Early intervention for children who are deafblind

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Executive Summary
Deafblindness is a very rare disability causing extreme developmental disadvantage. It affects all areas of development, including the formation of very early parent-child relationships, communication, cognition, motor and perceptual development and social and emotional development. These effects begin from birth.

Early intervention has been recognised for several decades as a means of ameliorating the developmental constraints associated with disability. The developmental consequences of deafblindness indicate a need for early intervention which involves families, a need for specialist intervention and a need for co-ordinated services.

For children with deafblindness, intervention must include the provision of information normally available through sight and hearing. This role may be undertaken by trained interveners or by parents or others in contact with the child.

Limited research has been undertaken regarding the benefits of early intervention for children with deafblindness; in part because the evaluation of early intervention in general is difficult and in part because the developmental effects of deafblindness present particular challenges and ethical issues for researchers.

Research with children with related needs (visual impairment, hearing impairment) indicates that intervention is most effective if it begins in the first months of life, is individualised, specialist and intensive, and targets areas of development particularly affected by the impairment.

Two research studies of early intervention with children with deafblindness (one - Project PLA1 - focusing on curriculum content, and one - Project VIP - focusing on service delivery) report overwhelmingly positive outcomes. Project PLA1 indicates that very early parent-child interaction and parental confidence, often derailed by deafblindness, can be enhanced by appropriate individualised, structured intervention. Project VIP indicates that the use of trained interveners, in conjunction with other forms of support, provides one appropriate model for the delivery of early intervention.

Considerable anecdotal evidence from a range of countries supports these findings.

The recommendations of the report include

- the provision of very early, specialist, individualised intervention focusing on supporting parent-child interactions and family relationships
- the involvement of parents as active partners at every stage of the intervention process
- the (developmental, medical, audiological and visual) assessment of children by professionals qualified and experienced in working with children with deafblindness
- the delivery of intervention by co-ordinated local teams with training and expertise in deafblindness and working with families.
• further research on the benefits of different forms and components of intervention for children with different needs, for different families and in different situations.
Introduction

Children who are deafblind have impairments of both vision and hearing. These impairments may be of any type or degree; the great majority of children with deafblindness have some useable sight and/or hearing. The term 'multi-sensory impairment' is often used as an alternative to 'deafblindness', because the latter implies profound deafness and total blindness to many people.

Deafblindness is a very rare disability, affecting approximately 1.8 in 10,000 children. Despite this, the range of conditions causing multi-sensory impairment is very wide. Sense (The National Deafblind and Rubella Association) report 86 different known causes of (congenital or acquired) deafblindness among the population known to them. A survey of 100 children under the age of seven attending the Sense Family Centre found that 30 different causes were recorded for the group.

The effects of deafblindness on development are not simply those of hearing impairment plus those of visual impairment. Deafblindness is a unique disability causing extreme developmental disadvantage, especially regarding access to information from the environment, communication and social and emotional development. In addition, the majority of children with deafblindness have further problems, such as physical disabilities or medical conditions.

The needs of the population have changed markedly in recent decades, for both biological and social reasons. Congenital rubella syndrome (the major cause of deafblindness in children until the 1980s) has been almost eradicated by rubella vaccination, whilst advances in medical technology and expertise have increased the survival rates of children born very prematurely or suffering severe infections. Many of these children sustain severe neurological damage and are profoundly multiply disabled as well as deafblind. Over the same period, perceptions of multi-sensory impairment among professionals, particularly teachers, have changed. Members of the Sense Family Advisory Service report an increasing awareness of the significance of sensory function in children with profound learning difficulties, whose sensory impairments previously were often not recognised or dismissed as unimportant. These factors, in combination, have led to an overall increase in the severity of disability associated with deafblindness.

This report investigates the potential benefits of early intervention for children with multi-sensory impairments. For several decades, early intervention has been recognised as a means of ameliorating the developmental constraints associated with disability or social disadvantage. The potentially devastating effects of deafblindness on early development have meant that the need for early intervention has long been acknowledged. Sense has a long history of providing early intervention services; the Sense Family Advisory Service began in 1983, and the classic texts in this field have been written by Sense staff or members.

A particular model of intervention has developed within the deafblind field, in response to the difficulties of deafblind people in gaining information from the environment. This model, somewhat confusingly, is known as intervention: the term is used technically to describe one-to-one working with a sighted hearing partner (an intervener), who provides the deafblind person with the information not delivered through sight and hearing. Interveners who work with children may need also to interpret the meaning of the information, in ways that the child can understand and use for learning. Interveners are...
usually paraprofessionals, but the process of intervening (the need to act, in effect, as the child's eyes and ears) may be carried out by parents or anyone else in contact with the child. (Other service delivery models are also used in the deafblind field, in conjunction with, or instead of, the use of interveners.)

The aims of this report are, firstly, to summarise the effects of deafblindness on early development, and to consider the implications for early intervention services; secondly, to summarise published studies evaluating early intervention programmes for children with multi-sensory impairments, and thirdly, to draw together the available evidence in order to suggest means of optimising the early development of children with deafblindness.

The sources of evidence for the report have been identified from literature searches, Web searches, specialist databases on deafblindness and contact with individuals responsible for specialist early intervention services or involved in relevant research.

The report is organised into the following sections:
- the effects of deafblindness on early development;
- the implications for early intervention provision;
- research on the effectiveness of early intervention for children with deafblindness;
- evaluation of research findings;
- other evidence on the benefits of intervention for children with deafblindness;
- conclusions and recommendations.
The effects of deafblindness on early development

Whilst nondisabled newborn babies show evidence of perception and discrimination through all sensory channels, their skills in gaining, integrating and using sensory information develop further during infancy\textsuperscript{15}. Very young infants are essentially dependent on touch, taste and smell, with hearing and vision gradually increasing in use\textsuperscript{16}.

The infant's dependence on other people provides a context in which human attributes (for example, scent, faces, voices) resonate with very early perceptual abilities. From the first days of life, babies and caregivers interact with each other, through looks, sounds and touch, building up their relationship and their understanding of each other. The bond between caregiver (usually mother) and infant is a vital first stage in the child's development of social relationships, communication and understanding.

Contact and interaction with the social and physical environment are easily jeopardised by sensory impairment. Hearing, which operates even in sleep, allows the child to maintain constant contact with the environment\textsuperscript{16}, whilst vision has been compared to a 'net that infants throw into the environment to gather new experiences'\textsuperscript{17}. Hearing and vision may be called the \textit{distance} senses\textsuperscript{18}, providing information about events beyond the here-and-now. Touch, taste and the balance senses are \textit{close} senses, limited to the immediate environment.

When one distance sense is impaired, information from the other may be used to compensate to some degree - a deaf person lipreading provides an example. For children with multi-sensory impairments, however, neither sense can be used to compensate, resulting in sensory deprivation\textsuperscript{5}. The effects of this are wide ranging. Children with deafblindness may not see or hear their mother's approach, so that her sudden touch means confusion rather than comfort and security\textsuperscript{19}. The interaction between mother and child will be disrupted because, even from birth, the child's signals and the mother's responses have significant auditory and visual components\textsuperscript{20}.

Research with blind children has emphasised the role of vision in the development of relationships\textsuperscript{21,22}, whilst deaf infants withdraw from interaction more quickly than hearing infants\textsuperscript{23}. Children with deafblindness, with both vision and hearing affected, are frequently unresponsive to adults, offering fewer, less readable signals and showing less enjoyment of interaction\textsuperscript{24,25}. Children born deafblind may not realise that they can affect what happens to them by communicating; they may not be aware of the effects of their own signals on others, or aware of an adult's attempts to respond. Mothers of children with multi-sensory impairments identify far fewer communicative behaviours and messages from their children than mothers of nondisabled infants\textsuperscript{26}.

Despite these findings, the communication between children with hearing impairment, visual impairment or deafblindness and their parents generally shows patterns of interaction similar to those of nondisabled children, although development may be very slow\textsuperscript{27}. Meaningful child-adult interaction for these groups appears to depend upon the ability of carers to respond to, rather than lead, the child.

Other areas of development are also affected. Nondisabled children start to explore their environment in the presence of a caregiver, to whom they frequently return. Children with multi-sensory impairments may be unable to maintain contact or to find the caregiver when they wish, and so may be unwilling to explore\textsuperscript{28}. They may have reduced opportunities to
move and limited experience of movement$^{29,30}$. Seeing the environment, particularly the people within it, is a strong motivator, both for mobility and for hand use$^2$. Whilst blind children use their hands to explore the physical environment through touch, deaf children who sign use their hands for interaction with the social environment. When both sight and hearing are impaired, the child's hands must function as sense organs and means of expression as well as tools$^{31}$.

Children who are deafblind may be unable to learn through observation, because they do not see or hear the results of their actions, or those of others. Incidental learning is simply not available. Sight and hearing provide information supporting anticipation, and hence control$^{14}$: children with multi-sensory impairment have been described as experiencing 'isolation amidst chaos$^{32}$ because of their inability to access distance information. Repeated failure to exercise control may lead to learned helplessness and passivity$^{33}$.

Children with deafblindness may be unable to understand their world in terms of time or space$^{32}$, because these are primarily experienced through hearing and vision respectively. The experience base and conceptual development of children who are deafblind will differ significantly from those of nondisabled children$^5$.

Deafblindness, then, affects all areas of development: the formation of relationships, emotional security, communication, cognition, motor development, perceptual development, self-awareness and independence. These effects begin from birth, jeopardising both the child's personal development and their situation within their family.
The implications for early intervention provision

The massive developmental impact of deafblindness has major implications for the provision of intervention. In brief, the developmental consequences of multi-sensory impairment suggest a need for early intervention which involves families, a need for specialist intervention and a need for co-ordinated services.

Parents are the key players in very early child development. Professionals need to work in partnership with parents, to develop a shared understanding of children's needs and how these may be met. In order to achieve this, professionals need to understand, not only the child's disability, but his or her key relationships, family structures and daily routines, family priorities and expectations. Parents may need a lot of support to overcome feelings of helplessness in the face of their child's needs, and to continue to search for responses from their apparently unresponsive child. Because the movements and expressions of deafblind infants are often slight and imprecise, and because they often cannot access the signals and responses of carers, parent-child interactions and relationships are jeopardised. Very early intervention is required to promote parent-child bonding and parents' sense of efficacy in caring for their child.

The need for specialist intervention can be inferred from the development of services for school-age deafblind children. The increasing awareness of specific needs related to deafblindness has led to the provision of various forms of specialist local support, including specialist advisory teachers, local units for children with multi-sensory impairments and interveners. A similar degree of specialism is needed for work with infants. The very low incidence of multi-sensory impairment makes it unlikely that generic professionals (or those trained to work with children with other disabilities) will have experience with deafblind children; it also means that there is no fund of community knowledge regarding deafblindness, from which generic professionals can draw. Children with multi-sensory impairments are very easily misassessed; there is a need to look beyond the child's overt behaviour, and to search for incongruities in development. An understanding of the developmental implications of multi-sensory impairment, and how these manifest in children's behaviour, is essential to this process. A knowledge of specialist teaching approaches, also, is vital for those providing intervention. Deafblind children are fragile learners, whose development can easily be harmed by unskilled teaching.

Because deafblindness is a complex disability, many different professionals may be involved with one child and family. The greater the number of professionals involved, the greater the potential for confusion and conflict, particularly when individuals address needs related to different disabilities. There is a need for expertise to be shared, and for effective inter-disciplinary working which supports, rather than overwhelms, parents and families. The appointment of a key worker (agreed by parents), who co-ordinates services and advocates for the family if necessary, may lessen the burden on parents. In America, emergent practice is to provide all early intervention in the 'natural environment' of the home, but there remains a need to provide opportunities for contact with other families with similar children (for example, through parent-child groups), in order to avoid parental feelings of isolation.

Recent models of early intervention for children with deafblindness have focused on the development of early parent-child relationships, using a transactional model of development (which links child development to the interactions between infants and their social environments). The aim of such models is to improve the quality of caregiver-
child interactions, by developing the abilities of caregivers to identify, interpret and respond to the often subtle and imprecise signals of their deafblind infants. Specific techniques are recommended to enhance interaction - for example, imitating and reflecting the infant's behaviours to aid the child's understanding that their actions influence the behaviour of others. Project PLAI, described below, is an evaluation of such a model in practice.

There is general agreement that early intervention is needed for children with disabilities, perhaps especially for those with sensory impairments. This agreement is grounded in the known effects of specific disabilities on development. Evidence to support the belief that these effects can be ameliorated by intervention, however, is less readily available, for a variety of reasons.
Research on the effectiveness of early intervention for children with deafblindness

Despite the consensus that early intervention should be provided, little research has been carried out to assess its effectiveness. In part this is because of the difficulties of evaluating early intervention programmes in general. Whilst there is general agreement that intervention should target the needs of children and families, most research has relied upon child-related outcomes - usually measures of progress within specific developmental domains. There are a number of problems with this approach: changes in attributes relevant to learning, such as curiosity and attention, cannot be assessed; standardised tests of performance are often inappropriate for children with special needs, whilst criterion-referenced assessments will vary between programmes and may be unreliable; children's progress during intervention needs to be compared to the progress they would have made without the intervention, and there are obvious ethical problems in denying intervention to some children who would benefit in order to create a control group. In addition, studies based on such measures cannot consider family-related outcomes (for example, satisfaction with services, ability to advocate for child's needs, quality of family life), or evaluate the process of intervention. Measures suggested in this area include children's health, parental adjustment and understanding of teaching principles; the take-up of other professional services; and the child's emotional stability and social integration. These measures have not yet been used in practice.

Children with deafblindness present particular issues for researchers, in addition to those discussed above. The very small number of children, the very wide range of needs, the changes in level of need in recent years, the interaction between multiple disabilities, the inconsistency of behaviour which accompanies epilepsy, variable sensory function, ill-health and many other conditions affecting deafblind children and the basic perceptual differences between subject and researcher, each add to the challenges of designing research studies which will provide valid, reliable results. In addition, there are particular ethical issues linked to the developmental implications of deafblindness. The reduction, distortion or absence of distance sensory information affects children's abilities to anticipate, act to change events, perceive consistency and structure experiences in space and time. In this context, activities which do not form part of a child's typical routine, or which introduce people unfamiliar to the child, may induce confusion and stress which cannot easily be dissipated.

Extensive Web and literature searches found only two studies dedicated to evaluating early intervention for children with deafblindness. Because of this, the findings of studies of children with related needs (visual impairment, hearing impairment, severe disabilities) will first be summarised; then the two studies of deafblind children will be presented in more detail.

Studies of young children with visual impairments suggest that the gains attributable to early intervention are greatest in areas specifically affected by visual impairment - for example, orientation and mobility. Gains in this area can be produced by increasing children's motivation to move (usually supplied by vision) rather than by work on gross motor development. Caregiver-child interaction, often derailed by blind infants' lack of eye contact and facial inexpressiveness, can be facilitated by teaching caregivers to interpret the child's (often much more expressive) hand movements.

Specialised, individualised, intensive intervention produces greater gains than generic
programmes⁵⁰, and individualised intervention specifically targeting visual development as well as general development produces greater global developmental gains than that targeting general development alone⁵¹. (This finding is predicted by the fundamental role of vision in early development.) Children beginning intervention very early (in the first months of life) benefit more than those beginning later⁵¹. Children with greater developmental delays (notably those born prematurely) may benefit from intervention with specific qualitative features (for example, reduced complexity of input)⁵⁰.

Studies of young children with hearing impairments have tended to emphasise language development and often speech development⁵². Intervention for these children involves both educational strategies and the provision (and use) of hearing aids. Children receiving intervention show considerably faster language development than would be predicted from maturation alone⁵³; children beginning intervention very early (before 6 months of age) develop better receptive and expressive language than those who begin later⁵⁴. Parents report an increased ability to manage their child's hearing loss following intervention, and are more able to stimulate communication and language development⁵³. Social support, from friends, family and/or professionals, predicts the quality of later mother-child interactions⁵⁵.

Intervention programmes for children with severe disabilities report positive outcomes, usually in terms of child developmental gains⁴⁸. Children with more severe disabilities, however, are consistently reported to make smaller gains on standardised tests than children with mild or moderate disabilities⁴⁷,⁵⁵; this is likely to be a function of the outcome measures used (usually straightforward comparisons of developmental age increases), which simply confirm that those with more severe disabilities learn more slowly.

Two studies dedicated to evaluating early intervention for children with deafblindness were identified. Both of these studies - Project PLAI⁴⁰,⁴¹ and Project VIP⁵⁶,⁵⁷ - are American.

Project Promoting Learning through Active Interaction (PLAI), funded by the US Department of Education, was a four-year research-to-practice project carried out by California State University in collaboration with the SKI*HI Institute, Utah State University⁴⁰,⁴¹. Project PLAI was designed to encourage mutually enjoyable interactions between deafblind infants and their caregivers and to support the infants' early communication development. An early communication curriculum, for use by early interventionists with families, was developed, implemented and evaluated. The curriculum, divided into five modules, had four objectives: to promote contingent responses by caregivers to children's behaviours; to identify interaction strategies appropriate for each child's disabilities; to develop and evaluate interactive 'contingency games' played as part of everyday routines, and to increase caregivers' feelings of competence and satisfaction in caring for their children.

25 children (aged 6-30 months) and their families completed the curriculum. All the children had visual and hearing impairments and none were using symbolic communication. All had moderate to profound developmental delays; half could not sit or move independently; half had been hospitalised at least once since birth; half had seizures; half had gastrostomy tubes; a third were on respirators, and a quarter had tracheostomies.

A range of measures were used in evaluation: recording sheets completed by caregivers for each module; interviews with caregivers at the beginning and end of the project; annual
focus group meetings of caregivers and interventionists; interviews and informal discussions with interventionists, and analysis of videotaped caregiver-infant interactions.

An emphasis of the project was the use of cues by caregivers to help the infants anticipate activities. Interviews with caregivers revealed an increase in both the number and the different types of cues used at the end of the project, compared to the beginning, and an increase in the variety of activities in which cues were used. By the end of the project, caregivers could consistently identify more of the children's needs and emotions, and viewed the children's behaviours as more purposeful. Caregivers reported that they felt they could communicate more effectively with the children, and that children anticipated more and participated more in activities.

The videotapes of caregiver-infant interactions during bathtime and playtime were coded for caregivers' use of cues to help the child anticipate activities, and aspects of caregiver-child interactive behaviours, using a rating scale adapted for use during the project. Significant differences were found between the number of cues used at bathtime at the beginning and the end of the project, and between the number of events cued at bathtime over the same period. Significant differences were also found in caregivers' degree of directiveness and sensitivity during bathtime between the beginning and the end of the project. Other aspects of behaviours did not show significant differences; nor were there any significant differences in the playtime situation. The authors suggest that the difference between bathtime and playtime may reflect the project's emphasis on everyday situations and routines: playtime seemed a more artificial activity to many caregivers.

Overall, the authors conclude that Project PLAI was successful in meeting its objectives. The first three objectives were achieved by caregivers’ completion of specific activities within the curriculum, and the fourth by caregiver reports of satisfaction with the project, increased communication with their children and increased sense of efficacy in interpreting and responding to children's behaviours. The early interventionists were also deemed to benefit, and in many cases to develop new skills, as a consequence of their participation.

Project Validation of the Intervener Program (VIP), funded by the US Office of Education, was a three-year evaluation of the Intervener Service Model developed in Utah by the SKI*HI Institute, Utah State University. This service, in which trained paraprofessionals (interveners) work with young children with deafblindness in their homes for up to ten hours each week, forms one component of the Utah early intervention programme for children with multi-sensory impairment; the second component consists of parent advisors from the Utah Schools for the Deaf and the Blind, working primarily with parents.

Interveners work under the direct supervision of the child's parents. Their role is to help the child to develop interactive behaviours by using tactile and/or other appropriate communication methods, and to provide sensory information and interpretation, acting in effect as the child's eyes and ears. In addition, interveners work on areas of individual need such as mobility, daily care, positioning and handling and massage.

Project VIP comprised five studies, carried out during the period 1989-1992. 28 children received intervener services during this time, and were the subjects of the evaluation. All the children had both hearing and visual impairments; 14 had learning difficulties, 22 physical disabilities, 7 emotional difficulties and 13 other learning problems.

The first study investigated the developmental progress of children with deafblindness who
received intervener services. The children were assessed at the beginning and end of a three-year period. Two methods were used to evaluate progress: comparison with predictions made using each child's 'developmental rate'\(^58\), and the calculation of a Proportional Change Index\(^59\) for each child, allowing comparison of their rate of development during intervention compared to before intervention. These measures indicated that the children made more progress during the intervention than would be predicted by maturation alone, and that the children showed accelerated rates of progress in all developmental areas whilst receiving intervener services.

The second study used a single-subject research design to investigate the effects of the intervener's presence on children's communication and self-stimulation behaviours. The number of behaviours of each type were counted for consecutive time periods when the intervener was (i) not present, (ii) working with the child and (iii) not present. The counts were repeated twice-monthly for each child throughout the project. Overall, an increase in communication behaviours and a decrease in self-stimulation behaviours was found during the intervener's participation for all children over the life of the project.

The third study compared the developmental progress of children receiving intervener services with others, judged to meet the eligibility criteria but not given interveners. These children (from other states not providing intervener services) were used as a control group. Children in the two groups (15 in each group) were approximately matched for age, visual loss, hearing loss, additional disabilities and developmental level. Children in both groups received services from parent advisors. Similar measures to those used in the first study were used to assess progress. The children receiving intervener services made greater developmental gains during the intervention than did the control group. An analysis of covariance was used to control for differences between the groups which might have affected the results; this showed the children receiving intervener services to have made more progress than the control group in all developmental domains. The perceptions of the children's parents were also compared. Parents of children with interveners showed a greater increase in positive perceptions than the control group parents, reporting improved emotional well-being, understanding of the child's difficulties and abilities to help the child.

The fourth study investigated the effects of interveners on families receiving services. A range of measures (including interviews, videotape analysis, case studies and questionnaires) were used to gather information from interveners, parents, siblings, parent advisors and intervener supervisors. Parents indicated that they felt less fatigued, under less strain and better able to cope with their children since receiving intervener services. They reported that the children gained 'great benefit' from the intervention, receiving more attention, interaction and stimulation, and offering more communication.

The fifth study used surveys, meetings, interviews and diary records to determine ways of improving the operation of the programme. This study resulted in recommendations regarding personnel, referrals, the employment of interveners and transitions to other programmes.

Overall, the authors conclude that the findings strongly support the use of interveners in early intervention with deafblind children and their families.
Evaluation of research findings

There are two questions underpinning research on the effectiveness of early intervention. The first, characterised as first-generation research, queries whether early intervention is effective. The second (second-generation research) asks which components and forms of intervention give the best outcomes for children and families with specific needs. The evidence presented above strongly indicates that early intervention is effective (i.e.: better than no intervention) for children with deafblindness. Analysis here will focus on the second issue: how to plan and deliver early intervention in order best to meet the specific needs of deafblind children and their families.

The findings from studies of children with visual impairments and children with hearing impairments indicate that intervention is most effective if it begins in the first months of life, is individualised, specialist and intensive, and targets areas of development particularly affected by the impairment. The need for further investigation of how best to focus intervention is stressed by researchers from both fields.

Comparisons of the relative benefit of different forms of intervention depend upon accurately assessing the outcomes. The difficulties of devising appropriate outcome measures have already been considered. Nevertheless, this is a key issue for children with multi-sensory impairments, because of the differences in learning style imposed by sensory disabilities.

The two studies specifically concerned with deafblind children focus primarily on different aspects of intervention: Project PLAI on curriculum content, and Project VIP on service delivery. Both report overwhelmingly positive outcomes.

Project PLAI curriculum is consonant with current thinking on the developmental implications of deafblindness. It is appropriate for use with very young infants, aiming to improve caregiver-child interaction and hence early relationships. It succeeds in structuring aspects of the very fluid process of caregiver-child interaction, and in evaluating the training of interventionists to work in this area.

Project PLAI assesses family-related outcomes, which are accepted as difficult to measure. The range of measures used supports confidence in the findings: particularly the combination of caregiver reports of perceptions of increased competence with objective measures of their competence in particular areas. This study indicates that intervention to support caregiver-child interaction, often considered intuitive in nature, can be structured in a way that assists caregivers to develop new skills in, and perceptions of, interaction with their deafblind infants.

Project VIP overcomes several of the difficulties commonly encountered in measuring child-related outcomes of intervention. The three-year duration of the intervention period is long enough to offset the initial developmental boost that typically occurs when an intervention begins. The measures of developmental progress are more sophisticated than in many studies, allowing intra-individual comparisons of progress before and during the intervention. These measures are far more appropriate for children with deafblindness, whose learning styles and rates are highly individual, than comparisons with other children.

Project VIP was carried out in the early 1990s, and thinking in some areas (for example,
the role of 'self-stimulatory' behaviours in development\textsuperscript{28} has moved on. Nevertheless, the range of measures reported, and the use of both child-related and family-related outcomes in evaluation, support confidence in the study's conclusions. In the UK, the use of interveners with preschool children is very rare: this study indicates that intervener services (in conjunction with other forms of support, as in the study) provide one appropriate model for the delivery of early intervention.

These two studies offer 'second-generation' information, in that they identify specific components of intervention found to benefit young children with multi-sensory impairments and their families. In addition, however, the studies act as worked examples of how particular research designs and methods can be used with children with deafblindness; this aspect should benefit future research on early intervention with this group.
Other evidence on the benefits of intervention for children with deafblindness

The paucity of research on the effectiveness of early intervention for deafblind children reflects in part the difficulties of designing and implementing research on this topic with this group. In part, however, it reflects a difference in emphasis between America and Europe: there are many European early intervention programmes for children with multi-sensory impairments, but their worth is generally accepted rather than proven. This corresponds to the situation for early intervention in general: there is more debate, and more research, in the US than in Europe, but nevertheless considerable early intervention provision in European countries.

For this reason, information from a number of European programmes is summarised below.

Work in the Nordic countries on very early communication has focused on mapping the early development of deafblind children, using the dynamics of early interaction between a nondisabled child and the social and physical environment as a model. The aim of this process is to find ways of facilitating communication development in deafblind children according to normal developmental principles. A longitudinal study of five deafblind children in Sweden examined parent-child interaction and the children's communicative development. Children's abilities to engage in meaningful interaction were found to depend upon the communicative styles of caregivers, and in particular their ability to follow, rather than to direct, the child in interaction. A more physical approach to following the child in interaction is described in work from the Netherlands. Specialist approaches involving moving in close physical contact with the child to receive and send minute body movement signals are claimed to increase the quality of parent-child interaction and hence the quality of early relationships.

Case studies in the UK have provided anecdotal support for the benefits of early intervention. In one study, the curiosity and confidence in movement of a very young deafblind child were tentatively attributed to the very early introduction of a structured massage programme. In another study, three young children with multi-sensory impairments attending a specialist centre providing intensive intervention made considerable sensorimotor and social-emotional progress (compared to their previous development) over a 9-month period.

The need to view parents as partners in intervention, emphasised by many authors, is a central tenet of work by the Sense Family Advisory Service. There exists a very considerable body of anecdotal evidence supporting the benefits of their family-centred approach to both children and parents.
Conclusions and recommendations

In this report, the developmental consequences of deafblindness have been evaluated in terms of their implications for early intervention, and research findings on the benefits of early intervention for children with multi-sensory impairment have been examined. The conclusions from these two approaches regarding effective early provision for infants with deafblindness are the same, and are summarised below with their implications for service provision.

There is a clear need for specialist local support for children with deafblindness and their families. This support should begin in the first months of the child's life. It should involve parents as active partners and should be structured to increase their competence and confidence in advocating for their child and in meeting the child's needs. Intervention should focus on supporting parent-child interactions and family relationships.

Early intervention for children with deafblindness needs to be specialist and individualised. The needs and abilities of children, including those relating to the interactions between multiple disabilities, need to be assessed by professionals qualified and experienced in working with children with deafblindness. This applies equally to developmental, medical, audiological and visual assessment. The content and delivery of early intervention should be agreed with parents and reassessed regularly, also with parents. Very early intervention with deafblind children may be delivered in part by interveners, working directly with the child. Whether or not paraprofessional interveners are used, their primary role (supporting interaction with the environment by providing information normally available through sight and hearing information) will need to be fulfilled, and should be recognised as essential.

Early interventionists need training both in working with families from diverse cultural and social backgrounds and in deafblindness and how to meet the needs associated with the impairment. All professionals involved with deafblind infants should understand these issues. Specialist training courses on the education of children with multi-sensory impairments are available (and usually mandatory) for teachers, and training is also available for interveners. Training in multi-sensory impairment for health and social services professionals requires further attention. The provision of joint training for professionals from different disciplines might promote more effective inter-disciplinary working with these children.

The professionals involved in supporting deafblind children and their families should work as a team, co-ordinating their input and sharing expertise. Particular care should be taken to avoid giving conflicting advice, especially when different aspects of the child's needs suggest differing interventions. The use of key workers should be actively considered, particularly where many professionals are involved or where the co-ordination of input adds to parental stress. The location of intervention should be that which best meets family needs.

A better knowledge base is needed regarding early intervention with deafblind children. Further research is needed on the benefits of different forms and components of intervention for children with different needs, for different families and in different situations. It is clear that early intervention benefits children with deafblindness: the needs now are for sufficient appropriate provision, and for the individualisation of intervention in order best to meet the needs of each individual child and family.
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