

What integrated working practices support or hinder effective referral pathways from Health to Education services for blind and partially sighted babies and young children?



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Practitioner-led research 2008-2009

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This report is part of CWDC's Practitioner-Led Research (PLR) programme. Now in its third year, the programme gives practitioners the opportunity to explore, describe and evaluate ways in which services are currently being delivered within the children's workforce.

Working alongside mentors from Making Research Count (MRC), practitioners design and conduct their own small-scale research and then produce a report which is centred around the delivery of Integrated Working.

The reports are used to improve ways of working, recognise success and provide examples of good practice.

This year, 41 teams of practitioners completed projects in a number of areas including:

- Adoption
- Bullying
- CAF
- Child trafficking
- Disability
- Early Years
- Education Support
- Parenting
- Participation
- Social care
- Social work
- Travellers
- Youth

The reports have provided valuable insights into the children and young people's workforce, and the issues and challenges practitioners and service users face when working in an integrated environment. This will help to further inform workforce development throughout England.

This practitioner-led research project builds on the views and experiences of the individual projects and should not be considered the opinions and policies of CWDC.

**What integrated working practices support or hinder effective referral pathways from Health to Education services for blind and partially sighted babies and young children?**

**Julie Jennings  
RNIB National Development Officer: Early Years**

## **Acknowledgements**

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Special thanks also go to the three LA services who contributed their time and experience to this study.

## **Abstract**

Evidence indicates that young children and parents benefit from receiving specialist visual impairment (VI) education service support from an early stage following identification of a child's sight condition. Early referral is key to this. Although there are screening protocols for some very specific eye conditions, such as retinopathy of prematurity, there is no vision equivalent to Universal Newborn Hearing Screening with its related referral guidance.

The aims of the research were to identify the pathways for referring blind and partially sighted babies and children from Health to Education; and explore models of effective practice in three VI services, i.e. one inner city authority in the east, one rural authority in the west, and a consortium from the south. The first stage of the research was a literature review in order to identify the pathways for referring blind and partially sighted babies and children from Health to Education.

The second part of the study sought to address the second aim: to identify models of good practice in a small sample of local authorities and where there were delays in referring from Health to Education to understand the reasons for these delays.

As a result of the study, it is recommended that key factors should be in place to support integrated working practices between Health and Education to facilitate effective referral procedures. These factors should include:

- an embedded Early Support or a Team around the Child approach;
- established multi-agency groups with a focus on visual impairment;
- the appointment of a paediatric ophthalmologist to lead on children's issues;
- attendance by VI service staff or ECLO at paediatric eye clinics;
- incorporating hearing and vision services into LA sensory support services.

These should be set out in written agreed protocols between LA education services and Health.

**Julie Jennings**  
**RNIB National Development Officer: Early Years**

## Introduction

The Royal National Institute of Blind People (RNIB) is the leading charity offering practical support and advice to anyone with a sight problem. It provides a range of services for children and families, including advice on supporting the learning of blind or partially sighted children.

My role as National Development Officer: Early Years is to take the lead in policy work relating to early childhood provision, developing links within RNIB and with external agencies; and to support the development of services for young children with visual impairment from birth to five years.

There is currently no known research study that provides a detailed analysis of the factors that lead to or prevent effective cross-sector partnership working to ensure prompt referrals of blind and partially sighted babies and young children from Health to Education. Research evidence is needed to support an understanding of the factors that lead to delays in referral, and to identify models of good practice in collaborative working across the two sectors. This study aims to add to the literature available on this subject.

## Aims of the project

‘A key global challenge is the promotion of early detection of ophthalmic disorders in children, so that specific treatment can be started within the critical periods of visual maturation, together with the provision of **appropriate developmental and educational interventions**, genetic counselling, and advice and support to families of affected children.’ (Rahi and Dezateux 2002, p. 1083)

The aims of the study were to identify

- the pathways for referring blind and partially sighted babies and children from Health to Education; and
- models of effective practice in a sample of local authorities (LAs).

This was in order to gain a clear understanding of two main strands

- factors that hinder the referral of babies and young children from Health to Education services; and
- factors that lead to the establishment of good partnership working between Health and Education services.

With a clear understanding of these factors, it would be possible to promote models of effective procedures across the country and support better working practices for young children and their families.

A key focus for the study was, therefore, to identify the working practices that would support best outcomes for young children with a visual impairment.

## Context

Evidence indicates that young children and parents benefit from receiving specialist visual impairment (VI) education service support from an early stage following identification of a child’s sight condition (Keil 2005). Early referral is key to this. Although there are screening protocols for some very specific eye conditions, such as retinopathy of prematurity, there is no vision equivalent to Universal Newborn Hearing Screening with its related referral guidance.

Despite government commitment to integrated working practices and early intervention for babies and young children with disabilities, there is anecdotal evidence to suggest that referral arrangements from Health to Education services for blind and partially sighted babies and young children vary considerably across the country. Where established referral procedures are not in place, this may lead to delays in provision of specialist VI education

services' support for babies and young children and their families, and risk of developmental delay.

This is particularly important given that there are now – for the first time – nationally available centrally funded materials for families with a young child with a visual impairment through the Early Support programme.

Early Support is the central government mechanism to improve services for young disabled children from birth to five years and their families. The Early Support Developmental Journal for babies and children with visual impairment, developed by members of the Developmental Vision Team at Great Ormond Street Hospital/Institute of Child Health in consultation with families and practitioners, was launched in September 2006.

This provides a tool to help families track and understand the development of their young children in partnership with the professionals who work with them. It has a key part to play in raising awareness of the critical role that vision plays in early child development and in encouraging earlier referral of visual disorders so that babies and families get the kind of support that they want as soon as possible.

## **Methodology**

### **Desk research**

The first stage of the study was desk research to review literature relevant to the study and to identify the pathways for referring blind and partially sighted babies and children from Health to Education. Much of this literature was familiar to the project leader as part of ongoing work as RNIB National Development Officer: Early Years. Information was collated from government guidance and strategy reports, journals, and research reports. However, there is likely to be literature elsewhere that has not been accessed.

The desk research also looked at nationally available information with a view to identifying existing examples of regional good practice in England.

Because visual impairment is a low incidence disability, the examples were necessarily limited, but these included:

- case studies published on the Early Support website which provide examples of what are regarded as good practice models of inter-agency working between Health and Education
- evidence obtained from the NFER/RNIB national survey of VI services, carried out in December 2007 and published in July 2008, which

provides some quantitative data about the types of referral arrangements in place between Health and Education across England.

For a summary of the desk research, see Appendix 1.

## **Primary research: LA case studies**

The second part of the study sought to address the second aim: to identify models of good practice in a sample of local authorities and – where there were delays in referring from Health to Education – to understand the reasons for these delays.

The desk research was used as a way of refining approaches to this part of the study, informing the development of the interview framework for the LA case studies.

No specific LAs were identified through the desk research as the NFER/RNIB survey, to maintain confidentiality, was unable to name services; only Cambridgeshire was identified through Early Support and they had taken part in an earlier project. Consequently, LAs who would be prepared to take part in the study needed to be recruited in another way.

Therefore, a summary of the study brief was circulated by the project leader at two meetings, the focus of which were early years and visual impairment

- the RNIB/VIEW Early Years Focus Group
- the Early Years and Visual Impairment: South East group.

From these, three VI services expressed an interest in taking part in the study. They all felt that they had good systems in place but were keen to reflect on these further. The three VI services provided a good cross-section: one inner city authority in the east, one rural authority in the west, and a consortium from the south. For a description of the three participating services, see Appendix 2.

Each of the three heads of service was asked to investigate the ethics procedures for their LAs. Following this, it was agreed that, as long as no individual children or families were used or named in the study, no specific permission was necessary. However, any use of the LA name would have to be agreed by their PR officer.

Information from the LAs was gathered in three ways.

1. The desk research provided a basis for the questionnaire to be sent to the case study services: the Early Support Service Audit Tool (DfES 2004) provided a good framework for an initial audit of referral procedures. The Service Audit Tool (SAT) facilitates multi-agency service review and planning for service improvement. It helps users reflect on how services for families might be developed and is best used by multi-agency groups working together



to plan for integrated service provision. It encourages users to ask two questions:

- How well do we work with families?
- How well do we work together and with other services?

The material provides a set of standards, supported by indicators that provide examples of good practice to aid reflection and discussion. Linked evidence forms help users focus on one standard at a time, thinking about the evidence they can provide of effective practice in their area or of the impact of service change. In particular, Functional area B focuses specifically on Referral, identification and initial assessment (see Appendix 3). This was sent to each of the LA VI services to complete independently.

2. There were also emerging questions from the desk research (see Appendix 4) which shaped the follow-up interview schedule. This was used for the focus group discussion which was convened with the three heads of service and the project leader to discuss the findings in more detail.

3. As a result of this meeting, it was decided that each of the LAs would submit information on referrals of children under two years over a period of three years (September 2005–July 2008). A framework for collecting this information was developed with RNIB's research department (see Appendix 5).

## Findings

The key findings from the review of literature are outlined below.

### **Screening and referral procedures for children with a visual impairment**

The incidence of visual impairment is very low: there are estimated to be only 4,108 children with a visual impairment, including those with additional needs, under the age of five years in England (Morris and Smith 2008). Consequently, any referral procedures in place are utilized relatively rarely.

Screening procedures are set out in the National Screening Committee Child Health Sub-Group Report on Vision Screening (Hall and Elliman 2006): all newborn and 6 to 8 week old babies should be examined as part of the routine review to exclude retinoblastoma, glaucoma and cataract since they are treatable and, respectively, life and sight threatening; and a specialist neonatal ophthalmic examination is recommended for babies at a known higher risk of visual disorders, such as very low birth weight and pre-term babies or babies with a known hearing impairment or with other major disabilities.

The Child Health Promotion Programme (DH 2008) states that one of the core functions is, for babies with health or developmental problems or abnormalities, early referral to a specialist team.

In terms of referral procedures, the review of literature found that the NHS (2008) guidance, *Transforming Services for Children with Hearing Difficulty and their Families*, outlines good practice for a specific group of children. It defines the role of paediatric audiology networks in delivering high quality services through:

- early identification of hearing difficulty and rapid, definitive assessment and differential diagnosis
- rapid referral to the hearing support service provided by the local authority; and
- clear referral criteria, direct care pathways with minimal steps and rapid referral to specialist or sub-specialist care.

Currently there is no equivalent guidance for visual impairment which would form the basis of a referral pathways approach for health and education.

The Common Assessment Framework (DCSF, 2007) is a standardized approach to conducting a generic assessment of a child's additional needs and deciding how those needs should be met. It can be used by practitioners across all children's services in all local areas in England. It aims to help early identification of need, promote coordinated service provision and reduce the number of assessments that some children and young people go through.

The review found evidence (Becta VI Forum 2008) that some VI services consider that the Common Assessment Framework (CAF) may not be as appropriate for children whose sole need is a visual impairment as they follow other referral routes. It was suggested that the quality of CAF training will be central to embedding robust systems of assessment that would trigger a CAF referral if any concern about vision was raised for children with additional needs.

Finally, there are quality standard documents in relation to sensory support services:

- *Quality Standards in Education Support Services for Children and Young People with Visual Impairment* (DfES 2002)
- *Quality Standards for Special Educational Needs (SEN) Support and Outreach Services* (DCSF 2008).

However, neither of these outline referral procedures in the context of integrated working.

## **First experiences for parents and children**

In relation to early support for babies identified with a visual impairment, and their families, research has shown the need for specialist early intervention. RNIB (Cole-Hamilton 1996; 1998) carried out research with parents throughout the UK to explore parents' experiences when given the diagnosis of their child's eye condition. The research illustrated that, when first learning that their child has a visual impairment, parents feel supported by rapid referral processes.

Dale and Sonksen (2002) have argued that early intervention may minimize the risk of developmental setback that has been identified in some young children with profound visual impairment. If babies with a visual impairment are identified early and intensive health and education developmental support is provided in the first two years of life, including visual promotion (for form vision), it can lead to improved outcomes in the development of social and communication skills.

Part of effective early support is raising awareness of the potential developmental, emotional and social implications of childhood visual impairment across agencies, to ensure prompt referral from Health to Education services. The early involvement of visual impairment education services can support parents in promoting their child's early development and learning using the Early Support materials, and in particular the Developmental Journal for babies and children with visual impairment.

## **Existing models**

The key findings from the desk research into existing models are outlined below.

Only one example of referral pathways specific to visual impairment was found in the Early Support Programme. This was the Cambridgeshire Service for Visual Impairment who reviewed their initial assessment of need as part of Phase 1 work. It was found that a key feature is the ability to progress from sharing the news, to assessment and on to a positive joint management plan of medical, educational and social support discussed with parents, all at the same appointment. An internal evaluation was carried out among parents and professionals and found that parents very much valued the co-ordinated clinics with a written summary and an agreed plan. The evaluation also found that the clinic had been instituted with minimal change in professional workload and without extra expenditure.

As part of the NFER/RNIB Survey (Morris and Smith 2008), information was gathered on health service referrals for babies and children with visual impairment. They found that, considering the move to integrated children's services, relatively few VI services (2 per cent) reported that they had a

service level agreement in place with health services for referring children with VI under the age of five. Despite this, several services specifically noted that they had a multi-agency approach to referrals. The most commonly reported system of health service referrals was an established arrangement with individual health professionals from one or more hospitals or health service providers (48 per cent). Encouragingly, referrals which were ad hoc were less common (11 per cent). Other VI services reported a mixed strategy for referrals. None of the reporting services indicated that a referral system was not in place.

## **Findings from primary research: LA case studies**

Emerging themes from the LA case studies are organized under the two strands of the study.

### **Factors that hinder the referral of babies and young children from Health to Education services**

A single point of entry for referrals within an open referral system was considered necessary: services did not want a gatekeeper. Protocols that are based on generic rather than specialist areas were considered to be not fit for purpose for visual impairment. For example, one case study showed that integrated teams that were locally driven, rather than coming together around a specialism, may not be as effective for a low incidence impairment: specialists, such as ophthalmologists, would need a way to be part of the teams to prevent another layer of referral going through the integrated teams.

This was seen as the main issue for the Common Assessment Framework: where specific referral pathways were in place for visual impairment as a single disability, the CAF was not necessary; its role for children with visual impairment in addition to other needs was yet to be tested.

Education was thought to be more proactive in promoting partnership working. Although the referral form was seen as the responsibility of Health, they did not take the lead in establishing protocols for joint working. In addition, some ophthalmologists appeared to wait for a specific diagnosis before referring; therefore it was proposed that it would be more effective to register 'serious concern' to trigger earlier referral.

There were issues around information sharing which were seen to work against partnership working: for instance, encryption systems and different databases made effective referral more difficult. In addition, certain populations such as asylum seekers seemed more likely to have delayed referrals.

Raising awareness of the importance of vision was also considered an issue, particularly for GPs as a universal service, for health visitors in respect to their

changing role, for parents through the Personal Child Health Record or 'red book', and for children's centres as part of their community role. Blair (2009) confirms that

'strengthening the relationships between health visitors and children's centres with the use of skill mixed teams is likely to be beneficial, particularly in ensuring the delivery of the Child Health Promotion Programme.'

Funding systems were variable: one LA had no pooled budgets but service level agreements, one engaged in joint commissioning, and one was dependent on integrated service hubs. However, this did not seem to be a major factor.

### **Factors that lead to the establishment of good partnership working between Health and Education**

Several factors emerged that were considered to support partnership working around referral pathways.

All three LA VI services were part of a sensory service, incorporating hearing impairment and visual impairment, rather than standalone VI services. Sensory services were seen to be better placed to implement effective referral pathways as they are able to apply HI protocols to VI, reflecting the importance of the UNHS and its associated guidance, such as maintaining 'no waiting' lists and being on call 52 weeks.

Most inappropriate referrals were seen at school age, rather than in early years, which would suggest that the recommended screening protocols are working well. This was corroborated by the evidence from the referral information for the three LAs:

- the majority of referrals were from a paediatric ophthalmologist; and
- the main eye conditions fell within the screening protocols: cataract, glaucoma, retinopathy of prematurity or retinoblastoma.

All three LA VI services had a form of multi-agency group coming together around VI which might include paediatric ophthalmologist, community paediatrician, orthoptist manager, QTVI, parents, social services, local voluntary association. These supported partnership working when meetings included joint training, evaluation of services and decision-making. Also, regular meetings with primary care trusts were considered to be necessary for the efficient exchange of information.

Stable staffing in health and education services was seen as a key feature. This supports the NFER/RNIB research findings that arrangements between individuals were key to efficient referral pathways. Stable staffing would support continuity in these arrangements.

Attendance by the VI service or Eye Clinic Liaison Officer at paediatric ophthalmology clinics, in addition to the provision of information for parents, such as VI service leaflets, was seen to support effective referral. The appointment of a paediatric ophthalmologist was also seen as a key factor: all three LA services had paediatric ophthalmologists in place.

Early Support or a Team around the Child (TAC) approach was present in all the LAs and was considered a key driver, whether from within the sensory services or through another agency such as a voluntary organization. It encouraged LAs to reflect on frameworks that identified responsibilities, policies and procedures. Only one LA had specific written protocols with Health in place; the other LAs were to follow up this aspect of their service.

The study also confirmed that written agreed criteria for referral from Health to Education should underpin integrated practice in the area of identification and referral.

## **Implications for practice (including integrated working)**

The study confirmed that the incidence of a severe visual impairment in very early childhood at a local level is rare and it may be that this low prevalence of visual impairment in childhood has to a large degree precluded proactive joint working.

It also confirmed that conditions that cause a serious and permanent impairment of vision leading to a substantial disability are normally present at birth and that the screening protocols available for this population are working well. However, a specific link between screening protocols and referral procedures for young children with a visual impairment was not made explicit in guidance, despite a general context for integrated working.

The study also confirmed that existing models for referral pathways were typically based on established arrangements between individuals rather than more formal service level agreements. The implication is, therefore, that to enable effective referral systems between Health and Education, specific vision screening and referral protocols are required.

## Conclusion

From the study, it is recommended that key factors should be in place to support integrated working practices between Health and Education to facilitate effective referral procedures. These factors should include:

- an embedded Early Support or a Team around the Child approach
- established multi-agency groups with a focus on visual impairment
- the appointment of a paediatric ophthalmologist to lead on children's issues
- attendance by VI service staff or ECLO at paediatric eye clinics
- incorporating hearing and vision services into LA sensory support services.

These should be set out in written agreed protocols between LA education services and Health.

To support the development of local agreed protocols, it is recommended that the development of guidance in line with the NHS (2008) good practice document for hearing services is considered. This should set out equivalent procedures for visual impairment services that encompass

- early identification of visual difficulty and rapid, definitive assessment and differential diagnosis
- rapid referral to the vision support service provided by the local authority
- clear referral criteria, direct care pathways with minimal steps and rapid referral to specialist or sub-specialist care.

A follow-up study, using these findings, would be needed to engage with VI specialist health professionals as a limitation of the current study was that it was able to gather an education viewpoint only. The aim would be to test out the feasibility of the proposed guidance materials to support better outcomes for children with a visual impairment and their families.

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# Appendix 1 - Review of literature

## Part 1

### 1. Characteristics of visual impairment

Research shows that numbers of children with a visual impairment are low: there are estimated to be only 4,108 children with a visual impairment, including those with additional needs, under the age of five years in England (Morris and Smith 2008). Epidemiological research (Rahi and Cable 2003) indicates that children with the most severe levels of visual impairment are more likely to

- have been premature
- be of South Asian origin
- have associated neurological problems
- have a condition which is not treatable
- have had their condition from very early life (identified in the first year)
- have similarly affected siblings
- be from areas of disadvantage.

### 2. Screening procedures

Screening is aimed at the primary prevention of visually impairing disease (such as retinopathy of prematurity) as well as reducing the impact of already established disease (such as congenital cataracts).

The Child Health Promotion Programme (2008) describes the screening schedule for vision at three stages

- physical examination of the eyes by 72 hours from birth
- physical examination of the eyes at six to eight weeks; and
- all children should be screened for visual impairment between four and five years of age by an orthoptist-led service.

This study focuses on those children identified in the first two physical examinations who may have serious disorders of vision.

These procedures are set out in the National Screening Committee Child Health Sub-Group Report on Vision Screening (Hall and Elliman 2006): all newborn and six to eight week old babies should be examined as part of the routine review to exclude retinoblastoma, glaucoma and cataract since they are treatable and, respectively, life and sight threatening; and a specialist neonatal ophthalmic examination is recommended for babies at a known higher risk of visual disorders, such as very low birth weight and pre-term babies or babies with a known hearing impairment or with other major disabilities.

### 3. Diagnosis and referral

The literature review sought to identify existing guidance on diagnosis and referral following screening, in the context for integrated working. This is clearly stated in the National Service Framework for Children, Young People and Maternity Services (2004) and the Child Health Promotion Programme (2008), which updates Standard One (incorporating Standard Two) of the NSF.

The NSF sets the standards for children's health and social care, and the interface of those services with education. It explicitly endorses an Early Support approach as a means to achieve better co-ordinated multi-agency support for families with a young disabled child. Standard 8 Guidance states that local authorities, Primary Care Trusts, NHS Trusts and schools should ensure that

'Diagnosis and identification of disability or complex health needs (which may not be a single consultative event) is followed quickly by a multi-agency comprehensive needs assessment which follows the *Framework for the Assessment of Children in Need and their Families*, and for children from birth to third birthday the *Together from the Start Guidance*.' (p. 22)

The CHPP states that one of the core functions is

'to recognize disability and developmental delay. This includes a responsibility to provide information, support, referral and notification to others, and in particular there is a duty to inform the local education authority if it is suspected that a child may have special educational needs.' (p. 17)

It suggests that, for babies with health or developmental problems or abnormalities, progressive support should include

- early referral to a specialist team
- package of additional support and monitoring, as assessed by health professional and drawing on the Early Support Programme. (p. 41 etc)

Transforming Services for Children with Hearing Difficulty and their Families (2008) outlines a good practice guide for a specific group of children. It defines the role of paediatric audiology networks in delivering high quality services through

- early identification of hearing difficulty and rapid, definitive assessment and differential diagnosis
- rapid referral to the hearing support service provided by the local authority
- clear referral criteria, direct care pathways with minimal steps and rapid referral to specialist or sub-specialist care.

Currently, there is no equivalent guidance for visual impairment which would form the basis of a referral pathways approach for health and education as stated in recommendation 11 of the RNIB Early Excellence Partnership Project evaluation report

'Blind and partially sighted children and their families to have parity with deaf and hearing impaired children in terms of the early intervention and support that is required by the neonatal hearing screening programme.' (Keil 2005)

#### **4. Delivering services: the current context for integrated working across agencies**

*Every Child Matters: Next Steps* (2004) and the Change for Children Programme outline some key aspects of integrated working ([www.everychildmatters.gov.uk](http://www.everychildmatters.gov.uk)). Those that are relevant to this project include

- integrated working
- setting up multi-agency services
- Common Assessment Framework
- information sharing
- ContactPoint
- Common Core of Skills and Knowledge
- lead professional

The CHPP discusses some of these aspects in the context of 'multi-skilled teamworking' and states that

'the key to success is a shared understanding - both by parents and by all the practitioners involved - of the roles, responsibilities and potential contribution of the different practitioners and organizations... Teamworking across service boundaries requires practitioners to

- Develop trusting relationships, based on a shared purpose, values and language;
- Know when and how to share information appropriately;
- Make use of common processes, such as the Common Assessment Framework; and
- Nominate a lead professional to co-ordinate activity.' (p. 67)

The Common Assessment Framework (CAF) is particularly relevant to this study with its emphasis on multi-agency cooperation and collaboration based on a holistic understanding of children's needs. A DfES report (Brandon et al. 2006) offers a 'snapshot' of activity in 12 English areas chosen by the DfES to trial CAF and the lead professional ahead of the national roll-out. The key

research question was 'What helps or hinders practitioners in implementing common assessment and lead professional work?'

Factors identified in enabling easier implementation were:

- clear strategy with good local guidance
- awareness raising across whole area, repeated regularly
- phased roll-out, rather than 'big bang' requiring everything in place at once
- multi-agency training
- good IT system in place.

The study also identified factors that caused problems:

- focusing exclusively on local issues rather than learning from other areas
- delayed strategy based in theory on 'learning on the ground first' with no clear guidance
- too much individual discretion (not in itself a bad thing) can lead to confusion
- over-reliance on DfES training materials which have not been adapted to meet local needs or use local examples.

There is some anecdotal evidence from a recent discussion about CAF between LA VI Service staff on the Becta VI Forum.

The VI Forum is a UK based e-mail discussion group for teachers, teaching assistants and other professionals working with children and young people who are blind or partially sighted. Organized by Becta, the government agency leading the national drive to ensure the effective and innovative use of technology throughout learning, the VI Forum already has hundreds of members whose expertise and experiences are shared on a daily basis. The VI Forum is an open discussion group which means that all discussions are publicly available and all messages sent to the VI Forum are stored in a publicly available archive, but personal permission was sought to use the following quotations:

'We are having to ask schools to fill in the first 3 pages of the CAF form as a referral but at the moment we take referrals from other agencies in the old fashioned way! This does not mean that we go on to complete a CAF for all the children referred to us even where there is a multi agency approach. We would only complete the full CAF if despite everyone's best efforts there were still concerns about the child's needs being met. At the moment we are fortunate that it hasn't had any impact on our working relationships with schools and other agencies. If we only took children with a CAF what would happen to those whose parents do not give permission?' (Team Leader Sensory and Physical Team)

'In our local authority we certainly don't use the CAF for normal SEN referrals and continue to use our standard referral form. We would only

use the CAF for a particularly complex multi-agency case. The time and cost implications of using the CAF for all sensory referrals would be mind boggling. Of course, if there was a concern raised as a result of the VI assessment then the use of the CAF would then be considered.' (SEN ICT Advisory Teacher)

'We keep getting cases which were referred on a CAF form months ago and have only just got to us, whereas referrals used to take only days. It's totally against the spirit of Early Support Developmental Journal etc. It has separated all the professionals that used to work together - nobody wants to take responsibility for it. I have been told that it has completely snarled up the Panel meetings for statutory assessment (this is hearsay!) We don't need 17 pages to assess that a child has a visual impairment and needs help!!!' (Head of VI Service)

This suggests that CAF may not be working for children whose sole need is a visual impairment. It is suggested that the quality of CAF training is central to robust systems that would trigger a CAF referral if any concern about vision was raised for children with additional needs.

However, integrated working is not simply about processes: attitudes and values are also important. Building Brighter Futures: Next Steps for the Children's Workforce (2008) includes Annex B: Children's Workforce Network's Values for integrated working with children and young people which sets out a series of values statements in relation to integrated work with a range of colleagues.

In addition, some recent research has attempted to focus on contributing aspects of integrated working.

1. Evaluating the early impact of integrated children's services (2008) describes four levels of descriptors

Level 1 - changes to inputs, processes, structures

Level 2 - changes to experiences, attitudes

Level 3 - changes to outcomes for children, young people and their families by key group

Level 4 - institutional/systemic embedding

2. Supporting theory building in integrated services research (2008) highlights four dimensions to consider

- the extent of integration
- the integration of structures
- the integration of processes
- the reach of organization.

3. Multi-agency working and its implications for practice: a review of the literature (2007) identifies key factors as

- working relationships
- multi-agency processes
- resourcing multi-agency work
- management and governance

## 5. Quality standards

There are some quality standard documents in relation to sensory support services which refer to integrated working:

- Quality Standards in Education Support Services for Children and Young People with Visual Impairment (2002):  
Standard A6 There is liaison between VI specialists and professionals from other agencies; also, that where there is close involvement, joint assessments are considered with individuals focussing their input around their own area of expertise
- Quality Standards for Special Educational Needs (SEN) Support and Outreach Services (2008):  
Standard 15 There is collaboration with other service providers to ensure that services are complementary, simple to use, effective and joined-up to deliver a better service to the user.

However, neither of these outline referral procedures in the context of integrated working.

One part of the linked materials underpinning the Early Support Programme - the Early Support Service Audit Tool (SAT) - makes specific reference to referral procedures. The SAT facilitates multi-agency service review and planning for service improvement. It helps users reflect on how services for families might be developed and is best used by multi-agency groups working together to plan for integrated service provision. It encourages users to ask two questions:

- How well do we work with families?
- How well do we work together and with other services?

The material provides a set of standards, supported by indicators that provide examples of good practice to aid reflection and discussion. Linked evidence forms help users focus on one standard at a time, thinking about the evidence they can provide of effective practice in their area or of the impact of service change.

In particular, functional area B, focuses specifically on Referral, identification and initial assessment.

## **6. First experiences...for parents**

In relation to early support for babies identified with a visual impairment, and their families, research has shown the need for specialist early intervention. RNIB (Cole-Hamilton 1996; 1998) carried out research with parents throughout the UK to learn about the experiences of parents when given the diagnosis of their child's eye condition. One of the findings showed that, when first learning that their child has a visual impairment, parents feel supported by rapid referral processes. The guidelines produced as an outcome of the research suggest three levels

- from primary care staff to a GP, optometrist or paediatrician
- from GP or paediatrician to an ophthalmologist
- from ophthalmologist to local authority visual impairment teaching service.

## **7. First experiences...for infants**

The NSF outlines the benefits of early intervention for infants

'Delaying early intervention can result in irretrievable loss of function or ability...or the intervention being less effective. Early intervention has a positive effect both in terms of promoting development, and minimizing decline or regression among children with developmental difficulties.' (p. 23)

Dale and Sonksen (2002) have argued that it may be possible to minimize the risk of developmental setback that has been identified in some young children with profound visual impairment if babies with a visual impairment are identified early and intensive health and education developmental support is provided in the first two years of life, including visual promotion (for form vision).

Part of effective early support is raising awareness of the potential developmental, emotional and social implications of childhood visual impairment across agencies, to ensure prompt referral from Health to Education services.

The early involvement of visual impairment education services can support parents' in promoting their child's early development and learning using the Early Support materials, and in particular the Developmental Journal for babies and children with visual impairment.



## **Part 2**

### **1. Early Support**

Only one example focuses specifically on visual impairment.

As part of Phase 1 work in the Early Support Programme the Cambridgeshire Service for Visual Impairment reviewed their initial assessment of need, to include:

- communicating the news to families following identification of disability and the implementation of the Right from the Start template
- joint assessment of children by professionals from more than one statutory agency and joint review of child progress and support arrangements
- the development of Family Support Plans as an outcome of initial assessment of need

Interagency working in Cambridgeshire on behalf of children with visual impairment (birth to 19) began over 15 years ago when a Children's Vision Team was set up, co-ordinated by the Consultant Community Paediatrician. It included senior VI teacher, educational psychologist, rehabilitation worker, head orthoptist, community nurse and various therapists. Arising from this joint working, a decision was made in 1991 to establish a visual assessment clinic for children under 5 years. This currently involves community paediatrician, VI teacher and orthoptist.

The clinics are set up to provide a play environment. A key feature is the ability to progress from sharing the news, to assessment and on to a positive joint management plan of medical, educational and social support discussed with parents, all at the same appointment. An internal evaluation was carried out some time ago among parents and professionals and found that parents very much valued the co-ordinated clinics with written summary and agreed plan. The evaluation also found that the clinic had been instituted with minimal change in professional workload and without extra expenditure.

One outcome of the study was the production of a protocol for the development of interagency vision teams throughout Cambridgeshire which included:

1. sharing the news
2. joint assessment
3. joint management plans.

### **2. NFER/RNIB Survey**

The NFER/RNIB Survey (Morris and Smith 2008) gathered information on health service referrals for babies and children with VI. They found that, considering the move to integrated children's services, relatively few VI services (two per cent) reported that they had a service level agreement in

place with health services for referring children with VI under the age of five. Despite this, several services specifically noted that they had a multi-agency approach to referrals. The most commonly reported system of health service referrals was an established arrangement with individual health professionals from one or more hospitals or health service providers (48 per cent). Encouragingly, referrals which were ad hoc were less common (11 per cent). Other VI services reported a mixed strategy for referrals, as one service summarized:

‘Most referrals come through the early years support panel which is multidisciplinary but some come via child development centres or eye hospitals.’

None of the reporting services indicated that a referral system was not in place.

## **Appendix 2 - Description of participating local authorities**

### **LA 1**

The Sensory Inclusion Service is a joint arrangement Service between two local authorities, Telford and Shropshire, and the local NHS. It is a centrally retained service which is free at the point of delivery. The main partner agencies of SIS are the PCT, the local Acute Trust, The Children with Disabilities Team, Connexions for Youth, regional specialist NHS centres dealing with sensory impairment and local schools and settings.

The Service has close links with the local Acute Trust and the Primary Care Trust and a qualified teacher of the visually impaired is present at the paediatric eye clinics. The eye clinics are staffed by a paediatric ophthalmologist, a clinical assistant to the ophthalmologist and orthoptists. The presence of a QTVI facilitates support and information for families at the point of diagnosis and a referral to SIS within an agreed referral criteria. It also provides an opportunity for information to be exchanged between the agencies present and ensures the very best provision for children with visual impairment.

In addition the Service joins with PCT and Acute Trust to hold joint assessment clinics which provide in depth assessments of the child's functional vision.

### **LA 2**

Leicester is the most populous city in the East Midlands with a population approaching 300,000. The population is diverse, with the expectation that by 2011 Leicester will be the first city in Europe to have a majority non-white population. Leicester has traditionally attracted asylum seekers and refugees and more recently migrant workers from the European Union. Leicester has some of the most deprived areas in England. The City Council has an extensive regeneration programme.

The Children's and Young People's Services is committed, together with its Strategic Partners, to working together for a brighter future for Leicester's children and young people. One of the Strategic Partners is Leicester City NHS. Leicester has the twentieth most deprived NHS area in the country.

The Children's Centres programme is well established and there is a roll-out of locality based integrated multi-agency provision. Leicester was a pilot authority for Early Support and the scheme is now embedded within the Children's Centres.

Leicester is committed to an Inclusive Education system and was one of the first authorities in the country to provide successful mainstream provision for children with a visual impairment.

The Visual Impairment Team is part of The Special Needs Teaching Service within the Access, Inclusion and Participation Division.

The team has good links historically with the Ophthalmology Department at Leicester Royal Infirmary and with The Specialist Community Health Service. Some of the children supported are treated at Great Ormond Street Hospital and Moorfields Eye Hospital, both based in London.

Support is needs-led and is available on a peripatetic basis to children 0-19 years and their families, and to schools and settings within the authority.

### **LA 3**

The Sensory Consortium Service (SCS) is an Education Service for Children and Young People with a Visual / Hearing or Multi-sensory impairment. The Service works across 6 Unitary Authorities (Slough, Royal Borough of Windsor and Maidenhead, Bracknell-Forest, Wokingham, Reading and West Berkshire). The Service also works across 2 PCTs in addition to 3 Sensory Needs Social Care teams.

There are 12 qualified Teachers for Visual impairment (10FTE) in the Service in addition to 3 Specialist Teaching Assistants (2FTE) who have accredited VI qualifications in addition to Braille and Mobility. Currently the Visual impairment team works with 314 children aged 0-19yrs of which 20% are pre-school children (excluding Local Authority Special school work). 17 of these children are or are going to be Braille or Braille / print users. Our six authorities provide a varied ethnic picture and many of the children who will learn Braille do not have English as their parents' first language.

The SCS has a long history in working with Pre-school children and has operated the same response and similar involvement criteria for children with visual impairment as have been part of the more widely publicized protocols for children with hearing impairment. The SCS first engaged with Early Support in 2003 when accepted on the ES project to set up bilingual specialist support for newly diagnosed families. We also participated with some of our families in the pilots for the development of the Family Plan. A year later we were again part of another ES project to enable better referral processes with joint assessment and intervention clinics with Health. In all cases the project ways of working were adopted as part of the ongoing Service delivery and so we had the advantage of a headstart when the Early Support materials were released in 2005.

## Appendix 3 Early Support Service Audit Tool B1

### Functional Area B: Referral, identification and initial assessment

#### Theme: How we work together and with other services

<p><b>Standard: B1</b>  <b>There are clear and agreed policies and practices for referral; these make all relevant services easily and quickly available to families, so that families are not left in need. They include integrated referral procedures with a single point of entry and a multi-agency referral panel, wherever possible.</b></p>		
<p><b>Summary of strengths and areas for improvement</b></p>		
<p><b>Strengths</b></p>	<p><b>Areas for improvement</b></p>	
<p><b>We now need to:</b>            (identify priorities in relation to this standard, including timescales and roles, where applicable)</p>	<p><b>We will achieve this by:</b></p>	<p><b>Roles and responsibilities</b>            (indicate strategic implications below)</p>
<p><b>The steps towards this will be to:</b>            (identify short and medium-term actions with approximate dates and roles)</p>		
<p><b>Implications at strategic level</b></p>		

**Functional Area B: Referral, identification and initial assessment**  
**Theme: How we work together and with other services**

<b>Standard: B1</b>								
There are clear and agreed policies and practices for referral; these make all relevant services easily and quickly available to families, so that families are not left in need. They include integrated referral procedures with a single point of entry and a multi-agency referral panel, wherever possible.								
<b>What this means for us as service providers</b>	Our overall practice is: (shade in)							
	Not in place	Emerging	Partly in place	Established (majority of indicators in place)	Achieved through other indicators	Fully in place	Exceptional practice	Not applicable
	N	I	P	E	EO	F	A	N/A
<b>Indicators contributing to attainment of standard</b>	<b>Evidence of our current practice in relation to indicators and/or additional/different indicators that help us achieve this</b>							
<p>a) There is agreed, clear policy and practice for receiving referrals, whether through practitioners or self-referring parents at:</p> <ul style="list-style-type: none"> <li>• individual service level;</li> <li>• multi-agency service level.</li> </ul> <p>b) An agreed format for new referrals includes a central point of administration where practical and a designated practitioner who has responsibility for dealing with all new referrals at:</p> <ul style="list-style-type: none"> <li>• individual service level;</li> <li>• multi-agency level.</li> </ul> <p>c) Each service has clear written eligibility criteria for the families they can help. These include information about disabilities and needs, age of child and locality and are regularly distributed to all agencies.</p>								

d) Staff are well informed about their own and other services and can support parents' access to the 'total service' they require.

e) Where families can self-refer, services make information available about referral procedures to families in its locality, such as:

- eligibility criteria;
- how to contact the service.

Parents are encouraged to make contact where they have any concerns.

f) A named practitioner is designated to contact self-referring families within an agreed timescale.

g) Procedures for the processing of multi-agency referrals include the recording of unmet need i.e. when a referral is appropriate but a service cannot be provided.

h) Referrals are processed on a regular basis so that waiting times are minimized. This process includes procedures for informing families, when a referral is inappropriate and another route is suggested.

i) Referral procedures are reviewed regularly in a process in which practitioners, families and managers reflect on practice and suggest improvements. These are incorporated into the service improvement plan.

## **Appendix 4 Questions arising**

1. How does the CAF work for children with a visual impairment?
2. Is there commitment at all levels, including senior level?
3. Are skills and expertise shared eg through joint training?
4. Are resources distributed equally with pooled budgets or written agreements around funding?
5. Are there clear lines of communication and opportunities for discussion, information sharing?
6. Are aims agreed jointly, are there joint review and evaluation protocols and joint performance indicators?
7. Are roles and responsibilities between agencies clear eg are there shared protocols (SLA)?
8. Is there continuity in staffing?
9. Is there a paediatric ophthalmologist?
10. Is Early Support (or TAC) in place?



## Appendix 5 Referral chart

<b>Child</b>	<b>What age was the child when you received the referral?</b>	<b>Who referred the child? Eg ophthalmologist, paediatrician, GP, parent</b>	<b>What was the eye condition?</b>	<b>Did the child have additional needs?</b>	<b>Was the reason for the referral?</b>	<b>Was there a delay between the professional identifying the sight problem and making the referral to you?</b>	<b>If 'yes', what was the reason? Eg awaiting diagnosis; did not think education support was needed; did not know of your service</b>
1							
2							
3							
4							
5							

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