee families and Tamil and Somali-speaking families.

Visit www.espp.org.uk to find out more.

6 Keyworking, key workers and care co-ordination



'Children known to more than one specialist agency should have a single named professional to take the lead on their case and be responsible for ensuring a coherent package of services to meet the individual child's needs.'

Every Child Matters

Government Green Paper

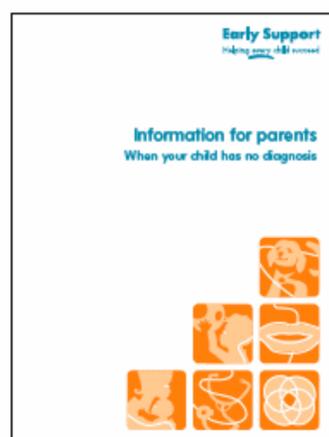
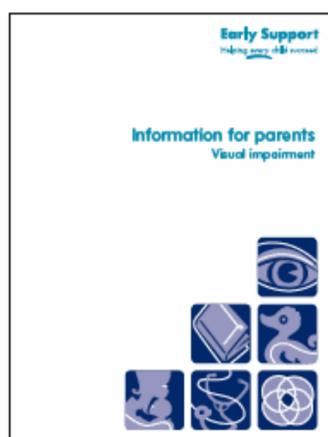
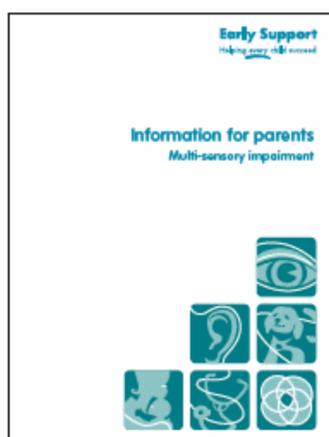
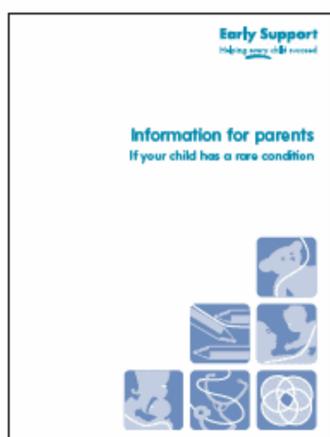
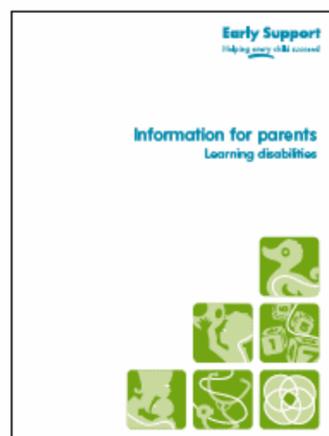
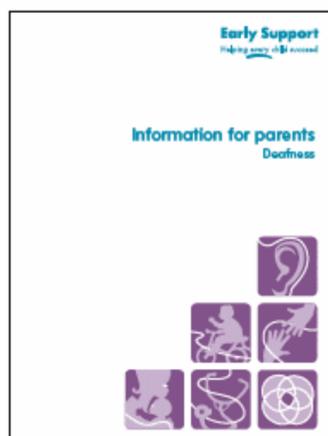
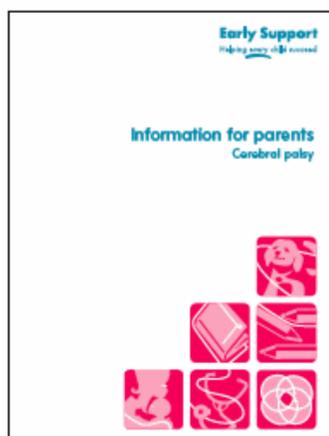
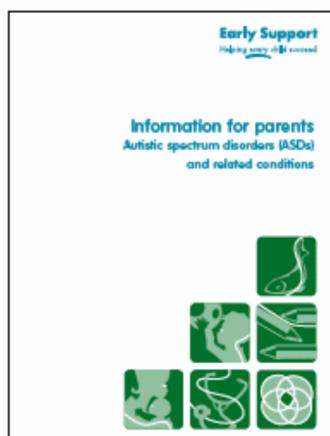
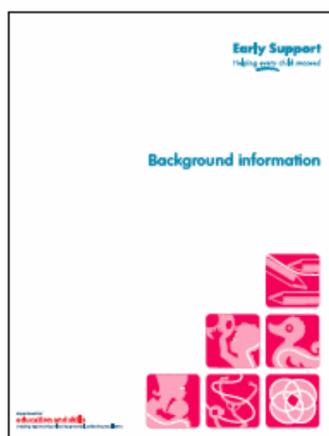
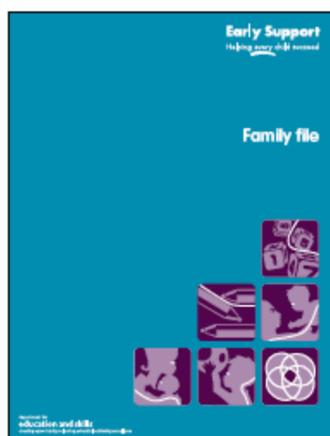
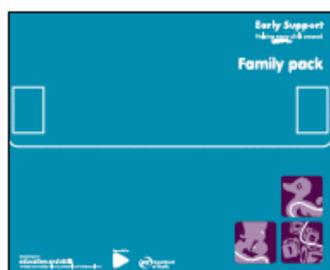
(September 2003)

Early Support Service Audit Tool

Standard B4: Referral, identification and initial assessment

There are clear policies and defined practices for identifying a key worker. A key worker is available to all families of children birth to three who require one and is allocated during the process of initial assessment. The role is needs-led, clearly defined and agreed with families.

See also **Standard C4: Ongoing support**





Keyworking, key workers and care co-ordination

Summary

This section:

- highlights the importance of embedding a system of keyworking or care co-ordination at the heart of service delivery to families and indicates resource implications for service managers
- discusses the nature of keyworking
- outlines a range of models for keyworking and key worker services
- explains how the Early Support materials help.

Sections 3.4 and 3.5 of *Together from the Start* should be read alongside this material.

Extract from *Together from the Start*

Effective use of keyworking is one of the key issues for improving standards. All children with complex needs and their families should be allocated a key worker who works in partnership with them, with the function of co-ordinating service provision and providing a clear point of reference for the family.

'In the early days it was like living in a 'fish bowl', people looking in on our lives, appointments here and appointments there, knocks on the front door with another professional asking us the same questions about our son. Enlightenment came in the form of our speech therapist who took on the role of care co-ordinator. She was our liberator, she knew the family well, she helped organise and plan and was someone I could express my feelings at during times of difficulty. It made, and still does make, a huge difference.'

Background

keyworking, care co-ordination, 'Team Around the Child' (TAC) approaches and key worker services are all mechanisms to ensure that families experience a better co-ordinated, holistic response from support agencies. Where mechanisms of this type operate, they are highly valued by the families who use them.

The Court Report (1976) and the Warnock Report (1978) emphasised the need for a 'named person' to act as a fixed point of contact for families using a range of services more than twenty years ago. The importance of providing 'lead professional' or 'key worker' support is being emphasised again in 2004 by the *National Service Framework for Children* and within moves to integrate services for children driven by the Government Green Paper *Every Child Matters*.

The time has come to:

- build on existing good practice by sharing the experience of key worker or lead professional services that are already in operation
- encourage new services to develop
- make service managers more accountable for the co-ordination of information and continuity of support provided for families where no obvious mechanism to promote keyworking is in place.

The Early Support initiative:

- actively promotes the extension of keyworking, lead professional and home visiting services
- is funding the development of services of this kind in 2004–06
- provides materials to help people who take on responsibility for care co-ordination do their job better.



Embedding keyworking within multi-agency planning for service improvement

Introducing a new key worker or lead professional service for disabled children is challenging and the experience of the last twenty years has demonstrated it is unlikely to be achieved without a deliberate act of will and dedicated resources. It is both:

- a significant indicator of commitment to improve the co-ordination of service delivery to families
- a significant factor in securing improved delivery of services provided by a number of different agencies.

New services are most likely to succeed and be sustained where they are planned, developed and funded as an essential component of larger and longer-term multi-agency initiatives.

Read more about this under **Models for service provision**

There are a number of different models for services and more than one way to achieve the objectives of greater continuity of care and better co-ordination of support. There are also clear resource implications where any service is being introduced for the first time. It is always the case that staff must have allocated and protected time to undertake the work involved. Other relevant issues are:

Read more about this under **Resource implications**

- the training needs of key workers or lead professionals
- professional supervision for those working in a keyworking role
- administrative support for care co-ordination processes.

What is keyworking?

Keyworking or care co-ordination describes any mechanism to check and improve the co-ordination of services provided by more than one agency to a client – in this case, a family with a very young disabled child. The more people working with a family and the greater the number of agencies involved, the stronger the argument for ensuring support is co-ordinated well.

Research demonstrates that families raising a disabled child with severe physical disabilities or profound and complex difficulties use many different services, attend many different hospital appointments and are typically supported by more than 10 different professionals on a regular basis. The arguments for providing care co-ordination for this population are compelling.

'The number of different professionals involved with these families suggest a high potential for difficulties of co-ordination between services and problems for parents in knowing which needs are more appropriately dealt with by which services.'

Sloper and Turner (1992)

Keyworking means:

- making sure that families receive complete information about the conditions or disabilities that are relevant to their child and about the help that is available, including entitlement to financial benefits
- ensuring that everyone has the information about the family and child they need to provide a good service
- co-ordinating assessment processes and service provision to minimise overlap, duplication of services and stress for the family
- establishing and maintaining a relationship that supports families in understanding and using information.

In simple terms, keyworking requires that someone takes responsibility for:

- co-ordinating and facilitating the total care package provided for a family
- providing and passing on information
- maintaining regular contact to ensure continuity of support.

Where joint planning processes are in place using a [Family Service Plan](#), effective keyworking ensures that the system operates smoothly and well.



What is a key worker or lead professional?

Extract from *Together from the Start*

A key worker or lead professional is both a source of support for the families of disabled children and a link by which other services are accessed and used effectively. They have responsibility for working together with the family and with professionals from their own and other services and for ensuring delivery of the plan for the child and family. Workers performing this role may come from a number of different agencies, depending on the particular needs of the child.

A key worker is a named person who helps families find their way through what may be a complex network of services. They act as a single point of reference for parents who need to ask questions about many different things and oil the care package provided for a family as a whole. Sometimes individuals who provide this sort of service are called a lead professional.

The core elements of the work of a key worker can be summarised under three main headings:

- information
- communication
- care co-ordination.

Key workers play an important role in relation to **information** by:

- checking families have all the information they need about any condition or developmental factor relevant to their child's situation – particularly important when a medical condition or disability has recently been identified or 'diagnosed'
- checking that families understand how 'the system' works for families with very young disabled children and that they have been told about services and financial help

Read more about this in **Right from the Start: talking with families about disability**

- providing the support that some families need to be able to access, understand and use the information they have received
- helping families reinterpret and revisit information as understanding of their child's situation builds over time.

Key workers or lead professionals support [communication between agencies and individuals working with a family](#), by making sure everyone has up-to-date information about the child's development and any recent events impacting on family life.

They [co-ordinate assessment processes, appointments and early intervention](#) so that families are not overloaded by too many contacts and that professionals work jointly with the family, wherever this is possible.

In relation to the flow diagram presented on page 15 and reproduced at the beginning of this section, these people are like 'glue' holding the whole process together. They:

- co-ordinate the processes involved in finding out what children and families need
- accelerate 'referral on' by helping to set up first contacts between families and agencies where this is possible
- bridge the gap from assessment to service provision by facilitating initial discussion and agreement of priorities between families and all the agencies they are in contact with
- ensure families receive the [Early Support Family Pack](#) and are supported to understand and use all the [Early Support](#) materials for families
- take responsibility for ensuring a [Family Service Plan](#) is agreed and reviewed regularly.



Providing continuity of support: the link with home visiting services

Key workers cannot help a family without knowing them and without being trusted. The 'softer' elements of keyworking, ie 'befriending' families and regular meetings to provide reliable information and support are also crucial. While the boundaries between 'befriending', 'counselling', being 'a shoulder to cry on' and simply being there for families to talk with are not always easy to define. This aspect of the work is very important.

Some families maintain most regular contact with a multi-agency centre like a Children's Centre, a local Sure Start programme or a centre that provides services additional to or different from universal, community-based support, for example, a Children's Development Centre (CDC). Where multi-agency intervention is clinic or centre-based, keyworking mechanisms are likely to be based there as well, although home visits may be added to strengthen the relationship between key worker and family.

Where families are visited regularly in the home by therapy services, Portage services or LEA advisory teaching services in the pre-school years, stable relationships are already likely to be in place between families and the professionals they see most regularly. This is fertile ground for a keyworking relationship to build on.

The [Early Support](#) initiative is funding the development of new key worker services on a range of models in 2004–06, including the development of existing home visiting services, like Portage, to take on broader keyworking or lead professional responsibilities. Where 'dedicated' services are being developed (see next section) the interface with regular home visiting services for families must be defined.

How the Early Support materials help

The [Early Support](#) materials for families have been specifically designed to help key workers or lead professionals do their job.

Information for families

The [Early Support Information for parents](#) booklets provide standard information about the characteristic nature and impact of a range of

conditions or disabilities. These can be used by key workers in the early days of adjustment and as time goes by to help families discover more about their child's situation.

The [Background Information File](#) in the [Early Support Family Pack](#) explains how statutory services work and about how to get financial help. It also explains some of the language that families hear and includes an extensive list of useful contacts and organisations. The material provides a resource which can be used by key workers over time to answer many of the questions that families ask.

The [Family File](#) in the [Early Support Family Pack](#) contains a section into which key workers can insert information about local services.

Making sure colleagues have the up-to-date information they need about families and children

The [Family File](#) in the [Early Support Family Pack](#) has an [Introducing ourselves](#) section which key workers can help families fill out. This material ensures there is a family-led statement about the child available which prevents parents having to repeat the same information to each new professional they meet. This material can be updated as time goes by and many families consent to it being shared with other professionals who are working with them.

Joint planning and review of service provision

The [Family File](#) in the [Early Support Family Pack](#) contains a [Family Service Plan](#) which directly supports joint discussion and agreement of priorities. Key workers take responsibility for ensuring a [Family Service Plan](#) is developed and reviewed.

[How to use this pack](#) in the [Early Support Family Pack](#) helps key workers and families discover together how best to use the materials in the pack to achieve better co-ordinated support. This publication contains an example of a completed [Family Service Plan](#) and [Introducing ourselves](#) template for information.

Read more about this in [Right from the Start: talking with families about disability](#)

Read more about this in [Making and reviewing joint plans](#)



Models for service provision

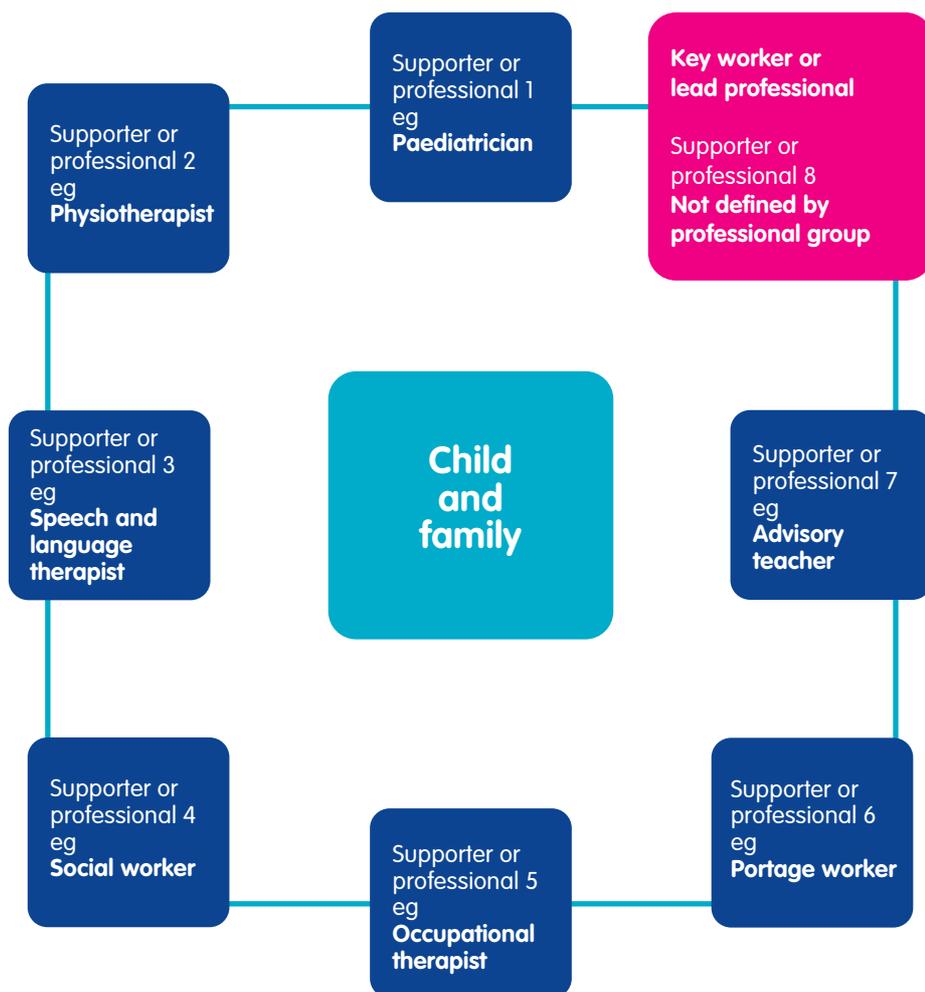
'Keyworking cannot be sustained, nor can it be wholly effective, if it is provided by individuals on an ad hoc basis. It needs to be located within a formal key worker service so that the role is recognised by practitioners in all agencies; the key worker is given adequate support and training in the role; and when a key worker stops working with a family, a replacement is provided.'

Mukherjee S Sloper P Beresford B Lund P (2000)

Keyworking and key worker services are already available in some areas but they are not all organised in the same way. Key workers are also called by different names in different places, for example, 'link worker' or 'care co-ordinator'.

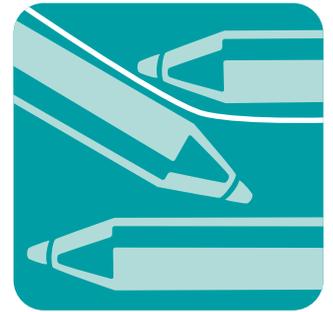
Key workers are defined not by the professional group they come from, but by the function they perform for families as service users. A key worker can be a speech and language therapist, an educational psychologist, an occupational therapist, an advisory teacher or social worker and may be employed by any of the statutory services (health, education or social services) or by a voluntary organisation. In the case of older children, someone from the local Sure Start programme or Early Years and Childcare Partnership could take on this role. The only practical constraint is where the nature of someone's job or existing caseload makes it difficult for them to maintain regular contact or make home visits.

The following diagram illustrates the basic idea underpinning a number of models of key worker services:



In *Team Around the Child (TAC)* approaches, one of the group of professionals in regular contact with the family becomes the key worker or lead professional for the family in addition to the work they are already doing with them. This means they take responsibility for facilitating the group processes needed to achieve a joint discussion involving all the agencies that are involved with the family, as priorities are identified, a plan is agreed and strategies are reviewed over time.

The core responsibilities of key workers on other models add other functions to this basic minimum. Core aspects of the work are to:



- make sure the family have all the information they need and where necessary, help families understand and use the information they receive
- ensure everyone holds up-to-date information about the child and family
- co-ordinate assessment support and intervention
- ensure a joint plan which keeps families at the centre of decision-making is formulated, involving all the professionals and agencies in contact with the child
- facilitate the regular review and updating of [Family Service Plans](#)
- maintain regular contact and where appropriate, provide emotional support.

In some places, a key worker or lead professional is someone who is already working with the family who then takes on a responsibility for co-ordinating the service provision package as a whole, which is different from and additional to other things they may be doing for the family. This is sometimes called a [non-designated](#) model of service provision.

In other places, people are employed specifically and exclusively to work as key workers (or link workers) with a larger number of families. This is sometimes called a [designated](#) model of service provision.

There are examples of designated services, which are provided by agencies independent of the other services used by a family – for example, a voluntary organisation.

On non-designated models of service provision a sensible assumption would be that whoever already maintains most regular contact with the family is the obvious person to take on key worker responsibility, where they are allocated time to do so.

Each of these models have their own advantages and disadvantages. Where non-designated models operate, more professionals find out more about the nature of multi-agency service provision in their area and come to understand the nature of keyworking. Families benefit from the fact that their key worker is an 'insider' and has the power to make things happen.

Where designated models operate, families will have a key worker who is more likely to be experienced in this role and who may be better placed to act as an independent advocate for them, should this be needed.

Where to find out more

To get a flavour of the range of services that are currently operating and to view a national survey of key worker services, visit www.ccnuuk.org.uk

Care Co-ordination Network UK (CCNUK) is an umbrella organisation promoting and supporting care co-ordination or keyworking for disabled children and their families in England, Northern Ireland, Scotland and Wales. Look for:

Care Co-ordination and Key Worker Services for Disabled Children in the UK

Greco V Sloper P Barton K
Research Works 2004-1
Social Policy Research Unit, University of York

Or contact **Interconnections**, an independent service which focuses on children with complex needs and their families, which can provide more information about Team around the Child services.

Interconnections

9 Pitt Avenue
Worcester
WR4 0PL
Tel: 01905 23255
Email: p.limbrick@virgin.net

'She's the health visitor and she's our friend and co-ordinator. If I need help, she's the person I'd turn to. I'd tell her anything. She helped me fill all my forms in, we had so much in our heads... Everything we had to find out we did through her. She came and did everything at home, it was a lot of help.'



Resource implications

Whatever model of service is introduced, it cannot be sustained if it is not resourced. The key elements to be funded are:

- additional allocated time for people acting as key workers or lead professionals to undertake the work involved
- training or preparation time for people taking on the role for the first time
- supervision time with a line manager focusing on keyworking issues
- administrative support to help with setting up joint meetings and writing or reviewing [Family Service Plans](#).

Where a designated model operates, the costs are transparent. Where a non-designated model operates, the same additional time and support is required, but it is needed to build capacity more generally and to replace staff hours across a number of different agencies. For many [Early Support](#) funded partners, establishing new key worker services for children with complex and multiple difficulties under three, the additional resource required translates into a requirement for 1.5–2 additional full-time equivalent staff.

Read more about
this under [Embedding
keyworking within
multi-agency
planning for service
improvement](#)

Where new services are established, it is likely to be appropriate to fund them from joint or inter-agency resources, as a core element of a multi-agency development plan, because key workers routinely work across agencies and all participating agencies benefit.

Job descriptions and competencies

The role of key worker or lead professional is a natural extension of what many people working for a range of services provide for families in an informal way already. Anyone taking on the role should:

- be known to the family and be acceptable to them as a key worker
- have a clear understanding of their role and responsibilities

- know where to find the information about disability and services that families are looking for and understand how the [Early Support](#) materials can help
- be competent to pass on information sensitively and flexibly to meet the needs of a range of families
- understand how the 'system' operates locally and who to contact to access particular services
- be able to 'think multi-agency'
- have sufficient authority to be taken seriously by providers of statutory services.

Where to find out more

Care Co-ordination Network UK has recently agreed and published a set of Key Worker Standards which can be viewed at www.ccnuuk.org.uk

Organisational Standard 9 says:

'A successful key worker service is dependent on:

A defined job description for the key worker manager, key workers and administrators. Where the service appoints non-designated key workers, amendments should be made to their current job descriptions to include their responsibility.'

The CCNUK key worker standards apply to all key worker/care co-ordination services, regardless of the model for service implementation used.



Practical examples

In 2004, most Pathfinders funded by [Early Support](#) were actively planning for the introduction of key worker or lead professional services or were expanding and developing existing service provision.

In 2002/03, the [Early Support Pilot Programme](#) funded a number of initiatives to explore how key worker services might be developed. You can read more about this work on the [Early Support](#) website at www.espp.org.uk in the [Partner activity](#) section.

The following examples are indicative of the multi-agency discussions which need to take place at local level when services of this type are planned.

In one area, activity concentrated on developing a specification for a key worker role. Draft statements looked like this:

- The key worker will be the main link between the family and services and a link between all the practitioners who are supporting the family. Practitioners may work together with the family through joint visits and/or joint sessions. The precise nature of the role will be agreed in consultation with the family and documented in a [Family Service Plan](#).
- Some families may not want a key worker. In these circumstances, a practitioner may still be nominated as key contact for the family to provide information and guidance when requested. They may also offer administrative support, inviting professionals to meetings etc on behalf of the parents.
- The key worker will help to answer questions about a child's particular disability, seeking information from colleagues or facilitating discussions between parents and practitioners better able to answer detailed enquiries.
- The key worker will ensure that families have the relevant information about benefits, transport and equipment, by signposting families on to the appropriate information agencies.

- The key worker will provide emotional support. Often this will be as an active listener and using counselling skills. More in-depth counselling support may be needed than a key worker can provide, in which case the key worker will ensure that families are introduced to appropriate agencies.

In another place, a range of professionals working with families with very young children with disabilities were interviewed and 30 families with children of pre-school age with disabilities or special educational needs returned postal questionnaires to inform planning. Five families were interviewed and shared their experience of services provided in the first year of children's lives. Among other things, these interviews highlighted the important role that community-based health visitors play in supporting families where there has been significant birth trauma, in the early stages following discharge from hospital.

An important conclusion was that the service should be governed and monitored by a multi-agency management group made up of all the agencies providing services for disabled children and service users. Another conclusion was that the work should be funded by a pooled budget, to which all children's services located in statutory agencies across the geographical area covered would contribute.

In a third initiative, a draft statement of competencies was developed to inform the development of a two-day training programme for potential key workers. Some elements identified were:

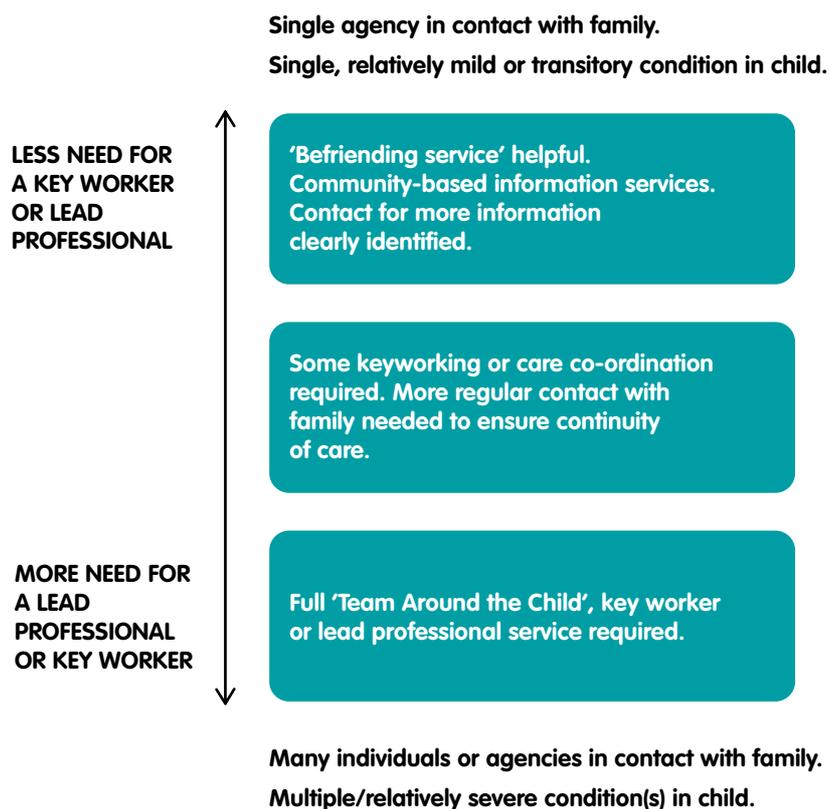
- The key worker is competent to form a relationship with parents within one or two sessions so that in most cases, families will feel confident in accepting him or her as a key worker.
- The key worker is competent as an active listener in un-hurried sessions at times of need.
- The key worker is competent to help the family understand any available information about their child and able to support colleagues in presenting new information sensitively.



- The key worker will be able to help families learn about all the relevant local, regional and national services, resources, voluntary organisations and information agencies that are available at appropriate times.
- The key worker will be competent to help families apply for any local, regional or national services, resources, equipment and financial support that is available.
- The key worker will be competent to work with the family and a range of other service providers to secure a well co-ordinated service, so that:
 - families do not experience gaps in service provision or duplication of services where this could have been avoided
 - an acceptable balance is achieved between sessions, the wellbeing of the child and the normal life of the family
 - programmes for the child are integrated as far as is possible into one, holistic approach
 - every practitioner working with the family is aware of what other people are doing
 - instances where families receive contradictory advice or information are addressed.
- The key worker will be competent to help parents gain confidence and skill in talking with professionals and competent to encourage practitioners to relate to parents as equal partners.

Who needs what?

The need for a lead professional or keyworking kicks in when a family uses services provided by more than one agency or where they experience multiple, fragmented contacts with one service (for example, many different hospital departments or clinics). The following diagram illustrates the basic point that the more services or agencies in contact with a family, the greater the danger of fragmented service provision and the more likely the need for a key worker.



However, at last two other factors are relevant:

Timing

Families who may not need consistent support from a key worker or lead professional service may need help in the early stages to:

- access information
- co-ordinate the assessment procedures which support initial discussions about what services or support might be needed by the child and family
- provide some emotional support.

Families who do not normally need a key worker may need one at times of crisis.



Family resources

Families who are less able to make proactive use of help and services need more help. Families who have difficulty accessing information in written or spoken English will also need more consistent support to negotiate service provision – ideally from a key worker or lead professional who shares their language and culture.

It might be expected therefore, that where key worker systems operate, caseloads will be dominated by regular and relatively frequent contact with families who have children with complex or profound disabilities, balanced by less regular contact with a larger number of families who:

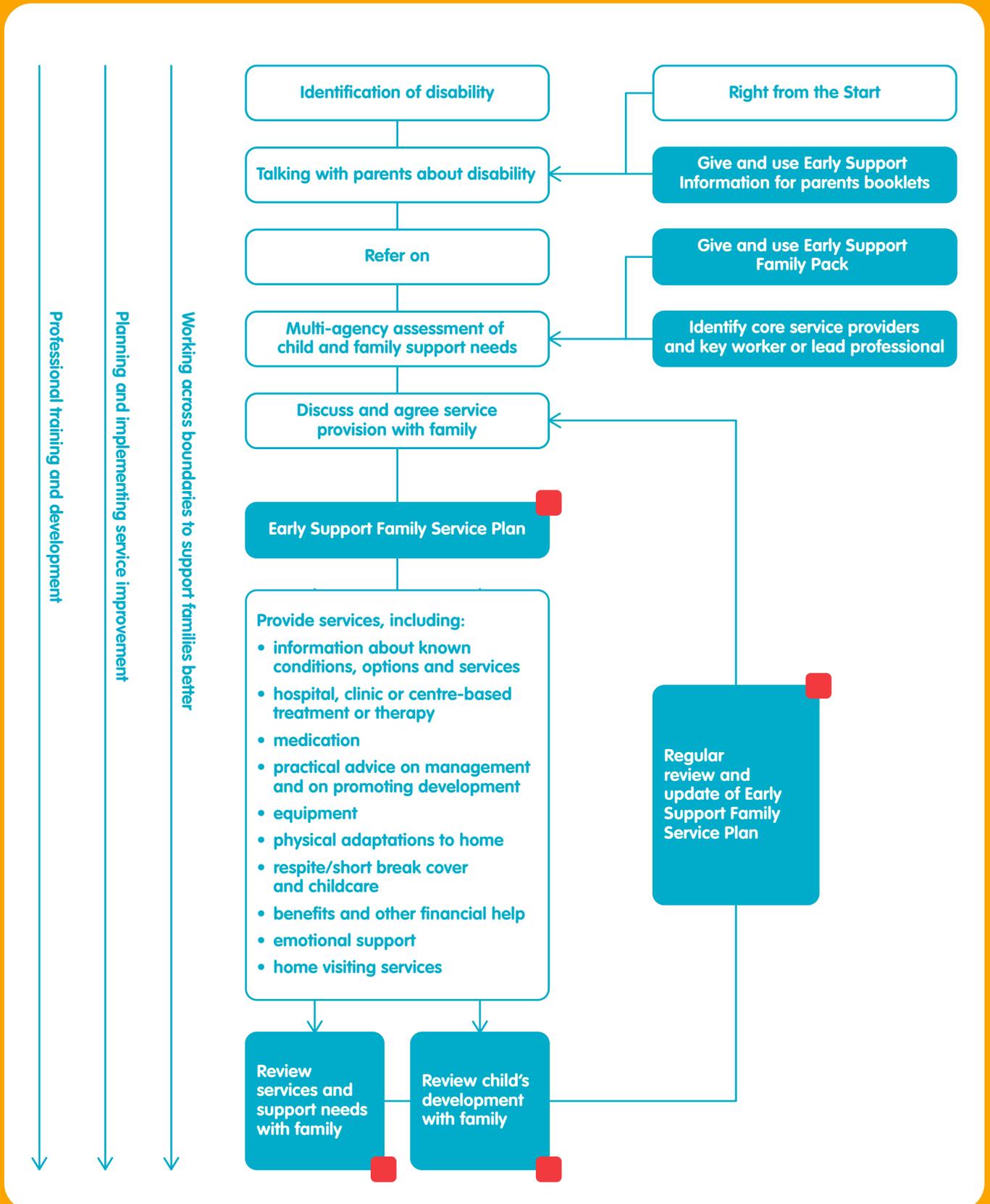
- interact with a smaller number of service providers but need help in the early days or at crisis points
- are ‘further down the road’ and require less help now than they did in the early days but still request occasional support to manage multi-agency support for their child.

A single, identified, and constant point of contact brings most obvious added value to families with children with complex and/or profound disabilities, because these families are in the most danger of not knowing who to go to for what, of getting passed around from one agency to another and of receiving conflicting information from different people. However, there should be enough flexibility in the system to respond to a wider range of families who request a service of this kind.

Research activity

Key worker services for families with young children who need additional help are currently developing on different models and at different rates in many places, often as part of broader initiatives to bring services for children provided by different agencies together.

7 Making and reviewing joint plans

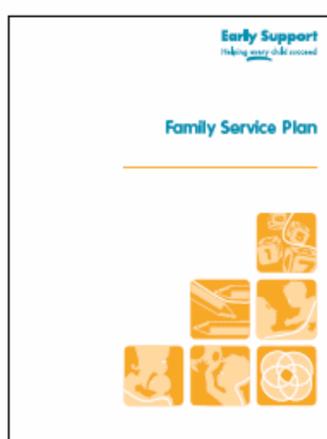
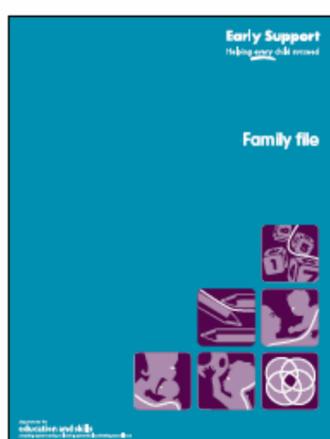
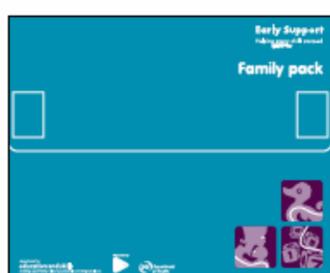


Early Support Service Audit Tool

Standard C1: Ongoing support

Written statements of policy and practice provide for families to be given a written integrated Family Service Plan after initial and subsequent assessments and after reviews. Each Family Service Plan:

- is drawn up in equal partnership with parents
- integrates plans from each agency
- is in a format that is accessible to parents
- follows Early Support guidelines.





Making and reviewing joint plans

Summary

This section explains:

- what a **Family Service Plan** is
- how the **Family Service Plan in the Family File in the Early Support Family Pack** can be used to promote a better co-ordinated approach to planning and delivering services provided by a number of agencies.

*'It should be emphasised in the materials for professionals that the **Family Service Plan** is an active, working, dynamic mechanism to support joined-up working practices, key workers, trans-disciplinary approaches etc... not a list of actions to be taken by different services.'*

Early Support Pathfinder

Extract from *Together from the Start*

'Parents want meaningful, joined-up assessment. In the early days, families and professionals, working together, need to:

- define the nature of the child's disability and impact on the family
- assess the level and type of service needed and agree the nature of the equipment, medical care, therapy, information and practical advice required
- agree how, where, when and by whom professional support will be provided
- agree how often the family will be visited in the home and by whom (where a home visiting service is available)
- agree how and when the appropriateness of the care/support package will be reviewed
- agree how, when and by whom the child's development will be monitored

continued...

- agree who will undertake the role of key worker.

Within a specified period after the early assessment, the family should receive a written summary of the above, in the form of a [Family Service Plan](#). The plan should be provided in a format that is accessible to parents.'

Introduction

[Family Service Plans](#) encourage joint, holistic discussion of service needs, agreement of priorities and regular review of any support that is being provided. They contribute to better multi-agency working by identifying the full range of support required, in a way that respects the perspective of families as service users.

The families for whom [Together from the Start](#) is relevant typically receive help from a number of different agencies. They may be in contact with health, education, social services and also receive support from the voluntary sector and other families with disabled children. In addition to rationalising the number of contacts between families and professional agencies, some co-ordination of early discussions about the help that will be provided is needed – particularly where families and children are using more than one statutory service.

The [Family Service Plan](#) in the [Family File](#) in the [Early Support Family Pack](#) provides a standard framework to support joint, multi-agency planning which keeps parents at the heart of decision-making about their child.

The plan does not replace other statutory assessments that may need to take place (for example by social services using the *Framework of assessment*). However, where [Family Service Plans](#) are used well and are already embedded in a developing relationship between families and professional agencies, they provide a useful starting point or 'catch up' mechanism for any agency coming into contact with a family for the first



time. They can prevent families being asked the same questions by different people where this is not necessary.

What is a Family Service Plan?

A **Family Service Plan** is a paper device to support joint discussion about:

- the services a child and family need
- priorities
- how understanding of a child's situation is developing
- how the services that are available locally will respond.

When a number of different services work with a family, it ensures that individual components of a service/care package are understood in relation to one another and more importantly, in relation to the overall aims and wishes of the family.

The plan records any decisions made about what will happen over the next few months. It is important to remember that 'filling in the paper' is in many ways less important than the discussion which precedes it.

Family Service Plans are already in use in some areas using a range of formats. They are a means to move on in a purposeful way from recognition of disability and service need to service provision.

Essential components of a **Family Service Plan** are:

- a statement of current priorities which is family-led but developed in discussion with the professionals and agencies supporting them
- a statement of which services will be provided with details of who will do what
- targets for the coming few months, if families find this helpful.

As the flow chart at the beginning of this section suggests, a plan can only be formulated when it is clear there is an ongoing need for support. Plans need to be reviewed periodically as an understanding of a child's situation grows and more information about their development becomes available.

Putting children and families at the heart of the planning process

Early Support Family Service Plans provide an opportunity for families and all the support services working with them to discuss and agree a plan jointly. The plan does not change the level and nature of services that are available locally. However, it does enable families to say clearly what they think they need and to prioritise the elements of service provision that they think would make a positive difference to their daily lives. Where more than one approach or therapeutic approach is available, it also enables those families who wish to do so, to state their preferences clearly.

Family Service Plans are not and should not be presented as statements of entitlement. It is important that families understand that writing down support requirements on a piece of paper will not secure services that are either not available at all locally or which are available, but constrained by budget.

One parent involved in developing and trialling Family Service Plans said she wished she had had it earlier, when she visited a new professional. It would have stopped them insisting on a particular approach to support, when a range of approaches had already been discussed and another chosen by the family. Now that a Family Service Plan had been written, she had sent it to the team with whom her family was meeting ahead of a first appointment to discuss possible surgical intervention, so the team were aware of her need for information but desire not to be pushed into a decision.

A family-friendly, family-led process?

It is the responsibility of a family's key worker or whoever is in most regular contact to ensure that the process of joint discussion leading to the writing of a **Family Service Plan** is co-ordinated, so that families do not meet with large panels of professionals unless they ask to do so.

Practical arrangements for writing the plan are best viewed flexibly. The paperwork can equally well be completed by:



- the family to record the service provision that has been agreed
- a parent with the support of professionals or with their key worker
- a professional where families do not wish or are not able to complete the paperwork.

However, the document should record only what has been discussed and agreed about what families need and about what happens next. It is important that families view the document as 'their own', and so as much as possible of what is written should use the parent's own words.

Timing issues: writing the first plan

Family Service Plans are most useful for families being supported by a number of different people or agencies, where they add value by provoking joint discussion between families and everyone involved with their child.

In **Early Support** terms, it is families who need and use the **Early Support Family Pack** who will benefit. The first plan should not be discussed before families have had some time to adjust to their situation, but should move forward quickly when parents see why getting some agreement about priorities and first steps might be a useful thing to do. Parents should not perceive it as a formal process, but as a means to an end, which is to sort out who is going to do what.

Sensitivity and judgement are needed to make good decisions about when to:

- introduce a family to the **Early Support Family Pack**
- talk about **Family Service Plans** for the first time.

Where professionals draw on previous experience of working with families, the issue of timing is likely to resolve itself naturally. The key point is that parents should never feel under pressure to complete a plan when they do not wish to do so, or do not think it is a useful thing to do – particularly when it is obviously more important to provide emotional support or information. Where families never see the utility of plans,

professionals may find it useful to use the materials to guide joint working with colleagues, but that is a separate matter.

Families who have a difficult first few weeks and leave hospital knowing that their child will need help will be actively looking for the information and support that the [Early Support Family Pack](#) can provide early on. Health visitors and others may therefore wish to introduce and use the materials to support the transition home. In these circumstances, making the first [Family Service Plan](#) can help as service provision is settling down in the early days, focusing everyone on what will happen in the days and weeks ahead. Very early plans of this type are likely to be tentative and incomplete. They can be used flexibly and changed as soon as new things are discovered about the child's situation.

Where recognition that a child and family need help from a number of different agencies develops more slowly over time, families should be introduced to the [Early Support Family Pack](#) when it is clear that there will be an ongoing need for support and that families need the information in the [Background Information File](#). In these circumstances, agreeing the first plan can help with the rationalisation of support that has built up in a piecemeal way over time.

Clearly children who need help from the early days onwards are likely to have a number of reviews and [Family Service Plans](#) before their third birthday. Children about whom there is growing concern over time are likely to have a plan for the first time in their second or third year of life.

Access issues: families for whom English is not the language of the home

There are obvious and particular sensitivities about using [Family Service Plans](#) with families who are not comfortable with written language or who use a language other than English in the home.

The process of discussing and agreeing options, priorities and services cannot move forward in the spirit intended without clear communication and a developing relationship between support services and families.

Read more about this in [Making sure families have the information they need](#)



Communication must be supported by spoken and sign language interpreters or ethnic minority community support workers when necessary.

However, the idea that **Family Service Plans** are simply not appropriate for these populations should be challenged. Where plans of this type are not being used, it is important to ask:

- How is service provision for the child being agreed and co-ordinated in the absence of a plan?
- How are families being supported to make informed decisions?
- Have families got all the information they need in their own language, in an accessible format or through an interpreter?
- What assumptions are made about what the family wants when communication is difficult?

Family Service Plans and the strategic development of services

Family Service Plans are an important component element of integrated, multi-agency responses to very young disabled children and their families. They encourage all the service providers involved to communicate better with one another and agree priorities with the family.

Where multi-agency co-operation is already well established, the joint writing and review of **Family Service Plans** facilitates periodic review of the child's situation and service requirements. Many local initiatives to improve the co-ordination of service delivery have led naturally to the development of **Family Service Plans** and key worker systems because these mechanisms actively support a 'whole system' response.

However, no piece of paper can bring about improved co-operation between service providers across agency boundaries and no professional can commit colleagues working for other agencies to providing support without prior discussion and agreement. There is also a danger that the inappropriate use of **Family Service Plans** in the absence of other service development initiatives introduces another bureaucratic

process into an already difficult situation, which adds little value from the family's perspective.

Family Service Plans operate best where multi-agency co-operation and working protocols are already developing and where families receive continuity of support, through a key worker or Team Around the Child (TAC) approach. They are most powerful when made and reviewed within a developing relationship between families and services, which supports understanding and use of information over time. To recap, the paper exercise functions as a trigger, which provides the opportunity to:

- review development
- review and adjust the service support package considered as a whole
- agree priorities for the next stage
- record conclusions for the information of others.

Family Service Plans and key workers or care co-ordination

Where no formal key worker system is in place, it is the responsibility of whoever has greatest continuity of contact with the family to ensure that co-ordinated planning for support arrangements takes place and that all the services in contact with the family are in communication with one another. **Family Service Plans** directly support this work.

Where a key worker has designated responsibility for co-ordinating service provision to a family, they co-ordinate the discussion and writing of a **Family Service Plan**, in partnership with parents or carers and any service providers already working with the family. Co-ordinating later meetings to support periodic, joint updating of the document is also an important part of their job.

Read more about this in **Keyworking, key workers and care co-ordination**



Practical example

In 2002/03 a multi-agency working group was convened in Salford to develop a [Family Service Plan](#) for use across health, education and social services. Although plans of this type had already been developed by the education service for one population of children in co-operation with families, there was little awareness of the plans at senior management level and therefore no guarantee that services provided by health or social services would be delivered. The initiative began with an information and planning day involving parents, audiological scientists, paediatricians, health visitors, speech and language therapists, voluntary organisations, the Portage co-ordinator, Sure Start personnel and representatives of Early Years Development and Childcare Partnerships in the area. The use of [Family Service Plans](#) was discussed at this day in the context of *Together from the Start*, and the need for a multi-agency response to service need.

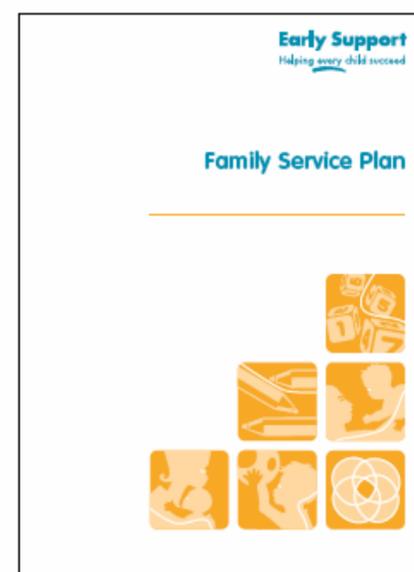
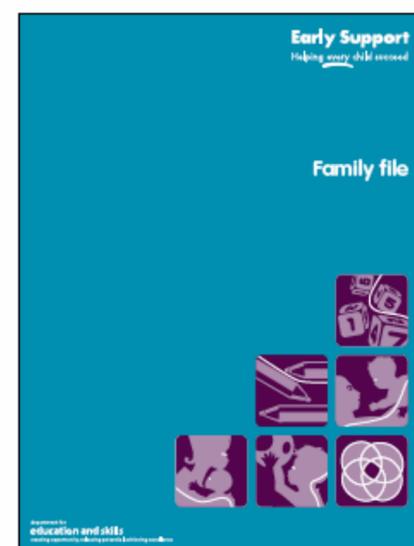
One year on, a format for the plans had been agreed and the use of [Family Service Plans](#) had been agreed at strategic and operation levels across education, health and social services. As part of Salford's work as an ESPP Pathfinder, use of [Family Service Plans](#) is becoming standard practice with larger populations of children and across agencies in the area.

How the Early Support materials help

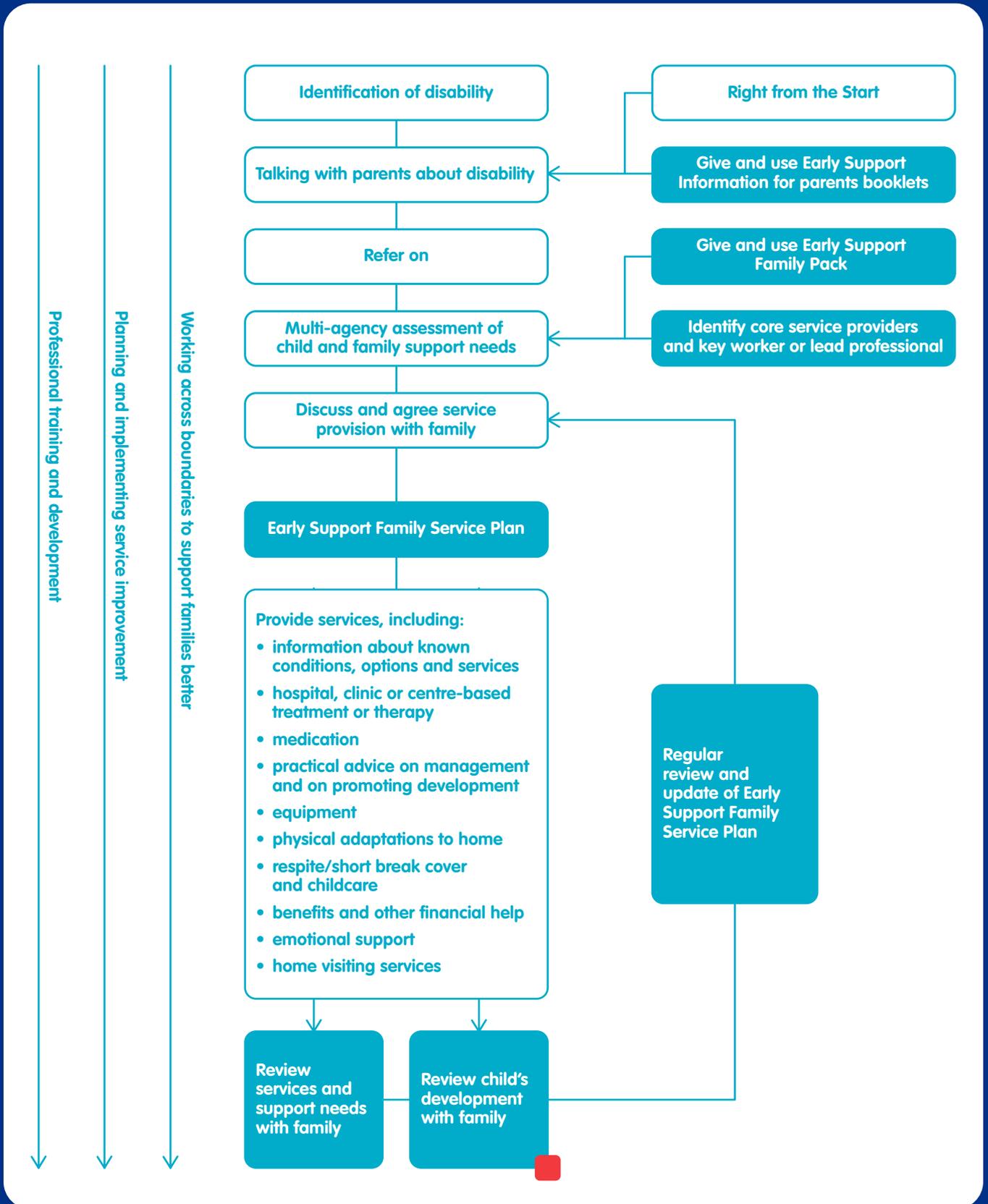
The **Family File** in the **Early Support Family Pack** provides a standard template for **Family Service Plans**. The prompts in the left-hand margin on each page indicate clearly who should lead on writing each section, although families are always free to ask the professionals working with them to fill in the plan on their behalf.

How to use this pack introduces families to **Family Service Plans** page by page. It also presents an example of a completed plan for a two-year-old girl. More examples may be viewed at www.espp.org.uk. Professionals are advised to use this material with families as they discuss the idea of drawing up a plan for the first time.

Families must be asked to give their consent for the plan to be circulated across the professional agencies working with them and to sign the declaration on the front page, because the plan may contain sensitive material about the child.



8 Monitoring change and development

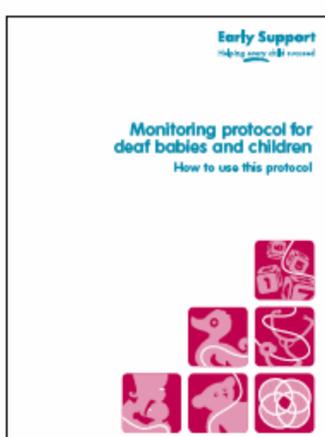
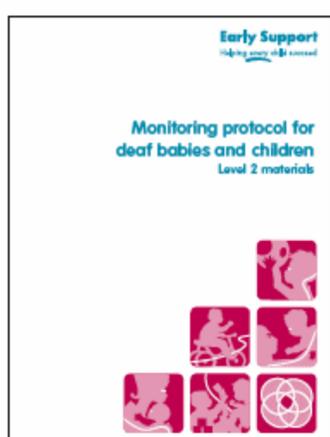
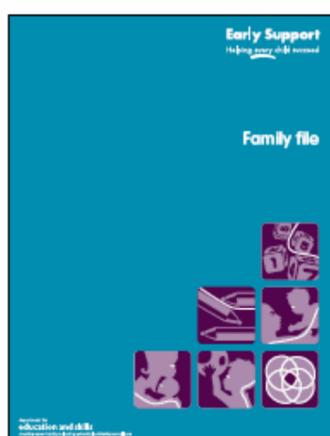


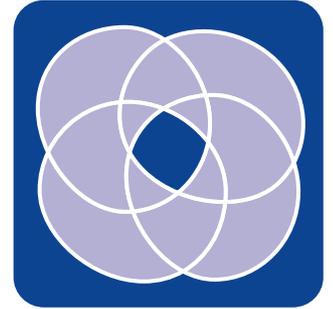
Early Support Service Audit Tool

Standard C2: Ongoing support

Written statements of policy and practice provide for ongoing integrated assessment processes, including the monitoring of each child's progress. Monitoring and assessment practice:

- is designed in partnership with parents
- is flexible to the situation and needs of each child and family's needs
- is integrated to avoid repetition and duplication.





Monitoring change and development

Summary

This section reviews why it is important to track children's development and progress over time and introduces some Early Support materials which can help.

Monitoring change and development?

Monitoring change and development usually means tracking a child's development and progress over time. However, for some families for whom *Together from the Start* is relevant, change means a deteriorating situation. This section does not address the sensitivities of working with families whose children have degenerative or life-limiting conditions, but focuses on children for whom it is appropriate, important and helpful to plot progress.

Why is it important to track development?

Ongoing monitoring of children's development over time, when families have moved beyond the process of initial assessment of needs is important to:

- help parents and carers understand what is likely to happen next and how they can best encourage progress
- mark progress and celebrate achievement in children who are facing significant challenges
- inform discussion between families and the professionals who work with them
- highlight development that is not following an expected pattern, where additional or different intervention may be required
- evaluate the impact of any early intervention and support that has been provided.

Evaluation or review of children's development is a standard part of professional practice. Those working with families with disabled children in the pre-school years use a very wide range of assessment procedures. Many of these are administered in clinical settings and yield a 'snapshot' of development at a given moment in time. Standard materials are also in use across 'mainstream' services provided by health visitors, Early Years and Childcare Development Partnerships and Sure Start local programmes. However, this is not always the kind of assessment that is most useful for families, nor does it necessarily involve them directly.

Where to find out more

Readers are reminded that *Birth to three matters* provides standard information about development from birth to three and is designed to be used with families.

The rest of this section is about the value of placing family-held developmental materials at the heart of joint working between families and professionals, where this is possible and parents welcome it.

Respecting the position and observations of families

'They know their bit, but they need to listen to us more. Particularly the mothers, because we're with them all day. They know more what the problems are but some doctors just think you don't count. It makes me angry. They're doing their best, I know, but they need to listen to us. After all, we all want the same thing – we're all there for the child, aren't we?'

Some discussions about children centre on clinical tests or screening procedures from which families are expecting to learn from professional expertise – particularly early on as the diagnostic process unfolds. However, as time passes, assessment of a child's general development and function should explicitly invite and use the contribution of the child's parents and family, as the people who know the child the best.



Naturally, occasional assessments of children's development using standardised and other tests also continue to be essential for many reasons. However, in general, assessment procedures that track development and build up a picture of what children are able to do in everyday situations over time are likely to be more useful in supporting ongoing discussion and work with families.

This is not just about valuing the perspective of families and using their knowledge of their child. It is about using ongoing evaluation to establish a shared framework of reference and vocabulary to discuss how to help the child and about building this up gradually as part of the support that families receive.

A key characteristic of the materials developed by [Early Support](#) to help with this aspect of work is that they stay in the family home and that monitoring activity is family-led. When families move from one place to another, they take the materials with them.

'Parents are going to know their child better than anyone else and I feel it is good to be in control.'

Why are standard developmental profiles important?

It is important that standard materials are used across the country to minimise confusion for families and to ensure that consistent support is given in different places. An important secondary consideration is that user-friendly materials inform professional understanding of the developmental processes involved and help the people who support families to do their job better.

Standard developmental profiles ensure that:

- families moving into an area or from one place to another receive consistent support, from professionals who use the same frame of reference and language and familiar paper materials
- some comparison of the effects of early intervention in different places and using different approaches is possible.

The second point is particularly important for low incidence populations with distinctive learning needs, where measuring and comparing the effects of early intervention and outcomes for young children has historically been difficult.

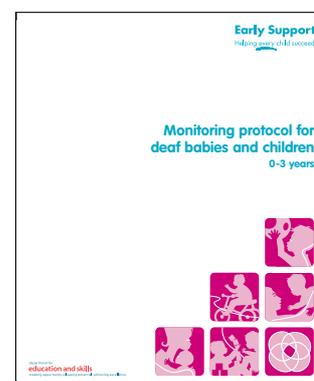
How the Early Support materials help

Early Support has developed material specifically to support working with families in this area. At the time of going to print, the [Early Support Monitoring Protocol for Deaf Babies and Children](#) was available and similar material for use with children with a visual impairment had been commissioned. Arrangements to explore the use of some parts of these materials with other populations – for example, children with Down’s syndrome, were also moving ahead.

The [Monitoring Protocol for Deaf Babies and Children](#):

- describes the development and progress over the first three years or so after identification of a hearing difficulty or deafness
- recognises the important information that families have to share about their child and enables professionals and families to share their observations
- provides a record for families of their child’s achievements, progress and development
- helps everyone to be clear about the significance of what a child is able to do, what the child will go on to do next and how this can be supported
- supports professional understanding of services to the child and family through shared, ongoing collection of evidence.

The [Family File](#) in the [Early Support Family Pack](#) also has an empty section into which parents are encouraged to insert any papers describing their child’s current stage of development. The section is called [What our child can do now](#). The contents of this section change over time as information which is no longer current is weeded out and updated.

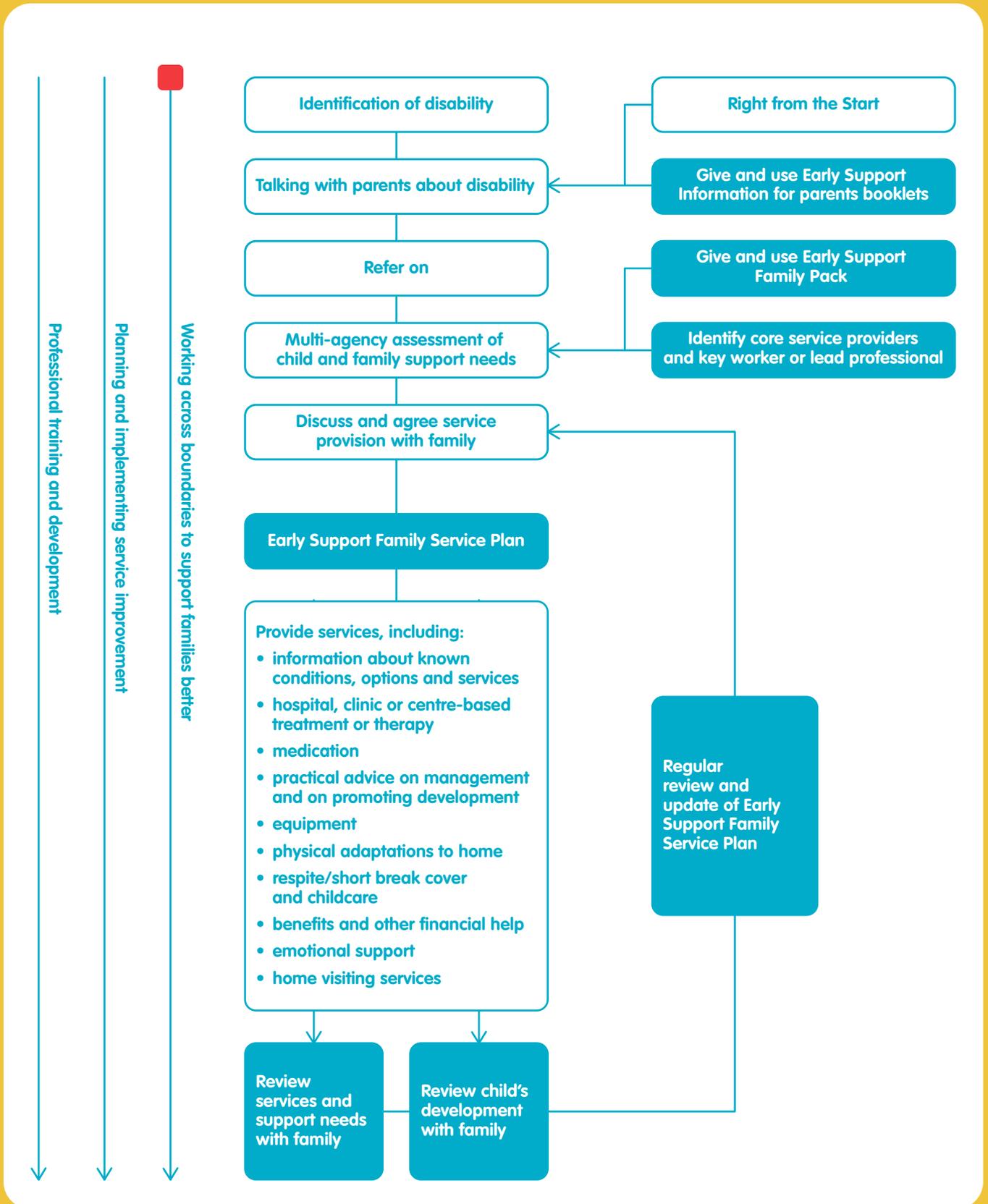


To find out what families are reading about this section, look at **How to use this pack**



Where families are using developmental profiles which build over time, they can insert the current pages into this section, or photocopy and use relevant material. The idea is that families only carry material in the **Family File** that it is useful to have to hand to support discussions with professionals – particularly professionals they are meeting for the first time.

9 Working across boundaries to support families better





Working across boundaries to support families better

Summary

This section highlights circumstances in which co-operative working across geographical boundaries is particularly important and explains how the Early Support materials help.

Boundaries?

This section concentrates on the complications of working across health, education and social services where agencies do not share common boundaries and issues associated with the very different sizes of administrative structures for relatively small populations of service users.

Read more about this at www.espp.org.uk

A good example is a large, county council working with the programme in 2004. In order to push forward multi-agency working across their area consistently, one local educational authority (LEA) was working with 13 Primary Care Trusts (PCTs). Looking at it the other way around, a programme partner in 2002/03 was obliged to work across five LEAs in order to achieve development across a single health authority. Also indicative is the funded partnership working across the administrative boundaries between a city and the county surrounding it.

Why are these factors important?

The fact that many agencies are not co-terminus can be a barrier to the development of multi-agency initiatives because it:

- complicates the processes of agreeing a common vision across agencies and of negotiating 'buy in' to standard protocols or procedures
- multiplies the number of joint meetings representatives from any one agency have to attend
- increases the number of contacts those driving change have to manage.

In general, this factor makes it more difficult to embed standard ways of working across the country. From the perspective of service users, this

makes it more likely that they will experience different ways of working and different criteria for service eligibility if they move house to live in another area, or are referred across boundaries for treatment or support.

Where administrative districts are small it is more difficult to develop differentiated services of high quality for relatively small populations. This factor impacts on capacity to develop support for particular populations of children and families, such as children with particular conditions or families who use languages other than English in the home.

In general, it is in the interests of the families and children that are the concern of *Together from the Start* that responsible agencies regard flexible working and partnership across boundaries positively as they plan for service improvement.

'This guidance is designed to support the development of specialist services for a clearly defined relatively low incidence population. Small authorities are encouraged to review their current service provision arrangements and to actively consider whether partnership arrangements with other LEAs could improve the quality and level of service they are able to provide.'

Developing early intervention/support services for deaf children and their families

(2003)

Sharing expertise and materials

The advantages of sharing expertise and materials across boundaries are most evident when families need specialist support which is not available locally or when there is obvious added value in concentrating resources in one place. One example of the advantage of working flexibly to provide earlier multi-agency assessment for families with deaf-blind children has already been discussed.

Read more about this in **Finding out what children and families need**



Extract from *Together from the Start*

Where families in one locality use many different languages, agencies may find it cost effective to share written information materials across local authority boundaries.

Practical example

In 2002/03 the [Early Support Pilot Programme](#) funded the development of a new library for families with young deaf children living in London. The initiative has now expanded around two centres, one in the North and one in the South of the city. The bases are open during normal working hours. They house a large stock of literature and provide free internet access for families who do not have this facility at home. Parents can read about the library, view stock and reserve books online at www.esppdeaflibrary.org.uk. Peripatetic advisory teachers are also able to borrow crates of books to use with families who receive a regular home visiting service. Another important function of the libraries is to collect together any information material that has been translated into different languages so that teachers and others can access it easily.

Using standard materials to promote continuity of care

Some of the complications discussed in this section will be addressed by the introduction, refinement and use of standard materials across the country.

Where no standard materials are available:

- families are more likely to experience very different working practices in different places
- positive initiatives at local level are unlikely to spread and influence practice in other places.

Read more about
Family Held Records
in [Sharing information
about families](#)

Family Held Records provide a good example to illustrate this point. The general importance of these materials as a means to share information with and about a family has already been discussed. Family Held Records

have developed in a number of places, using similar, but slightly different formats over the last ten years. Despite the fact that families who use them value these records highly, however, the pattern has been one of sporadic development at local level. No one model has bubbled up and become integrated into general practice. *Together from the Start* recommends the use of materials like this, but it is difficult to see how a standard version could spread across a complicated network of geographical and agency boundaries without support from a national initiative.

However, it is very important that flexible but standard practices and expectations do develop, because families routinely move from place to place. When their child has a particular medical problem, parents are likely to be referred to a secondary or tertiary service outside their area. It would be positively helpful in these circumstances if their paperwork were immediately recognisable to the people they meet. More importantly, it would be reassuring to parents coping with significant challenges to see a consistent system in place and familiar paperwork being used wherever they go.

Families are also mobile, moving house from one geographical area to another. In some cases, they move often. Standard materials encourage continuity of support for this population, some of whom are among the most vulnerable.

How the Early Support materials help

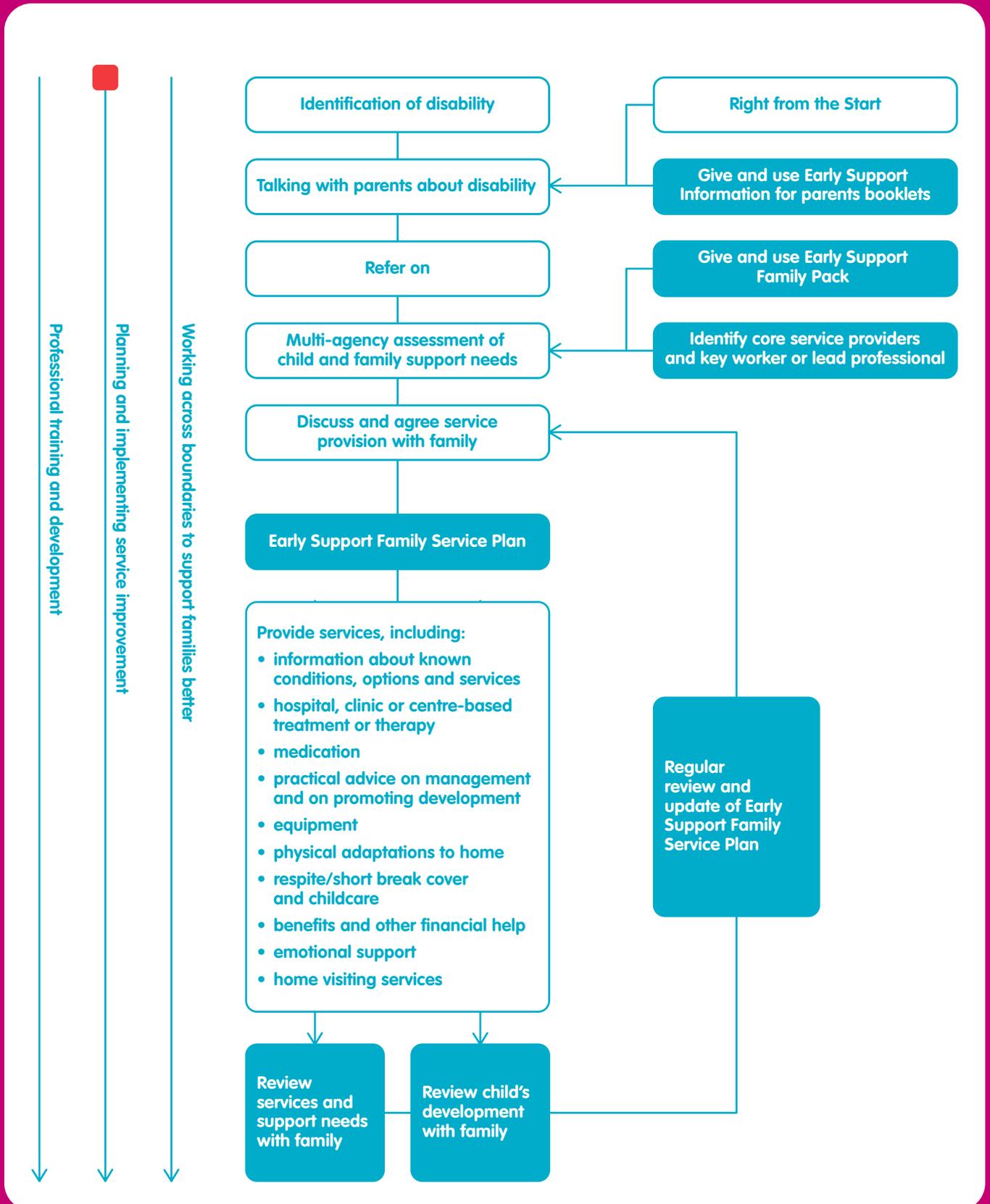
The *Family File* in the *Early Support Family Pack* is a standard Family Held Record for use across the country. It includes a *Family Service Plan*, which provides a common, flexible framework to support joint planning, discussion and review of multi-agency support for families. *Introducing ourselves* provides a standard format for summarising information that families would like any professional meeting them for the first time to know about their child.

The information for families contained in the *Early Support Family Pack* and the *Early Support Information for parents* booklets promote a more consistent approach to providing information, which is easy to accommodate across agencies and across geographical boundaries.

Read more about these materials in [Sharing information about families](#)

To find out more about what families are reading about these materials, look at [How to use this pack](#)

10 Planning and implementing service improvement



A joint strategic lead is needed to:

- initiate a multi-agency review of local need and mapping exercise of services
- develop an agreed multi-agency outcome-based measure for services
- establish joint accountability and milestones for achieving these measures
- facilitate the introduction of a key worker system across agencies and
- involve disabled children, young people and their families in service development and review.

Services for disabled children: a review of services for disabled children and their families

Audit Commission (2003)

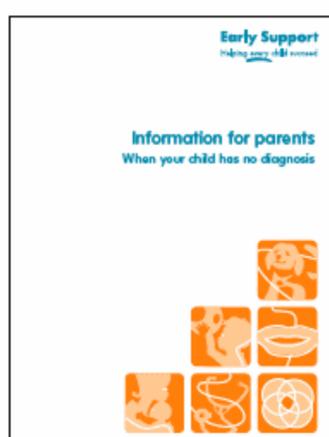
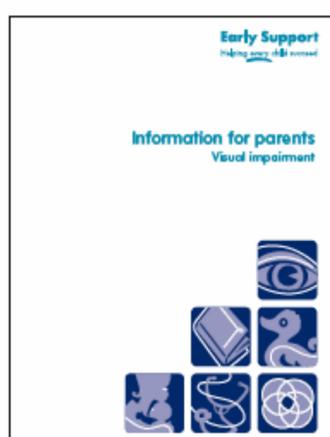
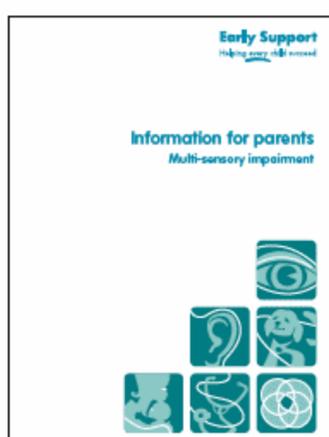
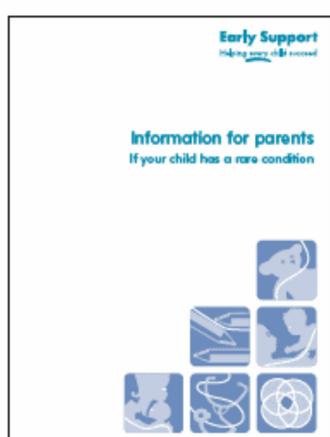
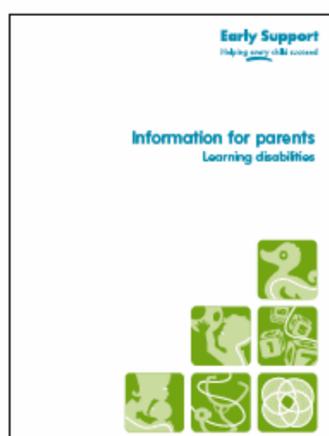
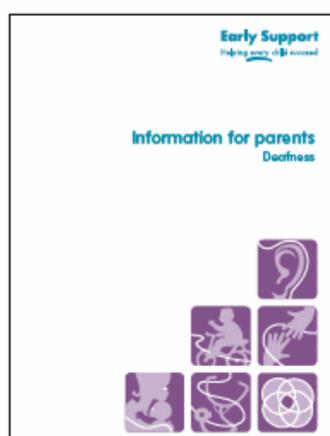
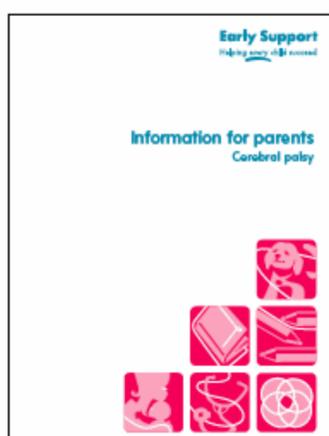
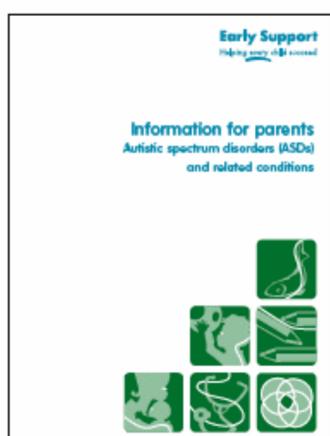
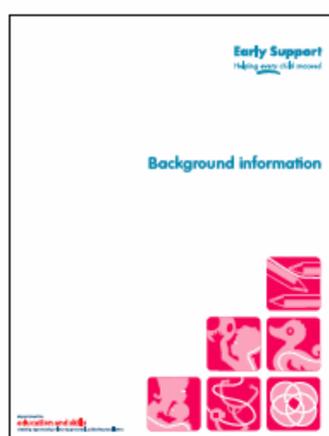
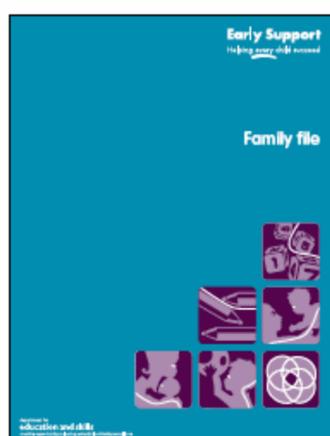
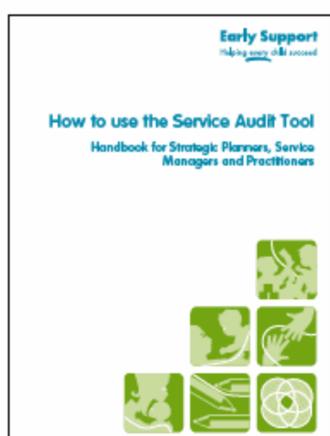
Early Support Service Audit Tool

Standards A1 A2 A3: Leadership, management and organisation

Aims and values reflect a clear vision of (and commitment to) providing a continuously developing, high quality and integrated service to families and children from birth to three years. There is a clear focus on outcomes for families.

Policies and practices are informed by the views of carers/parents and other service users.

Mechanisms are in place for monitoring, evaluating and improving services.





Planning and implementing service improvement

Summary

This section:

- explains the importance of embedding multi-agency service development at operational level within larger strategic planning processes
- emphasises the importance of incorporating a service user perspective into planning for change
- introduces the [Early Support Service Audit Tool](#), which is designed to help.

Extract from *Together from the Start*

It would not be appropriate to describe one service model that could be applied to all parts of the country. Characteristics of an effective service will depend on a host of local circumstances. However, it is possible to list those features that should be present. Services should audit the service in their area against the following features and develop an action plan showing how unmet needs will be met:

- Mechanisms are in place to enable joint planning between health, education and social services, involving voluntary and independent providers, resulting in a shared vision and strategy.
- Families of service users are effectively and appropriately engaged in the planning of service developments, where feasible.
- There are clearly defined processes for self-audit, planning and review.
- Performance indicators are jointly agreed and are regularly reviewed and monitored.
- Indicators include expectations of outcomes for children and families.

continued...

- There are measures of consumer satisfaction/client feedback.
- There is a system for longitudinal tracking of children.

Operational change and larger strategic processes

A multi-agency review of services and commitment at senior level are both needed to achieve positive and sustainable change. Initiatives at operational level usually cannot develop or be sustained without support from the top, because:

- changes in working practices and job descriptions need the active support of line managers
- sometimes change requires additional resource, and decisions about spending priorities can be taken only at a senior level
- complex processes like the introduction of new working practices or information systems across a whole administrative district and across agencies are best co-ordinated and driven 'top down'.

The importance of embedding joint planning processes, and the introduction of Family Service Plans and keyworking services within higher level planning processes has already been discussed.

The experience of **Early Support** Pathfinders and others suggests that a multi-agency planning group at senior level with a defined remit to review and manage services for disabled children is a necessary pre-requisite for success. The best groups incorporate service user and voluntary sector participation alongside health, education and social service interests.

Multi-agency strategic planning groups of this type are most effective when they are active and work to a plan. Their role is to:

- define a joint vision for joined-up, family friendly services
- cost proposed developments and identify new ways of jointly funding change

Read more about this in **Keyworking, key workers and care co-ordination**

Read more about this in **Making and reviewing joint plans**



- develop and agree an action plan
- monitor actual development against agreed timeframes and 'milestones'
- manage the implementation of the plan
- secure staff support for change at operational level.

The experience of [Early Support](#) programme partners to date has been that change is most likely to move forward quickly and be sustained where developments for young disabled children and their families are firmly embedded within larger strategic development processes. In the context set by the Government Green Paper *Every Child Matters*, this means understanding the expansion of key worker services and the routine use of the [Early Support](#) materials as facilitators, achieving the objectives set by larger policy initiatives for a particular population of children and families.

Incorporating a service user perspective

'The best way to make sure that services meet needs is to ask the people who use them for their views, experiences and preferences.'

Let me be me

Audit Commission (2003)

Using the experience and perspective of service users informs and promotes the development of flexible, competent and responsive services. It is the most direct way to identify priorities within initiatives to create more family-centred services and is a practical way to arrive at relatively cost-effective solutions that 'work for families'. Where informed and involved parents are consulted on a regular basis, they are likely to have realistic expectations of services and their involvement brings shared ownership of decisions and priorities for action.

Repeated legislation and guidance on health, education and social care highlights the need for user participation in planning and development processes. This is a dynamic, evolving field of activity within which it is particularly important to learn from good practice that is already established.

Where to find out more

If you would like to find out more about involving families who are service users in planning and decision-making, and to read about successful initiatives inviting participation, look at:

Section 1.4 of *Let me be me*, the Audit Commission handbook for managers and staff working with disabled children and their parents, which is called *Consulting and involving service users*.

Parent participation: improving services for disabled children

Parents' guide

Professionals' guide

Council for Disabled Children & Contact a Family (2004)

It is possible that parents involved in strategic planning processes may need support to be able to play their part well, but there is also a steep learning curve involved for professionals, where regular consultation with families has not previously been built into practice. In addition to a significant attitudinal shift, multi-agency planning groups need to address:

- how best to consult with service users at different stages or levels of development processes, in different ways and for different purposes
- how best to communicate the purpose and limitations of any consultation exercise to participating families
- building confidence that families regularly involved in strategic level planning processes represent the views of other service users
- maintaining input from families to planning and service development initiatives over time
- demonstrating the value of consultation to participating families by ensuring discussion results in positive change.



The contribution of multi-agency professional training events

The development and implementation of a strategy that provides leadership and exerts pressure on the system ‘top down’ is most effective when integrated with ‘bottom up’ processes to improve inter-agency working at operational level. Multi-agency training events have an important role to play within these processes. Professional training which positively encourages people employed by different agencies to meet and learn together can:

- enable personnel from different professional backgrounds to learn about and from each other in a neutral space
- allow personal networks of contact to develop across organisational boundaries
- short circuit the agreement of joint working practices at operational level.

Where multi-agency training events are directly focused on the distribution and use of the [Early Support](#) materials, they encourage a productive exchange of perspectives and increase the range of experience of working with families informing development. Events like this, which involve families as service users, are powerful facilitators, supporting and accelerating change.



How the Early Support Service Audit Tool can help

The [Early Support Service Audit Tool](#) directly supports:

- review of services for disabled children under three and their families
- planning for change
- the implementation of service development initiatives.

It is a pan-disability, multi-agency service audit instrument that sets out broad standards and more detailed indicators within those standards across four functional areas:

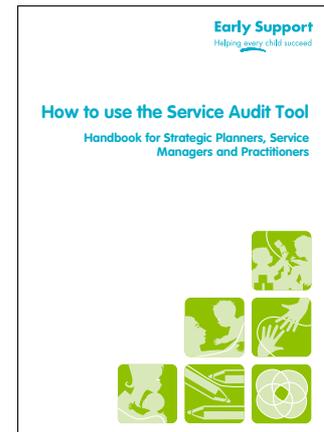
- A Leadership, management and organisation.
- B Referral, identification and initial assessment.

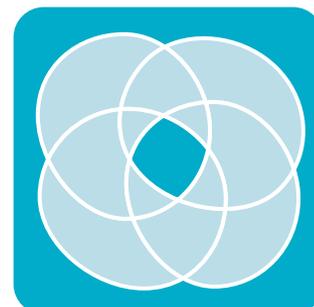
C Ongoing support.

D Providing and sharing information.

Senior managers and those who work on a regular basis with families are encouraged to review their practice and plan for development, by considering how their performance against standards and indicators is demonstrated a) in their work with families and b) in their work with one another as service providers.

A handbook for strategic planners, service managers and practitioners [How to use the Service Audit Tool](#) is also available.





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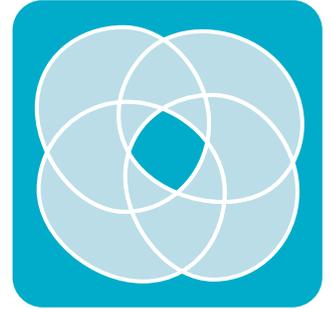
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Audit Commission
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Ref: LEA/0068/2003
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Together from the Start- practical guidance for professionals working with disabled children (birth to third birthday) and their families

Department for Education and Skills/Department of Health
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Department of Health
(2000)

***Quality Standards in Paediatric Audiology IV
Guidelines for the early identification and the audiological management of
children with hearing loss***

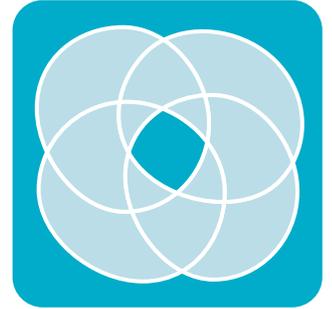
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***Parent participation: improving services for disabled children
Parents' guide
Professionals' guide***

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www.rightfromthestart.org.uk

Birth to three matters
Sure Start
(2002)



A note on quotations from parents

The quotations from parents supporting this text are important – they maintain focus on a service user perspective.

Where material does not come directly from an Early Support source, we have chosen not to attribute it in passing, to maintain pace for the reader.

We would therefore like to acknowledge with thanks the following sources for some of the material used:

Let me be me: a handbook for managers and staff working with disabled children and their families

Audit Commission (2003)

Expert opinions: a survey of parents caring for a severely disabled child

Beresford B

Telling it how it is

Britton C

Care Co-ordination Network UK website and materials

Parents' support needs

Limbrick-Spencer G

Right from the Start website and CDROM

Service needs of families of families with severe physical disability

Sloper P & Turner S

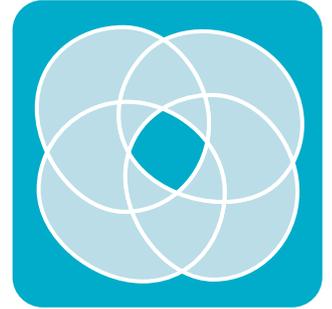
Just a shadow? A review of support for the fathers of children with disabilities

West S

Appendix 1: List of Early Support Pathfinders

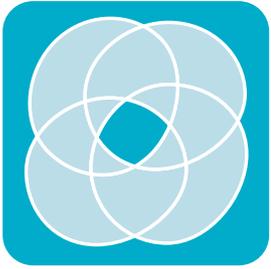
The following partners were working with the [Early Support Pilot Programme](#) in 2004:

London Borough of Barking & Dagenham
Blackpool Early Years Development Childcare Partnership
London Borough of Bromley – Phoenix Centre*
Coventry City Council
Cumbria LEA
Darlington Pathfinder Children’s Trust
East Sussex County Council
London Borough of Ealing*
London Borough of Enfield
Essex*
Gateshead*
Halton Council
London Borough of Harrow
London Borough of Havering
Kirklees Metropolitan Council
Leicester City & Leicestershire*
Liverpool LEA & Partners
Medway*
London Borough of Merton
Sure Start Middlesbrough
Norfolk County Council
North East Lincolnshire Council

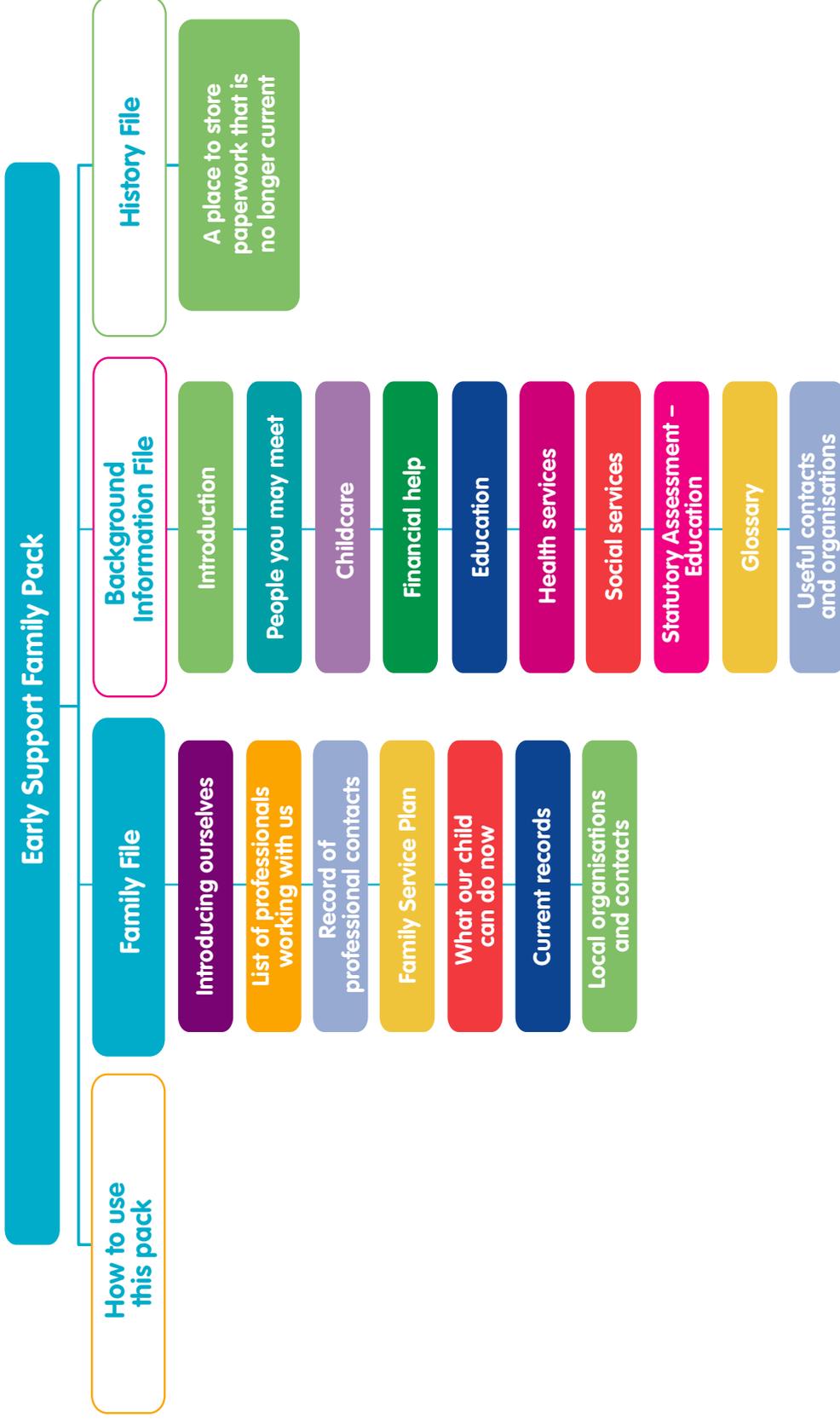


North Lincolnshire
North Tyneside Council
North Yorkshire (City of York and surrounding areas)
North Yorkshire (North Yorkshire County Council & Selby District)
North West Regional Partnership
Nottinghamshire Pathfinder Children's Trust
Poole, Bournemouth & East Dorset
Plymouth Early Years Inclusion Service
Rotherham Children, Young People and Families
Salford*
Solihull MBC – Education & Children's Services, Schools Services
South Tyneside Social Care and Health Directorate
Stockton Sure Start*
City of Sunderland
St Helens – Star Centre*
Sutton Trust for Children
Telford & Wrekin and County of Shropshire
Torbay Council
London Borough of Waltham Forest
Warwickshire County Council, North Warwickshire, Rugby & South
Warwickshire Primary Care Trusts
Wiltshire County Council
Winchester & Eastleigh Healthcare Trust & Hampshire County Council
Wolverhampton City Council & Primary Care Trust

* Indicates the first nine Pathfinders who have been working with the programme from January 2004.



Overview





Early Support

Helping every child succeed

Other publications

As part of the Early Support initiative, a range of booklets has been developed to help families find information about the factors or issues that are most important for their child.

If you would like a copy of any of the publications listed here, please contact DfES Publications (full details below) giving the reference number and title of the document or documents you require.

DfES Publications

PO Box 5050

Sherwood Park

Annesley

Nottingham NG15 0DJ

Tel: 0845 602 2260

Fax: 0845 603 3360

Textphone: 0845 605 5560

Email: dfes@prolog.uk.com

Information for parents booklets

Autistic spectrum disorders ESPP12

Cerebral palsy ESPP10

Deafness ESPP11

Down's syndrome ESPP13

Learning disabilities ESPP15

If your child has a rare condition ESPP18

Multi-sensory impairment ESPP9

Speech and language difficulties ESPP14

Visual impairment ESPP8

When your child has no diagnosis ESPP16

Publications for professionals

Professional guidance ESPP33

Service audit tool ESPP34

How to use the service audit tool ESPP35

Monitoring protocol for deaf babies and children ESPP29

How to use this protocol ESPP30

Monitoring protocol for deaf babies and children: Level 2 materials ESPP31

Development cards for parents ESPP32

The [Early Support Pilot Programme](#) (ESPP) is a Government funded programme involving the Department for Education and Skills, Sure Start and the Department of Health. The purpose of the programme is to improve the delivery of services to disabled children under three and their families. It promotes service development in partnership with health, education and social services, service users and organisations in the voluntary sector.

[Early Support](#) is putting into practice the principles outlined in the Government guidance document *Together from the Start*, which was published in May 2003. The guidance recognises that where children have special needs and disabilities, it is important that these are identified at an early stage and that identification leads directly to effective early intervention and support for families and children.

We would like to thank all the families, professionals and funded partners who contributed to the consultation process that produced this material. Particular thanks are due to The Royal National Institute for Deaf People (RNID), which hosts [Early Support](#) and works with Government to deliver it.

For more information about [Early Support](#) or to view any of the programme materials discussed in this publication, visit www.espp.org.uk

Copies of any of the [Early Support](#) materials listed in Appendix 2 can be obtained from:

DfES Publications
PO Box 5050
Sherwood Park
Annesley
Nottingham NG15 0DJ

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