Consultation

Developing Early Intervention/Support Services for Deaf Children and their Families

Executive summary

Overview

This is a consultation document containing draft guidance for LEAs. It considers the implications of very early identification of deafness through neonatal screening for existing service delivery to the families of deaf children of pre-school age.

The guidance is issued in the context of the implementation of Newborn Hearing Screening, previously known as Universal Neonatal Hearing Screening (UNHS), through a Department of Health pilot.

The guidance offers advice on:

- Aims for education service provision
- Partnership with parents
- Multi-agency working
- Developing professional knowledge and experience
- Evaluating service delivery

The appendices offer for comment professional competencies, a sample questionnaire for families, and suggested performance indicators.

Action required

If you wish to comment on any or all of the questions contained within the consultation document, please send your response to John Hall, Special Educational Needs Division, Area 2E, Department for Education and Skills, Sanctuary Buildings, Great Smith Street, London SW1P 3BT or by e-mail to: **John.HALL5@dfes.gsi.gov.uk**

The closing date for responses is 23 September 2002.

department for
education and skills

RNID
for deaf and hard of hearing people

Pupil Support
Equal Opportunities

Audience: All LEAs in England, Special Educational Needs (SEN) organisations
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Contents

Context

1. This guidance considers the implications of very early identification of deafness by neonatal screening for existing service delivery to the families of deaf children of pre-school age. The guidance is for Local Education Authorities (LEAs) and teachers of the deaf and other professionals working with very young deaf children and their families after deafness has been diagnosed and hearing aids have been fitted. It builds on existing good practice by LEAs in this area and promotes the development of professional practice in response to the introduction of neonatal screening for deafness.

2. This advice is offered in the specific context of the implementation of Newborn Hearing Screening, previously known as Universal Neonatal Hearing Screening (UNHS), in 20 health authority areas in England through a Department of Health pilot.[1] Currently, 1 to 2 children per 1000 are born with a permanent, significant degree of congenital deafness. Of the babies identified as having permanent congenital hearing loss at this early stage, an estimated 50% will have a moderate hearing loss, 25% a severe hearing loss and 25% a profound hearing loss (Davis et al,1997; Fortnum & Davis, 1997).

3. The median age of identification of congenital deafness will be lowered by Newborn Hearing Screening from 20 months to 3 months. For the first time, children with moderate, severe and profound levels of deafness will be identified routinely within the first two months of life (Davis et al,1997). Newborn Hearing Screening will bring earlier clinical diagnosis of deafness and earlier prescription of hearing aids. It will also bring an immediate increased demand for the professional support services required by families following identification of deafness. A higher proportion of the target population for services will be identified within the first two months of life and families will require support for a longer period of time.

4. LEAs will need to anticipate increased demand for early intervention/support services for deaf babies and their families, by planning for the expansion and development of existing services. They also need to consider the nature of effective, family-friendly, multi-agency service delivery for very early identified children with special needs and plan for the professional development of personnel working directly with the families of deaf babies.

5. Authorities will need to plan for a 52 week service for the families of newly-identified deaf babies and this raises important organisational issues in terms of flexible deployment of available staff. Some LEAs in adjacent areas may find it helpful to pool resources.

6. Developing early intervention structures, including support for LEAs to deal with the educational ramifications of Newborn Hearing Screening, is identified as an objective for the Special Educational Needs (SEN) component of the Standards Fund for 2002 –2003 (DfES document reference LEA/054/2001, issued to LEAs 28 September 2001).

7. This draft guidance is being is issued at the same time as *Together from the Start*, and has been developed alongside the work of the DfES/DH Multi-Agency Working Party for Children with Disabilities from Birth to Two. *Together from the Start* is designed to improve service provision for all disabled children in this age group. *Developing Early Intervention/Support Services for Deaf Children and their Families* considers particular issues for early identified deaf children and their families in the context of the implementation of Newborn Hearing Screening. The guidance is also framed against the wider backdrop of the SEN Code of Practice (2001) and the SEN and Disability Act 2001.

8. The advice contained within this document draws on the work of Elizabeth Andrews, Senior Education Policy Officer at the Royal National Institute for Deaf People, during a period of secondment to the Special Educational Needs Division of DfES.[2] The Department is very grateful for her contribution and that of RNID to the development of this material.

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[1] Information on this project is available at www.unhs.org.uk

[2] The full report by Elizabeth Andrews is available at www.dfes.gov.uk/sen

Why education service intervention is important for such young children

9. Deafness in young children interrupts the developmental process for acquiring spoken language normally observed in hearing infants. Where deafness is significant and permanent, the consequences of early failure to develop communication, language and speech are long term, wide-ranging and well-documented. Cognitive development, social development and later educational progress including literacy are all affected.

10. Early identification of deafness, combined with effective early intervention, offers the best chance of the language, communication and speech abilities of deaf children developing in line with the developmental pattern and time frame for hearing children. Effective support for families empowers parents to make informed decisions and take positive action on behalf of their child before language and communication deficit becomes established.

11. Earlier identification of deafness, when combined with effective service provision in the pre-school years, will dramatically improve the chances of successful inclusion of deaf children into mainstream schools and into society. It therefore has the potential to significantly reduce the long term costs to society of providing support services. However, to capitalise on the potential advantages Newborn Hearing Screening will bring, early identification and early intervention must be developed in parallel within a single, co-ordinated development strategy.

12. Evidence from the USA, where the development of deaf children identified and receiving early intervention/support services before 6 months of age has been tracked longitudinally against the development of children identified later appears to be extremely positive and has attracted world-wide attention (Yoshinaga-Itano, 1998; 2000).

Aims for education service provision

13. Early intervention/support services are provided to early identified deaf children and their families:

- to enable as many children as possible to enter the Foundation Stage with age-appropriate language, communication and speech
- to empower families to take positive action on behalf of their child by ensuring that they have access to unbiased, accurate and up to date information
- to provide practical advice and support to families through the very early stages of language, communication and speech development
- to establish effective use and maintenance of hearing aids, personal FM systems and/or cochlear implants in the home
- to establish sign communication in the home, where families elect to use sign combined with spoken language or British Sign Language

Health and Social Services staff also have important contributions to make in a number of these areas; the responsibility is not education's alone. For example, paediatric audiologists have an important role in identifying deafness, making, providing and fitting earmoulds, prescribing, reviewing and maintaining hearing aids, and considering with families and others the option of cochlear implantation.

Consultation questions

Q1 Do you think this list of aims for service provision is appropriate?

Q2 Are there any other aims you would like to see services aspire to?

Q3 Can you offer practice examples which illustrate effective strategies to achieve these aims?

Partnership with parents

14. Because of the very young age of the children involved, it is clear that the general principles of working in partnership with parents set out in the SEN Code of Practice (2001) have particular relevance. Sections 2:6 and 2:7 of the Code are particularly relevant:

> Positive attitudes to parents, user-friendly information and procedures and awareness of support needs are important. There should be no presumption about what parents can or cannot do to support their children's learning. Stereotypic views of parents are unhelpful and should be challenged. All staff should bear in mind the pressures a parent may be under because of the child's needs.
>
> To make communications effective, professionals should:
>
> - acknowledge and draw on parental knowledge and expertise in relation to their child
> - focus on the children's strengths as well of areas of additional need
> - recognise the personal and emotional investment of parents and be aware of their feelings
> - ensure that parents understand procedures, are aware of how to access support in preparing their contributions, and are given documents to be discussed well before meetings
> - respect the validity of different perspectives and seek constructive ways of reconciling different viewpoints
> - respect the differing needs parents themselves may have, such as disability, or communication and linguistic barriers

Multi-agency service delivery to families

15. A number of different agencies support families following early identification of deafness. All of the following may be involved to varying degrees, in addition to the standard support provided by general practitioners and health visitors to families in the first year of a child's life:

- paediatric audiologists
- teachers of the deaf working for LEA advisory/support services for deaf children
- educational audiologists
- speech and language therapists
- social workers

Health and Education are key players within the multi-agency framework of service provision for this population. While the involvement of Social Services is also important, current involvement of SSDs at local level appears to be subject to a greater degree of variation.

16. Teachers of the deaf working for LEA advisory/support services for deaf children make an important contribution to the support offered to families of deaf children in the pre-school years as part of a multi-agency package of support which provides clinical diagnosis of deafness, hearing aids, information and on-going practical guidance on how to develop language, communication and speech.

17. Evans & Robinshaw (1999) confirmed that, in practice, teachers of the deaf[3] working for LEA services are the main providers of early intervention/support services to families of pre-school age deaf children, including children in the age range 0–2. Following identification and disclosure of deafness, teachers may support families in the home on a weekly basis over a number of years, particularly where the degree of deafness is severe or profound.

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[3] Teachers of the deaf hold qualified teacher status and the mandatory qualification (MQ HI)

18. Some deaf children 0–2 and their families receive centre-based support from a multi-disciplinary team.[4] However, centres offering support of this kind are few in number and tend to be independent of statutory agency control.

19. The experience of implementing Newborn Hearing Screening in other countries suggests the following are essential to harness the potential benefit of early identification of deafness:

- clear systems for multi-agency service delivery to ensure continuity of support for families through the initial/follow up screens, confirmation of deafness and early intervention and support
- clear definition of where responsibility for the provision and funding of early intervention services lies
- clear quality assurance systems to evaluate the effectiveness of the early intervention services provided

20. In common with many other areas of activity, effective multi-agency working in this field requires:

- mutual respect between the agencies and professional groups involved
- clear role definition, particularly where roles and responsibilities in relation to a common client change over time
- a clear management structure with well-defined decision making and referral procedures
- transparent, practical communication mechanisms to facilitate the sharing and exchange of information between agencies
- regular scheduled meetings where participating agencies or team members can meet face to face to discuss issues of common concern

21. A mechanism to promote better multi-agency service delivery to the families of deaf babies at local level already exists in the form of Children's Hearing Services Working Groups (also known as Audiology Working Groups or AWGs). These groups bring paediatric audiology personnel together with teachers of the deaf, social workers, parents and other interested agencies. However, only 64% of health authorities are currently reported to have a CHSWG. Nearly all existing groups involve a teacher of the deaf, but only 36% of these include a parent representing the consumers of services (Bamford, 2000).

Consultation questions

Q4 What mechanisms exist in your area to ensure effective communication and co-ordination between services supporting families of early identified deaf children?

Q5 (Where applicable) what has been the added value of Children's Hearing Services Working Groups in terms of promoting multi-agency working?

Q6 Can you offer practice examples to illustrate effective multi-agency working in support of early identified deaf children and their families?

The early involvement of local education authorities

22. The very early involvement of LEAs with deaf children and their families is a logical extension of general principles which lie at the heart of *the SEN Code of Practice (2001)*, in particular, early identification of SEN and early intervention to promote development. The importance attributed to early identification and intervention is reflected in the fact that a whole chapter of the Code is devoted to those themes.

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[4] For example, the Speech, Language and Hearing Centre at Christopher Place (London) and the Elizabeth Foundation (Portsmouth and Bradford)

23. LEA services for very young deaf children and their families promote continuity of information, practical advice and support. Where they are already well-developed, they represent early investment to reduce the medium to long term impact of deafness and associated support costs.

24. Many LEAs already have well-developed advisory/support services working with deaf children under two and their families:

Berkshire Sensory Support Service

(Joint arrangement between 6 LEAs)

- the service supports 700+ children/pupils identified with a sensory impairment aged 0–16, of which 550+ HI, VI and MSI children/pupils 0–16 are actively supported by advisory/support service teachers
- 92% of children with sensory impairments are included in LEA mainstream schools
- all teachers working with deaf children in the pre-school years hold the MQ(HI) qualification and 2 hold an additional qualification as an educational audiologist
- weekly visits in the home from teachers holding the MQ(HI) qualification are provided for all severely and profoundly deaf pre-schoolers from time of diagnosis onwards
- the service currently supports 37 families with deaf children aged 0–3
- severely or profoundly deaf children 0–3 comprise 10% of the Sensory Consortium Service caseload but consume 23% of the time commitment of staff

Stockport

Service for hearing impaired children

- the service employs 2 teachers holding the MQ(HI) qualification who are early years specialists and who also hold a MSc in Audiology (Paediatric Habilitation)
- 1 to 4 deaf children of pre-school age are currently identified per annum
- pre-school deaf children receive 1 to 3 visits per week depending on severity of need from time of diagnosis onwards
- training, information and a telephone help-line are provided for child minders and early years providers working with deaf children of pre-school age

25. Working with the families of very young deaf children will clearly bring new challenges for all the professionals involved and requires a flexible attitude on service delivery options to be maintained as Newborn Hearing Screening is implemented. Evidence of existing LEA provision of high quality suggests that the process of developing early intervention/support services should be one of evolution, building on existing good practice.

26. By merit of their MQ(HI) training and experience, teachers of the deaf have particularly relevant knowledge, understanding and skill to contribute. It is for this reason that they are often identified as Keyworker, even in the case of very small babies. Families are looking for very specific information, knowledge and guidance to complement the information and equipment they receive from paediatric audiology services.

27. Teachers of the deaf can offer:

- applied specialist knowledge across a range of relevant disciplines, including language, communication and speech development, speech acoustics, audiology and deafness

- practical experience of promoting language, communication and speech in deaf children
- practical experience of using hearing aids and other amplification equipment in everyday settings
- information about the nature and impact of deafness and the range of communication and other options available to deaf children and their families
- practical experience of working with a wide range of deaf children (including children of pre-school age) in different settings
- an understanding of the outcomes that may reasonably be expected for deaf children when support is sustained and developed effectively over time
- up-to-date local knowledge of the range of education and other support options available to deaf children and their families

28. Families with early identified deaf children require continuity of support through the pre-school years from individuals who are knowledgeable about the nature and impact of deafness and competent to provide practical support. Some teachers working with the families of pre-school deaf children come into the work as early years specialists. Where this is not the case, custom and practice has identified the acquisition of skills required to work appropriately with families and young children in the home as an essential component of professional development for peripatetic teachers of the deaf.

Consultation questions

Q7 Do the featured examples reflect what you consider to be well-developed service provision?

Q8 Have you examples you can offer?

Developing professional knowledge and experience

29. Working with very young deaf babies and their families will bring new challenges for early intervention/support services already working with pre-school deaf children and their families from time of diagnosis onwards. In particular, the shift down the age range will require them to:

- support age-appropriate development of language and communication, and monitor progress from the neonatal stages onwards.
- provide balanced information on the range of communication and other options available in a format and at a pace appropriate to families of young babies
- promote optimal use of hearing aids in the home, where aids have been fitted very early to small ears
- support the integration of hearing aids and sign language (where this is the preferred option of the family) into the daily routines of young babies
- work sensitively and appropriately in partnership with families at a time when the parent-child relationship remains relatively fluid and vulnerable
- support a different process of adjustment to the news of permanent deafness than has characteristically been observed in the families of later-identified deaf children

30. A consensus statement listing the competencies required by teachers of the deaf and others working with this population is available to support an audit of training need as part of planning for the introduction of Newborn Hearing Screening (RNID/NDCS, 2000). This document is attached in full at Appendix 1.

31. LEAs should prioritise the training needs of teachers of the deaf working with families of early identified deaf children within their planning. Joint training arrangements involving professionals from other agencies such as health and social services provide a particularly helpful vehicle for reinforcing effective multi-agency working and a sense of common purpose.

Consultation question

Q9 Is the statement of competencies at Appendix 1 a useful tool for identifying current knowledge and skills and addressing professional development needs?

Meeting the needs of children and families

32. Newborn Hearing Screening makes it possible for families to take very early action on behalf of their child and to intervene before language and communication deficit has become established. Where children have no other learning difficulty or disability, this brings a fundamental shift in emphasis away from remediation of a problem which has already developed, towards facilitation of development within the pattern and time frame expected for other children. In the case of the very young babies identified by Newborn Hearing Screening, professional support which aims to promote development in the child must clearly be mediated through the child's family.

33. Families must be at the heart of any decision making process about their child and need accurate, accessible, up-to-date information to support their understanding of how to respond positively to deafness in their child and to decide what to do. In particular, they require:

- seamless, well co-ordinated and adequately resourced support services delivered at local level
- accessible information delivered at an appropriate pace, about:
    - the nature and impact of deafness
    - the likely impact of deafness on their child's development
    - the range of communication and other options available
    - the use and maintenance of hearing aids and other amplification equipment
    - the range of educational support options available to deaf children of pre-school and school age in their area
    - the rights and responsibilities of families under SEN legislation
- the opportunity to meet with other families with deaf children in the area and with a range of deaf adults
- practical help and support in:
    - developing early interaction and communication
    - developing language and their child's ability to listen using hearing aids and other amplification devices
    - establishing and sustaining effective use and maintenance of hearing aids in the home
    - learning how to use British Sign Language or sign communication, where this is part of the communication approach they have chosen
- active involvement in the monitoring of their child's development and any related decision-making about their child's developing needs
- empathetic, sensitive support in adjusting to the news of permanent deafness in their child
- where a child has a disability or learning difficulty in addition to deafness, information about how the factor of deafness impacts on their child's situation and effective co-ordination of all the agencies offering support

Consultation questions

Q10 Do you agree with this list of service expectations? Are any important elements missing?

Q11 Can you offer any practice examples illustrating service support that families have found particularly helpful?

Developing existing service delivery to families

34. While there is clear evidence of good practice and satisfaction amongst families as consumers of LEA services in some areas (Powers et al 1999), the evidence base supporting a systematic, critical review of the quality and consistency of current service provision is undeveloped. However, a recent wide-scale survey of LEA service provision using the Deaf Early Education Services Index (DEESI)[5] supports anecdotal evidence that the variation in level and quality of services received by families at local level is very wide.

35. It is therefore important that strategic planning in advance of the implementation of Newborn Hearing Screening includes a review of current service provision and development of mechanisms to evaluate the effectiveness of the services provided for deaf babies and their families. Recommendations for performance indicators for service provision and outcome measures are made below.

36. Evidence on the accessibility of existing early intervention and support services for families of ethnic and language minority groups further suggests that language interpreting services to support partnership with parents should be expanded. Similarly, initiatives to share written information for families in a range of minority language across local authority boundaries should be actively encouraged (Turner & Lynas, 2000; Chambra et al,1998).

Structural issues

37. This guidance is designed to support the development of specialist services for a clearly defined, but relatively low incidence population. Partnerships between LEAs which extend the depth and range of support that teachers of the deaf and others are able to provide are already well-established in some areas. The development of this guidance has been informed by discussion with the following existing partnerships:

- Dorset County Service for Hearing-Impaired and Visually-Impaired Children (for Dorset County Council, Bournemouth Borough Council and the Borough of Poole)
- Berkshire Sensory Consortium Service (SCS, for Bracknell Forest Borough Council, Reading Borough Council, Royal Borough of Windsor and Maidenhead, Slough Borough Council, West Berkshire District Council, Wokingham District Council)
- Bristol Sensory Impaired Children’s Service (for Bristol City, South Gloucestershire, Bath & North East Somerset and North Somerset)
- Kingston Upon Hull (for Kingston Upon Hull, East Riding of Yorkshire, North East Lincolnshire and North Lincolnshire)
- Middlesbrough (for Stockton, Hartlepool and Redcar and Cleveland)
- Shropshire (for Shropshire and Telford & Wrekin)

[5] Bamford J et al *Assessing Service Quality in Paediatric Audiology and Early Deaf Education* (2001)

Bristol identifies the following as aspects of service provision it would be difficult for participating unitary authorities to provide if they were operating independently:

- a specialist early years HI team capable of providing differentiated support
- a specialist team providing support for MSI children
- educational audiologists to support the families of young deaf children
- opportunities for families to meet with other families in the area with deaf children- it is only possible for LEAs to set up cost-effective support groups where the LEA population is large
- professional support and continuing professional development for teachers of the deaf from colleagues undertaking similar work within a larger team
- audiological support in the form of a Hearing Aid Technician

The consortium arrangement based in Kingston upon Hull employs a total of 6 teachers of the deaf holding an additional qualification as an educational audiologist within their HI team, which in itself is an indicator of the benefits of operating on a larger scale. These staff have a key role to play in providing early intervention/support services to the families of pre-school deaf children. Newborn Hearing Screening will bring some adjustment to caseloads for individual members of staff to accommodate increased demand for these services, but the head of the advisory/support service commented that in general ‘the advantage of a joint arrangement is that we can meet new challenges more easily’.

38. Small authorities are encouraged to review their current service provision arrangements and to actively consider whether partnership arrangements with other LEAs could improve the quality and level of service they are able to provide.

Evaluating the effectiveness of services: outcome measures for children

39. The key measure of effective service provision in the first three years of life is the proportion of deaf children with a permanent, congenital average hearing loss greater than 40dBHL who move through Foundation Stage with age-appropriate language, communication and speech. Age-appropriate language and communication is needed if the achievements of deaf children are to fall within the expected range for Communication, Language and Literacy and other Stepping Stones defined by the *Curriculum Guidance for the Foundation Stage* (DfEE/QCA 2000) and Baseline Assessment.

40. An estimated 40% of deaf children have an additional disability or learning difficulty, which may make the achievement of age-appropriate language and communication an unrealistic target. Where this is the case, achievement of developmentally appropriate levels of language and communication remains an important goal.

41. However, expectations should be high where children do not have a disability or learning difficulty in addition to deafness, where they have been identified within the first two months of life and their families have received early intervention and support on a regular basis from time of diagnosis onwards.

42. ‘Age-appropriate language and communication’ for these purposes means within developmental norms defined for hearing children by the South Tyneside Assessment of Syntactic Structures (STASS) (Armstrong & Ainley) and/or for users of *British Sign Language by British Sign Language Development: Receptive Skills* (Herman, Holmes & Woll).

43. One possible indicator LEAs might wish to consider is a trend towards 60% of their deaf children achieving age-appropriate language and communication at 3 as a result of earlier identification and intervention. This would be over a 5 year period from the time that Newborn Hearing Screening is first implemented in their areas.

Consultation questions

Q12 Do you agree with the working definition of "age-appropriate language and communication" offered in paragraph 42?

Q13 Is the expectation described in paragraph 43 a reasonable target? if you disagree, what do you think it should be?

Outcome measures for families

44. The very young age of the children that are the subject of this guidance means that key elements of intervention and support for the child are mediated through the child's family. Families have important information to contribute on how effectively the services provided have met their needs. A simple proforma is attached at Appendix 2, to measure how families rate the services provided to them. It provides one fairly straightforward means of asking families for their views, but it clearly it should be supplemented by other steps such as regular discussions and structured interviews.

Consultation questions

Q14 Is the questionnaire at Appendix 2 fit for purpose?

Q15 Is there a danger that parents will be reluctant to give negative answers for fear of losing services?

Q16 Do you have other suggestions for how outcomes for families might be defined and measured?

Performance indicators for service delivery

45. Performance indicators provide one mechanism to evaluate the consistency with which early intervention/support services are being provided for children and their families. A suggested catalogue of performance indicators incorporating measures from a number of LEAs that already use measures of this kind is attached at Appendix 3.

Monitoring progress in the pre-school years

46. Discussion of appropriate monitoring arrangements for such very young children is still developing, as experience of working with early identified babies and their families emerges. Many LEAs already videotape pre-school deaf children in conversation with adults every six months as a standard part of their support to families. Videotape allows families and teachers of the deaf to look for evidence of development in the child together. It also provides the basis on which to reflect on those patterns of interaction/conversation between adults and children which are fundamental if language and communication are to develop.

47. LEAs should look for evidence of the following:

- general development against developmental norms for hearing children in the first year of life
- the child's developing ability to attend to/respond to sound and voice using hearing aids and/or cochlear implant
- the child's developing ability to attend to/contribute to conversational interaction
- the child's developing understanding and emerging use of spoken language
- the child's understanding and emerging use of British Sign Language or sign communication to support spoken language, where a sign bilingual or total communication approach is being used in the home

48. The following can be used to monitor the very early stages of communication and language development:

- *Video analysis of pre-verbal communication behaviours* (Tait)
- *Pragmatics Profile for early Communication Skills* (Dewart & Summers 1989)
- *Developmental Sequences of Co-occurring Processes in Early Communication* (Kurtzer-White in Luterman et al 1999)

Consultation questions

Q17 What elements do you think are essential to describing and tracking progress in deaf children from 6 months to 18 months of age?

Q18 Can you offer examples of monitoring and accountability mechanisms that have worked well, in terms of securing consistent, high quality support for children and families?

Appendix 1: Professional competencies

RNID/NDCS joint initiative on training issues for professionals working with deaf children under five and their families
(2000)

Statement of Competencies Required by Professionals Working with Deaf Children 0–2[6] and their Families

Professional attitudes

- Professionals should approach work in this area with the expectation that they must work in partnership with families, with parents fully involved in any decision-making processes affecting the provision of support to their child.
- They should respect the right of parents to receive comprehensive, accurate information about their child and service options and understand that families deserve continuity of care.
- They need to understand that every family is different and to be flexible in the way that they work with the families on their caseload.
- Professionals need a positive 'can do' attitude and a professional disposition which means they are there to 'support' but not to 'rescue'.
- They also need to be aware of the rapidly changing context for this specialist work and demonstrate a commitment to keep their professional knowledge and skills up-to-date.
- Professionals need the interpersonal skills relevant to a family centred approach and the interactional skills required for engaging the attention of very young deaf infants.
- Some of the decisions that families are required to make on behalf of their deaf children are controversial. Professionals should demonstrate willingness to support families in the decisions they take.

Statement of professional competencies

1. Working in partnership with parents

Knowledge

- Understanding of different models of family-centred and child-centred support
- Knowledge of the literature relating to family dynamics
- Knowledge of confidentiality and data protection issues
- Knowledge of Child Protection issues and related procedures

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[6] This paper refers specifically to professional support for the families of deaf babies, but many of the competencies defined are equally relevant for professionals working with deaf children and their families through the Foundation Stage (3-5)

Skills

- Ability to tailor support to individual family need including a range of cultural and minority ethnic perspectives and to respond flexibly to changing need
- Ability to communicate clearly in spoken and written mode
- Ability to work with interpreters to communicate effectively with families using British Sign Language or a spoken language other than English
- Ability to involve parents in forward planning and in the development of an agreed family plan to support the development of the child
- Ability to listen actively to parent's priorities and concerns and to respect the perspective of the family
- Ability to respect and support individual styles of parent-infant interaction
- Ability to build trust and demonstrate sensitivity to parents' feelings
- Ability to empower families and to build self esteem by transferring information and skills and encouraging families to recognise their ability to affect their child's development and progress
- Ability to view the infant's needs in the context of the family's needs and to encourage parents to adopt this perspective
- Ability to support families in recognising the child's strengths, the nature of any problems and the progress made
- Ability to act as an effective advocate on behalf of the child and family when this is required
- Ability to develop parents' confidence to communicate effectively with professionals in order to work in partnership and contribute to documentation

2. Early development

Knowledge

- Understanding of normal child development 0–2 in relation to psychological, social and behavioural development, motor development and cognitive function
- Knowledge of normal child development 0–2 in relation to interaction and play and understanding of the significance of developing interactive play for young children
- Knowledge of theories of language development
- Understanding of normal patterns of early speech, language and communication development (including pre-verbal stages and transition to symbolic language) in hearing infants
- Knowledge of early listening and attending behaviour and normal patterns of early vocal behaviour
- Understanding of normal patterns of developing communication in deaf families where British Sign Language is the language of the home
- Understanding of the relevance of cultural background to development
- Understanding of the potential effect of other disabilities when combined with deafness and awareness of the relevance of prematurity
- Understanding of the very early stages of development in the context of the Early Years curriculum
- Understanding of the theory and application of a range of communication approaches for deaf children under 5 and the implications for deaf babies and their families
- Knowledge of a range of effective techniques to facilitate the development of spoken language and communication

Skills

- Confident baby handling skills
- Ability to engage the interest of very young deaf infants and to use daily routines to encourage the development of language and communication
- Ease of interaction with very young hearing impaired infants and ability to promote language development through games, activities, play and songs
- Ability to work through the family and advise on and support the process of language acquisition
- Ability to model appropriate communication and play strategies
- Confidence in managing challenging behaviour from very young infants

3. Audiology

Knowledge

- Knowledge of screening, surveillance and audiometric principles and procedures appropriate for under 5s with particular emphasis on those for neonates and infants/babies (including Newborn Hearing Screening and associated protocols)
- Understanding of the process of identification and audiological profiling and ability to understand and explain the results of audiological investigation
- Up-to-date knowledge of local contacts for screening/assessment programmes and understanding of why it is important for families to attend follow up appointments
- Understanding of the consequences of false positive and false negative results
- Knowledge of basic procedures used in Special Care Baby Units
- Knowledge of the relationship between audiological techniques and a child’s developmental stage
- Awareness of the importance and significance of aetiological investigation and how such investigation should be organised
- Awareness of the factors affecting successful hearing aid fitting and management
- Familiarity with the range of technical aids/devices appropriate for deaf infants 0–2
- Awareness of new hearing aid technologies and assistive listening devices
- Understanding of the need for on-going monitoring of hearing levels to alert the family and professionals to any deterioration or fluctuation in hearing levels
- Knowledge of surgical interventions and assessment procedures for cochlear implantation and awareness of associated issues
- Confident knowledge of how to encourage development of auditory skills using hearing aids and/or cochlear implants
- Ability to explain the results of audiological assessment clearly

Skills

- Competence in managing amplification hardware with young infants (hearing aids, earmoulds, huggies, cochlear implant devices)
- Competence and sensitivity in supporting parents to develop confidence handling amplification hardware
- Ability to monitor progress in the use of hearing aids
- Accurate observation/recording of developing hearing function

4. Deafness

Knowledge

- Knowledge of the causes of deafness in babies and young children
- Knowledge of the nature of different types of hearing loss
- Knowledge of likely impact of different degrees of deafness on the development of spoken communication and social and cognitive development
- Knowledge of the impact of age of diagnosis and first hearing aid fitting/start of habilitation on subsequent development
- Understanding of the diversity to be observed within the population of deaf adults and of the relevance of equal opportunity and disability rights issues
- Understanding of Deaf culture and up-to-date knowledge of local organisations for deaf people
- Understanding of the importance of facilitating contact between the families of deaf infants and a range of deaf adults
- Basic knowledge of British Sign Language

Skills

- Ability to communicate informed, balanced and realistic expectations about the challenge of deafness
- Skill in encouraging positive attitudes towards deafness
- Sensitivity in encouraging early contact with other families with deaf children and deaf adults following confirmation of deafness in an infant
- Ability to communicate effectively with deaf adults

5. Providing information

Knowledge

- Understanding of the importance of clear written materials to support verbal information given to parents in the early stages of a child's development
- Awareness of the need to provide information in a range of written languages and through British Sign Language in response to individual family need
- Knowledge of family dynamics and of the importance of pacing the information provided to parents
- Knowledge of how to inform parents' expectations of child development including the development of spoken language and/or British Sign language

Skills

- Effective interpersonal/communication skills and an ability to respond flexibly to a range of information needs in different families
- Ability to provide and reinforce information with sensitivity to families under stress or in shock
- Confidence in explaining the basis for suggestions/advice given to parents
- Ability to explain a range of test results and their possible implications in an accessible way
- Ability to produce paper format materials for parents in Plain English and to recognise when translation into another language is required
- Ability to inform while giving choice
- Ability to build trust and become a reliable source of information and advice without encouraging a dependent relationship

6. Providing emotional support

Knowledge

- Knowledge of a range of models of counselling and their application and limitation in relation to supporting families of deaf children under 5

Skills

- Ability to support parents emotionally and socially as they adjust to confirmation of permanent deafness in their child
- Ability to support parents when a diagnosis of deafness is equivocal
- Ability to encourage families to develop coping strategies and to find support systems outside the immediate family
- Ability to combine recognition of professional boundaries with empathy and support
- Competence in managing workload when a quick response is required (for example at the time of a new referral)

7. Monitoring progress

Knowledge

- Familiarity with an array of assessment instruments and monitoring techniques appropriate to deaf children 0–2
- Understanding of the importance of video-tape analysis in monitoring and developing parent-infant interaction
- Knowledge of protocols for statutory assessment leading to a statement of special educational need

Skills

- Confident use of appropriate assessment instruments and techniques to monitor speech, language and communication development
- Ability to observe adult-infant interaction and to use these observations constructively
- Ability to observe and record an infant’s non-verbal behaviour accurately
- Ability to interpret the results of a range of assessment procedures appropriately and to produce clear reports for parents and others
- Ability to use observation/other information to frame learning goals and to inform the development of an appropriate framework for development- in particular an individual programme for the development of communication/listening skills

8. Managing/co-ordinating service delivery to families

Knowledge

- Understanding of the roles, skills and responsibilities of all the professional groups and statutory services working with deaf children under 5 and their families
- Familiarity with local processes for referral to other agencies (for example for developmental assessment and genetic counselling)
- Awareness of the importance of visual development for deaf children and local arrangements to screen vision

- Knowledge of the activity of national organisations representing deaf people in the voluntary sector and contact details for local support groups provided by such organisations
- Understanding of how to deliver a co-ordinated service to children with multiple disability
- Up-to-date knowledge of the range of educational provision available for deaf children from 5
- Ability to audit service delivery to the families of young deaf children

Skills

- Ability to work as a member of a team comprising other professionals and voluntary agencies to provide a seamless, family friendly service
- Confident understanding of those aspects of case work that fall outside their own professional remit

Appendix 2: Sample questionnaire for families

Question 1

How regularly did you have contact with your HI/VI/MSI teacher this year? ☐

From your point of view, was this:

Too often ☐ About right ☐ Not often enough ☐

Question 2

Overall, how would you rate the Service you have received in terms of …

	Excellent	Good	Satisfactory	Not very good
How easy it was to get help and support when you needed it?	☐	☐	☐	☐
How fast the service responded to enquiries?	☐	☐	☐	☐
How approachable staff seemed?	☐	☐	☐	☐
How reliably people turned up when they said they were coming?	☐	☐	☐	☐
How well support was organised?	☐	☐	☐	☐
How well people communicated with you and kept you informed?	☐	☐	☐	☐

Any additional comments?

Question 3

How would you rate the quality and usefulness of the information/advice you received?

Very useful indeed ☐

Quite useful ☐

Useful ☐

Not as useful as I would have liked ☐

Not useful at all ☐

Any additional comments?

Question 4

Did you feel your support teachers were working in partnership with you?

Yes ☐ No ☐

Why did you feel this?

Question 5

If you used Action Plans with your support teacher, did you find them useful?

Yes ☐ No ☐

Any additional comments?

Question 6

Have you met other families with deaf children during your child's pre-school years through the Service pre-school facilities?

Yes ☐ No ☐

Any additional comments?

Question 7

If you did not meet up with other families, were you given the opportunity?

Yes ☐ No ☐

Did you meet deaf adults if you asked to do so?

Yes ☐ No ☐

Any additional comments?

Any other suggestions for how we could improve the service?

Please write them overleaf.

Note: This sample developed from materials used by a number of LEAs

Appendix 3: Performance indicators

Activity	Standard	Yes	No
Referral to LEA service	All families contacted and offered support within 48 hours of referral to service. All families visited within 1 week of referral to service.		
Family support	All families offered home visit programme on referral to service. Regular visits made by teacher of the deaf according to assessed criteria. 90% allocated visits made by teacher of the deaf within 39 week year. All emergency call outs from caregivers answered within 24 hours by phone or visit. Emergency call outs and support to newly diagnosed children provided through 52 week year.		
Information	All families given information pack on initial visit. All parents provided with information on: ■ Language development ■ Listening development ■ Communication options ■ Hearing aids ■ LEA service provision for deaf children ■ Educational placement options outside LEA ■ Useful toys and books ■ Voluntary organisations and other relevant support services ■ Social Services		
Hearing aid and radio checks	All hearing aids checked using a hearing aid analyser (test box) once per month Listening tests and earmould check at each home visit. All children with an average hearing loss >45dB offered use of a radio aid. All severely and profoundly deaf children offered use of auditory trainers in the home. All families supplied with a set of accessories to maintain any equipment used at home.		

Activity	Standard	Yes	No
Assessment of developing language and communication	Baseline video record of child within 6–10 weeks of initial referral. Video record of child with caregiver(s) once every 6 months Development in child assessed every 6 months with families following agreed guidelines.		
Meeting other families	All families given information about the LEA service group and invited to attend. All families given information about National Deaf Children's Society and local NDCS group		
Family support group MSI	All families with children with multi-sensory impairment given information about the group and invited to attend. All families given information about SENSE and local SENSE support Transport with disabled facilities offered where possible		
Supporting other professionals	Information and support offered to child minders working with early identified deaf children? Information offered to Health Visitors visiting the families of early identified deaf children? Information and support offered to Playgroup or Nursery School staff?		
Professional development programme	Professional development needs of teachers working for the LEA service audited once per year Range of training opportunities for teachers working with very young children and their families provided locally/regionally Accredited training for staff working with this population funded when requested Training opportunities provided locally for LEA staff with professionals from Health and Social services		

Note:

This sample compiled from examples used by Shropshire & Wrekin and Staffordshire, and items on the Deaf Early Education Services Index (DEESI)

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