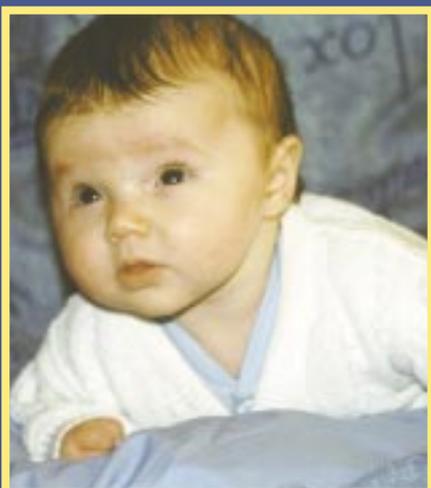




Quality Standards in the

Early Years:

Guidelines on working
with deaf children
under two years old
and their families



Quality Standards in the Early Years:

Guidelines on working
with deaf children
under two years old
and their families

The National Deaf Children's Society
15 Dufferin Street, London EC1Y 8UR

NDCS Helpline: 020 7250 0123 (voice & text)
Open Mon-Fri 10am-5pm

E-mail: helpline@ndcs.org.uk

Website: www.ndcs.org.uk

Fax: 020 7251 5020

Switchboard: 020 7490 8656 (voice & text)

ISBN 0 904691 66 7 January 2002

Front & back cover photos: Second from top © Neil Phillips
Second from bottom © Dave Higgleton
Bottom © Anne Holt

Contents

		page
1.	Targets	4
2.	Introduction	5
3.	Partnership with families	6-8
3.1	Key principles of working in partnership with families	6
3.2	What do families want?	6
3.3	Supporting families	7
3.4	Family-friendly hearing services	7-8
4.	Communication with families	9-12
4.1	The provision of information	9-10
4.2	Communication during the screening process	10
4.3	At the time of confirmation of deafness	10-12
5.	Working with families	13-25
5.1	Positive about deafness	13-14
5.2	Communication and language	14
5.3	Early years support	15-16
5.4	Multi-disciplinary working	16-18
5.5	The role of the key (link) worker	18-19
5.6	Education support in the early years	19-21
5.7	Audiological support in the early years	21-23
5.8	Support from social services	23-24
5.9	Support groups and voluntary organisations	24
5.10	Deaf adults	24-25
5.11	Assessments	25
6.	Developing partnership in the strategic management of services	26-27
7.	Acknowledgements	28
8.	Appendix I	28
9.	Appendix II	28
10.	References	29-30

1. Targets

"It would be good right from the start, to have access to a co-ordinated team of different professionals who could supply parents with up-to-date, impartial information, but also allow families to make their own decisions about how they communicate with their child, which hospital they attend and where their child goes to school."

Parent's comment

"Identification of deafness by six months of age, followed by appropriate intervention is the most effective strategy for the normal development of language in deaf and hard-of-hearing infants and toddlers."

(Yoshinaga-Itano, 1998)

More than two children a day, or 840 children a year, are born in the UK with significant permanent deafness. Until there is full implementation of universal newborn hearing screening (UNHS) throughout the UK, later diagnosis of deafness will have a significant adverse effect on the lives of deaf children and on their ability to develop fluent language skills in order to understand and influence the world around them.

The National Deaf Children's Society (NDCS) believes that parents have the most important influence on their deaf child's life. Parents have a right to know that their child is deaf at the earliest opportunity allowed by diagnostic techniques.

Therefore the NDCS believes that by April 2004:

There must be nationwide introduction and full implementation of universal newborn hearing screening so that all babies born with deafness are identified and supported within the first weeks of life. There must be sensitive follow-up care and appropriate support available across the UK for every deaf child and their family.

By April 2004:

All early years support services in the UK must be well co-ordinated and provided by well trained, qualified and skilled early years support workers who facilitate parents' ability to enable their babies to acquire the best language and communication skills they can through the mode(s) of communication chosen by the parents.



2. Introduction

The National Deaf Children's Society (NDCS) is an organisation of families, parents and carers which exists to enable all deaf children and young people to maximise their skills and abilities, and works to facilitate this process by every possible means.

At the NDCS annual conference in June 2000, the Health Minister John Hutton announced, on behalf of Yvette Cooper, Minister for Public Health, that the Department of Health had commissioned a pilot of universal newborn hearing screening (UNHS) in twenty health authorities in England. Following the outcome of this pilot, which is known as the newborn hearing screening programme (NHSP), it is anticipated that there will be nationwide implementation of UNHS. This document will be reviewed in 2004 following the evaluation of the NHSP.

The implementation of UNHS will have considerable implications for all services supporting very young deaf babies and their families. UNHS provides the opportunity for services to examine existing practice and explore ways in which services can be developed to ensure that all newly diagnosed deaf babies and their families receive the appropriate support to meet their individual needs.

A culture of service evaluation and continuous feedback, including the views of parents, families and service users, is critical to the development of good quality early years support services. Services must be capable of adapting to changes in technology and changes in other related services. The best quality services will have a culture of learning continuously from families, children and service users.

This document provides parental perspectives, positive guidelines and quality standards to enable providers of health, education and social services, as well as the voluntary sector, to deliver appropriate and effective support for deaf children from birth to two years of age and their families.

These quality standards complement the NDCS *Quality Standards in Paediatric Audiology - Guidelines for the early identification and the audiological management of children with hearing loss, Volume IV* (2000) and should be used in conjunction with that document and with the NDCS *Quality Standards in Education - England* (1999), which sets out recommendations for education services working with very young deaf children and their families.

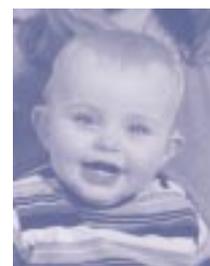
The NDCS uses the word 'deaf' to mean the full range of deafness. The phrase 'all deaf children' includes children with additional needs, from minority ethnic communities and from families that find it difficult to gain access to services.

The NDCS believes that services must develop strategies to support all deaf children and their families. Such strategies must include children with mild, fluctuating, sudden, progressive, late onset, or unilateral deafness and also children with auditory neuropathy (ie children who have normal peripheral hearing but who may have neurological deficits resulting in central auditory processing disorders).

This document uses the words 'parent' and 'family' to include the child's carer with parental responsibility.

The abbreviation 'QS' is used throughout to define quality standards that must be implemented, monitored and audited.

This document has been developed for health, education and social services and the voluntary sector in England. However the principles, practices and quality standards that are discussed in this booklet can also be applied in Wales, Northern Ireland and Scotland. Versions of this document for these three countries are due to be published in 2002/2003.



3. Partnership with families

"The chief reason why parents should be regarded as equal members of the team that cares for their deaf child is that they spend most of their time with their child and, arguably, are the most committed to their child's development."

Parent's comment

3.1 Key principles of working in partnership with families

Through its ongoing work with families of deaf children, the NDCS has identified a number of key principles to working in partnership with families.

Rights and responsibilities

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

Respect

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

Informed choice

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

Individuality

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

Equality

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

3.2 What do families want?

Services must be responsive to the needs of every deaf child and their family if the support provided is to be effective. In 1999 the NDCS asked parents about the effects of late diagnosis, and in 2000 a questionnaire was distributed to parents to gather their views on UNHS.

The outcome of this research showed that parents identified the following issues as being of primary importance for the provision of quality services for deaf children and their families. These were:

- early accurate diagnosis in an appropriate setting;
- the need for clear, accessible and balanced information on language and communication, children's development, parental support groups and additional sources of support;
- time with professionals to understand the implications of deafness;
- early follow-up appointments;
- well-trained and qualified staff who are deaf aware and who have empathy with, and an understanding of the child and their family;
- a positive encouraging attitude towards deafness;
- respect for the child and the child's family;
- co-ordination between services to eliminate conflicting advice; and
- long term, local quality services and support.

Two of the most important issues arising from these surveys were that families want unbiased information and qualified, experienced professionals who respect them and their child.

Supporting families

"Professionals working with parents of deaf children have a responsibility to foster and support partnership and empower parents to achieve their aspirations for their child."

(NDCS Quality Standards in Education - England, 1999).

"The family has the most direct influence on any child during his early years, and we need to therefore direct our resources to parents if we are to influence the child through his waking hours, rather than just for an hour's duration of our visit."

(McCormick, 1975)

The primary aim of all services must be to work in a child and family-centred way. Specific objectives of working with families should be to:

- empower parents to make decisions for themselves and their deaf child;
- enable them to communicate effectively with and support their deaf child;
- encourage open communication and mutual support within the family;
- enable parents to find their own support systems;
- help them to communicate with professionals in order to work in partnership;
- provide social and emotional support;
- enhance their confidence;
- increase their feelings of success;
- help them to explore their situation; and
- foster independence.

(adapted from Davis, 1993)

QS All services (health, education and social services) must develop a local joint written policy on working with all families with a deaf child in the locality covered. Parents of deaf children must be involved in the development and review of this policy.

Family-friendly hearing services

Family-friendly hearing services (FFHS) are at the core of good early years support services for deaf children and their families. The principles set out below apply to services provided by health, education and social services, as well as the voluntary sector. Crucial features of FFHS are the recognition that:

- families are all different;
- families and professionals should work in partnership, and that there should be partnership between agencies;
- families have a right to accurate, up-to-date and comprehensive information;
- families deserve continuity of care;
- the attitude of professionals should be characterised by listening;
- the family-professional dialogue should be undertaken in appropriate language;
- FFHS should be responsive;
- when a family cannot go to the FFHS, the FFHS should go to the family;
- family representatives should be involved in the strategic management of FFHS;
- the physical environment of the service should be family-friendly; and
- meeting the needs of the family is more important than adhering to targets and standards.

(Baguley, Davis & Bamford, 2000)



QS All service providers must be aware of the principles of FFHS and develop written local protocols based on these principles.

The family-friendly approach should permeate all services that support deaf children and their families. The value of working in partnership with parents is that service users' views will reveal the real requirements of good quality FFHS.

FFHS must provide hearing screening programmes, and authoritative paediatric audiology services, that work in partnership with the family, health, education and social services, as well as the voluntary and private sector services (NDCS *Quality Standards in Paediatric Audiology, Volume IV, 2000*).

QS Service providers must carry out an annual audit to evaluate the effectiveness and family-friendliness of their services, as well as identifying and implementing changes to improve service provision. As part of this audit, the views and experiences of parents of deaf children must be gathered.



4. Communication with families

"One often hears the distinction made between 'parents' and 'professionals' as if they are opposites – as if parents are not professional (or professionals) and professionals do not admit to being parents. The distinction tends to undervalue the role of parenting and elevate the status of the professional. It is a distinction that mothers of small children, who often lack confidence, will really buy into. It would be good if there were some way of avoiding the term 'professional'.

Parent's comment

Effective two-way communication with families and following their lead is critical to enabling parents to remain in control. Parents have the right to make decisions about their child's support and care and to expect that early years support workers will acknowledge their expertise.

4.1 The provision of information

"After they told me my baby was deaf, I had lots of questions. I knew nothing about deafness. I thought how can I support my child when I know nothing. Then I thought he is my baby and I am his mother and I will learn everything I need to know so that I can be the best mother I can. What I needed then was information. Then I realised I didn't know where to get this information from! I mean how do you ask for things you don't even know exist? It was a difficult process and I often stumbled across information by accident. There must be an easier way."

Parent's comment

QS Information given to families must be unbiased, comprehensive, clear, accessible and accurate. Parents must receive all information in their preferred language, and have equal access to their preferred forms of information. This could be written, verbal, video or audiotape.

Parents have a right to information so that they can make informed choices with regard to the health and educational support they consider to be the most appropriate for their deaf child.

As well as information on choices, rights and procedures, parents also need to be able to develop the skills to put these into practice. Where necessary, early years support workers specialising in deafness in very young children (see section 5.3), must empower parents to gain the skills they need to obtain, use and evaluate information.

User-friendly information for families with disabled children: a guide to good practice (Mitchell & Sloper, 2000) highlights the following as good practice when providing information to families:

- short guides that include essential local information;
- in-depth booklets that describe the range of support and services available; and
- support from locally based 'facilitators' or 'key workers'. It is often assumed that if written information is produced and disseminated to parents, they will be able to inform themselves and then act on this information. However, families who took part in the development of this guide also explained that they wanted someone to support and guide them.

QS Staff must be able to organise and provide support for the linguistic preference of parents, such as the provision of interpreters.



QS All staff must be trained in cultural and religious diversity, and have had deaf and disability awareness training.

4.2 Communication during the screening process

Screening babies for deafness can be a time of considerable parental or maternal anxiety. To minimise anxiety, screening programmes must be designed so that they can identify and respond immediately to the needs of parents, such as their linguistic preference. Clear information, positive attitudes, and reassurance from professionals emerge as the key elements in preventing anxiety experienced by parents during the screening process (Young & Andrews, 2001).

QS Parents must be given information about the screening process in advance. At the time of screening they must have the opportunity to ask questions and seek clarification.

The introduction of UNHS creates a need for clear, accessible and graduated information that is available to all parents going through the screening process. The Department of Health commissioned the NDCS to produce a series of information leaflets to be given to parents at each stage of the screening process. These leaflets will be used by all areas involved in the NSHP (see page 28 Appendix I).

QS All staff must have an understanding of national and local strategies and protocols for UNHS information provision.

4.3 At the time of confirmation of deafness

Confirmation of deafness is a process that takes place over a period of time. However when parents are first told that their baby is deaf, the language used by professionals and how they inform parents is critical. The way in which it is approached may affect the provision of all subsequent support, and will influence the speed, if not the extent, to which parents develop future strategies (Davis, 1993).

Many parents can recall exactly what happened and how they felt when they were first told that their child was deaf.

"All parents cope differently, and we were devastated at the news. We hadn't got a clue what it meant (our child being deaf). We couldn't absorb the information they gave us. We needed a follow-up appointment a few days later so that we could ask a list of questions."

"I feel the givers of any diagnosis should have good counselling skills, and there should be a follow-up team from social services, health, education and voluntary support. Everyone needs to know how this diagnosis affects families, and the impact on parents initially and on the child long-term."

Parents' comments

QS Health and audiology services must develop guidelines for staff on how confirmation of deafness is given, when and where this should happen and who should tell parents that their child is deaf.

At the time of confirmation, services must be able to adapt to the needs of individual families. Knowledge, understanding and implementation of good practice are fundamental to making sure that families do not undergo unnecessary stress and anxiety.

A very useful resource when considering what is good practice when working with parents is *Parent guidance: the needs of families and of the professional worker* (McCormick, 1975). McCormick highlights the following issues:

- awareness of the stages and the varieties of reaction to the child's deafness is important;
- uncertainty is a great source of emotional distress for families; and
- the indiscriminate use of words by professionals can be upsetting.

QS All services must ensure their staff are trained to communicate appropriately, sensitively and effectively with families, particularly at critical times such as the time of confirmation of deafness.

QS At the time of confirmation of deafness there must be a professional present who is already known to the parents. Such professionals must have the time to share the news with the family. In addition, the member of the early years support team who is likely to become the family's key (link) worker should be present.

Sharing the news: good practice, procedures and training for informing parents of a diagnosis of a child's impairment (Thameside Community Healthcare NHS Trust, 2000) is a practical guide for professionals. It examines the issues which should be considered when informing parents that their child is deaf. The key points include:

- too many people can be overwhelming and frightening;
- parents should feel in control of what happens;
- parents need someone to talk to about their concerns;
- up-to-date information for parents on services and parents' groups should be available; and
- good liaison with GPs and health visitors is important.

Right from the start (Leonard, 1999) also highlights a number of issues to consider at the time of confirmation which include:

- parents prefer not to be told alone and may need the support of their partner, a friend or relative;
- where one parent is told separately, arrangements will need to be made as to how the other parent and family members will be told;
- the professional giving the news should be known to the parent; and
- parents should have some initial information to take away with them.

QS Parents must be given accessible information that they can take away with them at the time of confirmation. This must include details about who will be contacting them, when this will be and where they can obtain further information and advice.

Professionals should reflect on their practice at the time of confirmation of deafness, as well as other consultation and appointment times (Shaw, 1973). The following are some examples of key questions to ask.

- Did I put the parent at ease?
- How did I cope with anxiety/hostility?
- Did I listen well?
- Did I begin to see any problem from the parent's point of view?



- Did I clarify confused ideas?
- Did I go at the parent's speed?
- Did I provide relevant factual information when required?
- Did I give the session a pattern or framework?
- What skills do I need to develop most?

"I remember when we were told A was deaf. She was only a few weeks old and we'd been back to the clinic for a few tests so we thought something wasn't quite right. Even though we had started to suspect we still weren't ready for the news, although the audiologist who told us was great. Looking back now I imagine it wasn't easy for them, but they were honest and we could ask questions and when we left the hospital we knew our world was different, but we also knew we were going to get all the help and support we needed."

Parent's comment

QS The early years support services must be available immediately after deafness is confirmed. Early years support and education services must be informed of a child's confirmation of deafness within one day.



5. Working with families

"Parents hold key information and have a critical role to play in their child's education. They have unique strengths, knowledge and experience to contribute to the shared view of a child's needs and the best ways of supporting them."

(Special Educational Needs Code of Practice, DfES, 2001)

QS Parents must be fully involved in deciding on the support and intervention for their deaf child, as well as monitoring and evaluating the effectiveness of this provision. Service providers must develop guidelines on how to involve parents, paying particular attention to barriers that may impede involvement, such as language and culture.

"There should be no presumption about what parents can or cannot do to support their child's learning."

(Special Educational Needs Code of Practice, DfES, 2001)

Parents must be recognised as the first and primary educators of their children. When they are told that their child is deaf most parents may not know about the implications of deafness on language, communication, social and emotional development. Professionals working with families in the early years have a duty to enable parents to develop the knowledge and skills needed to support and encourage their child's development.

5.1 Positive about deafness

"My baby was premature and there were many complications. When they told us she was deaf they made it sound like her future would be very bleak, we were just pleased she was alive. But it didn't stop there, nearly everyone we talked to showed us a lot of sympathy. What we really needed was a can-do attitude."

"(From a deaf mum) When D was diagnosed we were expecting him to be partially deaf – we were not expecting him to be profoundly deaf. We had no problem accepting his deafness. But the professionals treated us as hearing parents. They apologised for his deafness by saying sorry. It was very negative. How did they think we would feel being deaf ourselves?"

Parents' comments

"The NDCS believes that if support is given and positive attitudes are fostered, the challenge of deafness can be a rewarding experience for deaf children and their families".

(NDCS Visions and Values)

The majority of deaf babies are born to hearing parents with no previous knowledge or experience of deafness. This means the process of learning about deafness and trying to understand what this means for their child and family will initially be new to most parents (Young, 1999).

How deafness is presented to parents will influence their understanding as well as their expectations for their child. Early years support staff have a duty to ensure that deafness is not presented as only a medical or scientific issue and that they are positive in their approach to deafness.

"Early in a child's life, a parent will attribute meaning to being 'deaf'. That interpretation will have an impact on parental feelings and interaction with the child."

(Medwid & Weston, 1995)



There are two main models by which deafness can be understood, the medical and social models. The medical model sees deafness as an impairment. Deafness is therefore a medical condition and the appropriate response is to intervene and try to find a cure. This means the focus will be the child's deficient hearing, and this can be at the expense of seeing the whole child and their world. With this model, there tends to be emphasis on doing as much as possible to adapt the deaf child to the hearing world.

The social model of disability can also be applied to deafness. This approach sees society as disabling, rather than the individual's impairment. The deaf person is disabled or disadvantaged only because society does not make proper provision for deaf people. Therefore society needs to change to ensure that deaf people can access the world around them.

There is another approach that is linked to the social model and is the one favoured by many within the Deaf community. This sees deaf people as a cultural and linguistic minority whose language (British Sign Language) and cultural norms are as valid as those of any minority ethnic group. This approach compares deafness to being Welsh, for example, rather than to disability (Gregory, 2001).

Professionals working with families must create opportunities for families, so that they can develop their knowledge of the culture and history of deaf people, as well as an understanding of the diverse nature of the deaf community. This will mean actively engaging with deaf professionals, deaf families and others able to provide this perspective. It is important that deaf babies and children have access to peers who are also deaf.

QS All early years support workers must receive training that will enable them to communicate positively about deafness. This training should include information on the different models of deafness, as well as learning about how the use of these models can impact upon the deaf child and their family.

5.2 Communication and language

"Deaf children need to develop fluent language skills in order to understand and influence the world around them, by whichever approach is the most appropriate for the individual."

(NDCS Visions and Values)

Parents need to be able to choose a communication method that is in the best interests of their child and that enables their child to influence their environment, express their feelings and concerns and participate in the world of imagination and abstract thought. The child's communication method should promote enjoyable, meaningful communication amongst family members, enabling the child to be part of the family and to know what is going on around them (Colorado Department of Education & Colorado Families for Hands and Voices, 2000).

QS Professionals working with the deaf child and their family must provide unbiased and accurate information on all communication methods.

This will enable the family to decide which approach to communication will best suit their child and the wider family. The parents' choice of communication method for their deaf child should be respected and supported by professionals working with the family. Early years support workers and service providers have a duty to ensure that subsequent provision and support provided to the family is of a high quality and effectively delivered.

Early years support

"When parents first find out that their child is deaf, it is at that point some initial help and advice must be offered. Here an appointment should be made for the parent/guardian in a few days time to discuss what the child might be offered. Groups/individuals should be made available for the parents. There should be dates and plans of future meetings/counselling/help."

Parent's comment

"A primary goal of early intervention should be to 'empower' parents to advocate effectively, make decisions and solve problems for themselves."

(Bailey, 1987)

The family, at and immediately following the confirmation of deafness, must be provided with unbiased information, along with co-ordinated, immediate and easy access to FFHS. This support should be available all year round and for as long as the family needs it. Services should be able to address the needs of diverse families such as working parents, single parents, low-income families and families from minority ethnic communities.

QS Services must be flexible and available at times that suit families, such as at evenings and weekends.

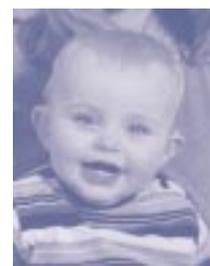
If professionals are to meet the needs of families it is important that they assess and understand these needs. The Bailey and Simeonsson (1988) survey, which has been adapted for use in the UK (Dalzell, 2000), categorises family need in terms of need for information, support, community services, financial need and any other identified needs.

"The goal of early intervention is to strengthen parental confidence and skills as they learn about hearing impairment. Parents must be at the centre of each early language session and be given information, skills, techniques and access to resources in order to make informed choices about their child."

(Stokes, 1999)

Parents are the best facilitators for encouraging their child's language and communication development. They will be best supported in this by a team of early years support workers specialising in deafness in very young children. Members of this team will come from a variety of backgrounds, for example:

- teachers of the deaf
- specialist speech and language therapists
- social workers
- health visitors
- paediatric audiologists
- educational audiologists
- child health doctors and other medical specialists with paediatric skills
- occupational therapists
- other parents
- voluntary sector workers



QS Early years specialists must be trained in:

- working in partnership with parents;
- working in partnership with other professionals;
- deafness;
- early child development;
- the development of language and communication;
- audiological support;
- emotional support and counselling skills;
- providing accurate and unbiased information;
- monitoring progress;
- managing/co-ordinating service delivery to families; and
- multi-professional working.

(RNID/NDCS Statement of professional competencies, 2000)

Audiology, education and social services must know the agreed national and local policies on service provision for very young deaf children and their families. Local services must ensure that the family is given every opportunity to discuss and explore issues relating to their child's deafness.

Local services must:

- promote equal opportunities for each deaf child supported by the service;
- ensure each deaf child has the opportunity to develop their full potential;
- raise awareness of deafness with the child's family and peer groups; and
- encourage opportunities for each deaf child and their family to meet other deaf children and their families and deaf adults.

5.4 **Multi-disciplinary working**

"I don't know why, but each time we went to see a professional I had to start from scratch and tell my story and explain what the other professionals had told me. Surely there must be a way of sharing information so time isn't wasted going over the same things time and time again."

Parent's comment

Following confirmation of their child's deafness, most parents will have contact with many different professionals from a range of services. Well co-ordinated and seamless services will help to ensure that families receive coherent and consistent support.

QS The consent of parents must be sought in relation to the sharing of reports and information between professionals. Parents must know to whom information about their deaf child and family is given.

Good quality early years support requires an open-mindedness towards the parent-professional relationship and a serious commitment to multi-disciplinary collaboration.

QS A true multi-disciplinary team must include parents and named individuals from all services, supporting the deaf child.

QS In order to work in a multi-disciplinary way, early years support teams must agree protocols for referrals, recording and sharing information, as well as planning, delivering and reviewing support to families and assessing deaf children.

Multi-disciplinary working can help professionals to become aware of the changing needs of very young deaf children and their families. This can help to ensure that the necessary support is set in place without delay.

In the very early years multi-disciplinary working is likely to include the following:

a. Planning and reviewing

Joint planning by professionals and parents is a crucial aspect of multi-disciplinary working. For planning to be effective, information must be available about the support provided by each service and how this support is accessed. Information must be shared between members of the team to avoid duplication and to aid communication. Parents and professionals must be able to discuss and agree on what support will be provided, how it will be provided, by whom and when it will be reviewed.

b. Assessments

Professionals involved in assessing a deaf child need to work closely together and with the child's parents. As with planning, a co-ordinated approach to assessments will ensure information and outcomes are shared with all of those within the team, including parents.

c. Joint visits and appointments

One key aim of multi-disciplinary working must be to reduce disruption to family life. Clear communication between agencies will reduce the number of meetings and appointments that parents have to attend. It is vital that families are not inundated with different professionals visiting the family home. Joint visits and appointments are examples of how this can be achieved.

There are many benefits of multi-disciplinary team working for professionals such as:

- it avoids duplication;
- interventions are made at the right time and can be assessed regularly to respond to the changing needs of the child and/or family;
- information is shared and communication improved;
- professionals learn from each other and about each others roles;
- the team can provide a supportive knowledgeable framework for making difficult or complex decisions;
- parents' knowledge and expertise is valued; and
- it creates opportunities to monitor and evaluate services and support, in a co-ordinated and consistent way.

QS In order to allow teams to work in a multi-disciplinary way, local health, education and social services must:

- have shared funding and resources;
- meet at least twice yearly;
- engage in multi-disciplinary training to develop good working relationships and good communication between agencies;
- have well-trained and experienced staff;
- develop compatible IT systems; and
- allow adequate staff time to collaborate on joint working and planning.



The two main challenges associated with multi-disciplinary working have been identified as funding and resources. Other major issues include the time involved in setting up initiatives, the subsequent work involved in implementation and the time needed to develop relationships with other agencies. The time spent working in a multi-disciplinary way is worthwhile in terms of future timesaving and improved working practices (Atkinson, et al, 2001).

Commissioners and providers of services must recognise that support for the deaf child involves health, education and social services. The *Health Act (1999)* enables health, education and social services to pool funds with integrated provision of services that can focus on the needs of the deaf child and their family.

5.5 The role of the key (link) worker

"Parents should be offered an advocate at diagnosis whose interest is the health, well-being and education of the deaf child."

Parent's comment

"Parents will need different levels of support according to circumstances and their confidence in dealing with complex procedures. Although some parents will be able to take advantage of opportunities to advocate for themselves, others may need further support to enable them to access the information and services."

(NDCS Quality Standards in Education - England, 1999)

QS There must be one key (link) worker responsible for co-ordinating the early years support services for the family, even though the responsibility for early years support may need to be shared.

Research has shown that families who have a deaf or disabled child report a common set of difficulties which include:

- trying to get professionals to understand their situation and their needs;
- recognition of their own knowledge of their child;
- finding out what services are available;
- gaining information about the roles of different services and professionals; and
- tackling bureaucracy and delays.

(Social Research Policy Unit, 2000)

QS The family must be informed about how they can contact their key (link) worker and to whom that role has been delegated if the key (link) worker is not available. The key (link) worker must be accessible to the family all year round.

In addition to the above, the NDCS survey on UNHS highlighted that families wanted a person to provide them with unbiased information, to offer advice and guidance in relation to their child's development and to put them in contact with other parents.

The key (link) worker will play a fundamental role in providing support to the family and acting as an important link between parents and professionals. Families must be involved in deciding who their key (link) worker will be. It is also vital that families know how they can request a change of key (link) worker, should the need arise.

QS Regardless of who becomes the family's key (link) worker they must have:

- specific training in working with pre-school age deaf children and their families;
- knowledge of local and national services for deaf children and how to access them;
- skills in presenting information without bias;
- knowledge and understanding of different communication methods;
- the ability to fully support a family in their choice of communication method;
- knowledge of who the key professionals working with the child and family are and how to contact them;
- counselling, communication and negotiation skills; and
- be able to introduce families to other families with deaf children and to deaf people.

A resource pack: *developing a key worker service for families with a disabled child* (Social Policy Research Unit, 2000) identifies a number of core elements of the key (link) worker's role, which are:

- **pro-active, regular contact**
Families are all different and so the amount of contact they will have with a key (link) worker and what form this contact takes, will need to be discussed and agreed between the family and the key (link) worker.
- **a supportive, open relationship**
- **a family-centred as opposed to a child-centred approach.**
Visiting the family at home can provide the opportunity for the key (link) worker to learn more about the family and meet with other family members.
- **working across agencies**
When a family has just learnt about their child's deafness the key (link) worker will have a very important role to play in providing them with information about the range of services available and how these services are accessed, as well as advocating for the family.
- **working with families' strengths and ways of coping**
Support offered to a deaf child and their family should be tailored to meet their individual needs. Key (link) workers will need to discuss with the family the support they wish to receive.
- **working for the family and not the agency**
The key (link) worker must be able to fully represent the interests of the deaf child and their family. This will mean the key (link) worker will need to have a level of autonomy necessary to act independently of any service.

5.6 Education support in the early years

"When the consultant told us K was deaf he also said that someone from the education service, probably a teacher of the deaf, would contact us soon. Although we had lots of questions about deafness and K's future we also thought well, he's only 6 months old what would he need a teacher for! Actually the teacher of the deaf spent time with me and my partner, giving us information, answering our questions and generally being very supportive. She gave us chance to make decisions for ourselves, as well as explaining things we could do to help K's communication to develop."

Parent's comment

The NDCS *Quality Standards in Education - England* (1999) sets out a number of recommendations for education services working with very young deaf children and their families. The following section should be seen as supplementary to this document particularly the chapters on 'Early Years Services and Provision' and 'Working with Parents'.



The Government's Green Paper *Excellence for all children: meeting special educational needs* (DfES, 1997) highlights the importance of early identification and appropriate intervention to improve the prospects of children with special educational needs. This has been reinforced through the *Special Educational Needs Code of Practice* (DfES, 2001) which places emphasis on working with parents, the early identification of children with special educational needs and the importance of early intervention.

The NDCS believes that education services for deaf children must start from the point of confirmation of deafness.

QS When a local education authority receives a referral that there is a deaf child under two years of age in the area, they must ensure that the family is contacted by a relevant educational professional, usually the teacher of the deaf, within one working day.

QS Following the initial contact, families must be visited by someone from the early years or education support service within two working days. The frequency of subsequent visits must be agreed with the family. However families must be offered a minimum of one visit per week.

"Parents should be consulted about the nature of the support they would like to receive. Some may prefer to attend a centre or to combine home-based with centre-based support.

(Special Educational Needs Code of Practice, DfES, 2001)

Parents must be given information about the range of educational support available including statements of special educational needs. This should include details about how to request a statutory assessment, how they can contribute to the process and where they can go for further information and advice.

QS Early years support teams must draw-up an individual programme of support for each deaf child. Parents must be involved in deciding the content of their child's programme. Such programmes must detail the aims of the support, when and how the support will be delivered, by whom, the role of the family and when it will be reviewed. These programmes must also specify the level of support from the relevant professionals involved, such as the teacher of the deaf.

Evans & Robinshaw (1999) found that teachers of the deaf are the main providers of pre-school educational support to deaf children and their families. The teacher of the deaf has a crucial role in empowering parents to support their deaf child. In the early years, and often in the later years, the focus of attention is likely to be on working with the parents and the wider family, rather than direct work with the deaf child. This should include providing families with unbiased, clear and accessible information and practical guidance on a range of topics such as:

- language and communication development
- audiological support
- social and emotional development
- the education system

QS The local education authority must develop good practice guidelines for working with parents of pre-school age deaf children. Parents must be involved in the development of such guidance and it must be reviewed annually.

"When you have a deaf baby there's so much to think about, so much to learn, so much out there you were never aware of before. I'm really glad we had a head start. We were told our daughter was deaf when she was 7 months old, although we were prepared after the first test that she would be deaf. You know people say deaf children have to live in a hearing world well I disagree, it's a hearing world and a deaf world. Looking back the support we had and the information we were given meant that we were always one step ahead, particularly when it came to our daughter's education. Having the teacher of the deaf and other parents to ask for advice were the two key things which helped us along the way."

Parent's comment

QS Parents of very young deaf children have a right to expect that any teacher of the deaf working with them will be qualified, skilled and experienced in working with families and pre-school deaf children.

5-7 Audiological support in the early years

The NDCS recommends that paediatric audiology services develop strategies to support all deaf children. This should include children with mild, fluctuating, sudden, progressive, late onset, or unilateral deafness and also children with auditory neuropathy (ie children who have normal peripheral hearing but who may have neurological deficits resulting in central auditory processing disorders) (NDCS *Quality Standards in Paediatric Audiology, Volume IV, 2000*).

QS Early years paediatric audiology support services must attain the standards detailed in the NDCS Quality Standards in Paediatric Audiology, Volume IV (2000).

5.7.1 Hearing assessment

QS Parents must be fully informed about the nature and extent of their child's deafness.

It is acknowledged that in very young babies (ie those under six months old) detailed behavioural assessment is difficult. Parents should be made aware of this so that they have realistic expectations of what testing can be carried out.

QS There must be agreed policy and protocols for the surveillance of progressive and late onset deafness in babies and young children, especially as the implementation of UNHS throughout the UK will mean that the universal infant distraction test at seven to eight months will be phased out.

QS A full developmental assessment must be offered for all deaf children and include vision and balance checks. Regular vision checks as identified by the NDCS/SENSE steering group must take place (NDCS/SENSE Quality Standards in vision care for deaf children, in publication, 2002).

5.7.2 Paediatric hearing aid provision and cochlear implants

QS Local services must work to the nationally agreed paediatric hearing aid provision protocols and paediatric earmould guidelines.

QS All deaf babies and children must receive optimal amplification and be provided with the most appropriate hearing aids, regardless of cost.



The correct fitting of suitable hearing aids is essential for deaf children. Children must be provided with the best hearing aids which meet their individual and diverse needs.

QS Early years support workers must work with families to set goals, implement and evaluate individual hearing aid management plans. To optimise the use of hearing aids and earmoulds, parents must have information and support about the maintenance of hearing aids and there must be an ongoing exchange of information between all team members.

QS The early years support services for deaf children and their families must work collaboratively to ensure that the provision of equipment used by babies, children and families is safe, effective and compatible.

Parents must be provided with appropriate information to help their observations of their child's responses to sound. Teachers and speech and language therapists know that videotaping has become an essential tool for charting the child's progress during the early years (Stokes, 1999). Parents are a critical source of valuable observations essential to the appropriate evaluation of hearing aid provision and their child's development, and they must be provided with ways of recording their own observations.

QS Parent-held records of the child's hearing aid provision, and any changes to that provision, must be provided. This is a vital part of good quality early years support so that up-to-date information can be communicated immediately to parents, early years support workers and the whole team.

For families considering the possibility of a cochlear implant for their child, cochlear implant programmes must provide them with clear, balanced and unbiased information. Professionals also have a responsibility to ensure that parents understand the implications of cochlear implantation and how this might affect their deaf child and the wider family.

QS All deaf babies and children must be appropriately assessed before cochlear implants are considered. This must include a consistent trial of the most appropriate hearing aids over a substantial period of time, taking into account the child's age-related development. Cochlear implant services must be guided by the NDCS/BCIG Quality Standards in Paediatric Audiology - Cochlear implants for children, Volume III (1999).

5.7.3 Aetiological investigations

QS Families must be offered the opportunity for their deaf child to have aetiological investigations. These investigations must be carried out in accordance with local protocols based on nationally agreed standards. They should be offered counselling to understand these investigations and the implications.

As certain tests must be performed within a few weeks of birth it is important that families are given this information so that they can make an informed choice. Families should also be made aware that it will not always be possible to obtain a conclusive result from such investigations. Some families may decline the offer of these investigations and their wishes should be respected.

QS Early years support staff must be trained to understand aetiological and genetic investigations, and local protocols and national standards, in order to be able to optimally support children and families.

5.7.4 Deterioration of hearing

QS A child with a sudden deterioration in hearing thresholds must be referred for full audiological and ENT investigation as a matter of urgency. They must be referred within one working day and seen within two days (NDCS Quality Standards in Paediatric Audiology, Volume IV, 2000).

The speedy referral of a child with a sudden deterioration in their hearing is imperative. With a sudden deterioration due to sensori-neural deafness, ENT services may be able to provide treatment that could prove beneficial, or reverse the deterioration if it is administered within a few days of onset. Furthermore, a deaf child with any sudden deterioration or change in their hearing must be assessed immediately in order for their amplification to be maintained at an optimal level.

5.8 Support from social services

Social services departments (SSDs) have responsibility for implementing the *Children Act* (DoH, 1989). They oversee the well-being of children defined as "in need" under the terms of the Act.

When deciding whether a child is a child in need, social services professionals need to think about what will happen to a child's health and development if services are not provided. A new set of quality standards on social services called *Deaf children: positive practice standards in social services* (Association of Directors of Social Services, et al, 2002) for deaf children provides detailed guidance on the issues facing deaf children and their families, the needs they are likely to have, and the steps that departments need to take in order to provide an effective service.

QS Social services must be informed when a child has been identified as being deaf, and be part of the early years multi-disciplinary team with roles and duties being clearly defined.

Local authorities also have responsibilities under the *Disability Discrimination Act* (DfES, 1995) not to discriminate against disabled people. This means that they need to ensure that all services are fully accessible. Again *Deaf children: positive practice standards in social services*, gives detailed guidance about ensuring that services are accessible to all parents, including deaf parents.

The key issue in the development of deaf children is access to communication and language. Social services have a role in facilitating this, monitoring arrangements made by other agencies and promoting the needs of deaf children with other local agencies. This may mean a variety of interventions, from advice and information and equipment, to language support services.

For children identified as deaf at a very young age, families' initial needs are likely to be for information and advice, assistance with claiming welfare benefits, and access to sign language or other communication tuition. Social services departments are also likely to be the lead agency in schemes that introduce deaf adults to hearing families with deaf children. As deaf babies grow into toddlers, access to play and leisure facilities will become increasingly important, as will opportunities for families to develop communication skills appropriate to relating to a very young child.

Some deaf children may not need sustained social services involvement. Like all children, there will be some deaf children who are disadvantaged, multiply disabled or vulnerable, and they will need access to the best possible service to safeguard them and to ensure their future well-being.



QS The needs of individual deaf children and their families must be assessed at the earliest opportunity in line with the Framework for the assessment of children in need and their families (DoH, 2000).

5.9 Support groups and voluntary organisations

"I cannot stress enough how important it was for me to meet with other parents of deaf children. As a single parent I really didn't have anyone else to share my experiences with."

Parent's comment

QS Information about voluntary sector services must be given to the family at the time of confirmation, at key stages throughout their child's life and when requested by the family.

The voluntary sector provides a diverse range of services for families and their deaf children. This can include parent support groups, playgroups, information and advocacy, such as the NDCS helpline, and regional or local support networks.

Local health and education services must provide parents with information about relevant support groups and voluntary organisations (*Education Act, DfES, 1996*).

In the NDCS survey on UNHS, parents were asked what information they thought would be useful for families who have just been told that their child is deaf. Parents identified that information should be provided on parent support groups. Parents valued contact with other families because it offered the opportunity to share experiences and to learn from one another.

5.10 Deaf adults

"Many parents were unaware of language development until they learned by accident from other parents...they do not have access to British Sign Language or have the chance to meet deaf adults. Deaf adults can give useful information on how deaf children progress into adulthood."

Parent's comment

Deaf children and their families must be able to participate positively in the shared experience of deafness. They must have access to the widest range of deaf people. This includes deaf people who use sign language or spoken language, as well as those who use both.

Involvement of deaf adults or young deaf people can inspire parents to think positively about the future for their child and to learn more about deafness and the deaf community. Deaf parents, for example, can give hearing parents help in understanding the visual means of communicating with deaf babies (Hindley, 2000).

QS Services must offer families the opportunity to meet with deaf adults, who have been trained to work with families with very young deaf children.

An example of one such programme is the NDCS language aide scheme. This scheme offers families the opportunity to be linked with trained local deaf adults who provide them with support at home in a number of ways:

- communication support, including basic signing skills;
- providing a deaf role model and insight into deafness and deaf awareness;

- regular contact at home from a skilled deaf adult;
- access to local and national advice and support;
- support complementary to that already received from local services;
- emphasis on support during evenings and weekends to involve all the family; and
- support that centres on nurturing the skills of the family.

An evaluation of the language aide scheme has shown benefits for families in several key areas:

- improvement in signed communication in the family;
- better understanding of deaf culture and deaf issues;
- powerful and positive experience of a deaf role model (the feature most valued by families);
- valuable and effective support for the family; and
- an improvement in communication skills and confidence of deaf children.

5.11 Assessments

"Good early years provision will develop from effective and child-centred assessment. It is essential that high quality, multi-agency assessment is available shortly after confirmation to begin the process of identifying the child's needs and support that they and their family will need in the early years".

(NDCS Quality Standards in Education - England, 1999)

QS Parents have a central role to play in the assessment of their deaf child's progress, and early years support teams must provide them with the support they need to carry out this active role.

As parents have unique knowledge and understanding of their deaf child they should have a primary role in assessing their child's development, particularly in the early years. Therefore the most valuable assessment tools will be those that enable parents to have the key role in observing, assessing and recording the development and progress of their child, so that they can fully evaluate and influence the adaptation and choice of intervention approaches used with their child.

QS All assessments must have a clear set of aims and outcomes which will be used to benefit the deaf child and their family. Professionals must give parents full information as to the purpose and nature of any assessment and tests, as well as details of the results and how they will be used. Parents must be given written copies of all results, reports and individual management plans produced.

Multi-disciplinary assessment of young deaf children should seek information on a range of areas, including:

- language and communication development;
- play, early social skills and emotional development; and
- hearing aid use and benefit.

QS Professionals must be well trained in assessment approaches. Many assessment approaches require parents' equal involvement and they too must have access to training to enable them to be fully involved.



6. Developing partnership in the strategic management of services

"I was recently invited to sit on a local audiology working group and, before I agreed, I questioned what I had to offer:

- *the daily experience of bringing up a deaf baby, a deaf child and a deaf young person;*
- *varied and long term experience of working with a selection of professionals;*
- *insights into what could have worked better for us as a family; and*
- *the shared experiences of other families I have known and those I have worked with in my capacity as an NDCS local representative and family support worker.*

What I don't do is to bring a pile of complaints and criticisms."

"As a group we are working towards a quality service for deaf children. We want to ensure the service we have locally is 'as good as it can be'. I am proud to be involved and contributing. I hope other services nationally will take on board the need for parents to be involved in their local provision of services."

Parents' comments

QS The children's hearing services working group (CHSWG) must be responsible for overseeing the implementation and monitoring of quality standards and good practice in the early years, as identified in this document.

The CHSWGs involving all those who support deaf children, are vital to the development of partnership and good quality effective multi-agency and multi-professional team work. CHSWGs should now be in place across the UK, with a named co-ordinator to act as a contact and reference point for the CHSWGs policies and audit (Hall, 1996).

QS Membership of the CHSWG must include services users and parents of deaf children, with representation from all those supporting deaf children in health, education, social services and the voluntary sector. Sharing and rotation of the role of chairing the group must involve all those represented, including parents.

The CHSWG must take responsibility for making sure that all services supporting deaf babies and their families work in a co-ordinated way, whether provided through health, education or social services.

Involving parents in the strategic management of services will help to ensure that such services are family-friendly and that they are equally based both on professional training and expertise, as well as the needs and experiences of parents.

QS Health, education and social services have a responsibility to ensure that adequate resources are available to support the CHSWG and to reimburse parents for their time, travel expenses and any child care costs incurred, to enable them to participate in the development of local services.

For the development of good quality FFHS and early years support, the principle aims of CHSWGs must be to:

- maintain as paramount the requirements of the individual child and family in the design of services;
- recognise and respect the contribution of all those involved with deaf children;
- optimise, share and maximise resources of all agencies for the benefit of the child and family without gaps or duplication of services, identifying where investment is required;
- develop strategies to identify the different requirements of each individual family; and
- develop appropriate services and strategies to support all deaf children and their families.

QS The CHSWG must ensure that:

- families are centrally involved in developing services and reviewing plans;
- parent and consumer satisfaction surveys are used regularly;
- families are involved in reviewing drafts of written/audio/video materials produced locally;
- families are invited to contribute to in-service training of staff;
- a suggestion book is kept in the waiting area for centre-based services and in the case of home-based service provision, families must be provided with a way of offering suggestions and ideas to help improve services; and
- families are invited to accompany teams viewing the working practices at other sites and accompany staff when meeting with decision-makers.

(adapted from DesGeorges, 2000)

It is the responsibility of the CHSWG to:

- keep up to date with relevant training courses provided through health, education, social and voluntary sector services for all staff supporting deaf children, and to determine the training and continued professional development needs of staff;
- develop policies for the exchange of information between professionals, agencies and families;
- ensure that mechanisms are in place so that families can discuss and explore issues relating to their child's deafness; and
- identify the practical barriers that may face families as a consequence of disadvantaged circumstances and develop practical solutions to overcome these barriers. For instance, the provision of baby sitting services and taxi vouchers has been known to help overcome barriers to families attending hearing screening follow-up appointments (Young & Andrews, 2001).

QS The CHSWGs must:

- carry out an annual survey of client satisfaction;
- ensure that hearing parents of deaf babies have the opportunity to develop awareness of the deaf community, deaf culture and deaf people's needs;
- develop and audit local policies and protocols for the delivery of multi-agency FFHS;
- publish an annual report;
- meet at least twice a year; and
- keep records of CHSWG meetings and attendance.

The CHSWG is responsible for ensuring that tuition and coaching in sign language and communication strategies are made available for families (including siblings) and professionals.

The CHSWG is responsible for ensuring that links are made with other services for deaf children such as paediatric cochlear implant programmes, local Sure Start, Early Excellence, Parent Partnership and other relevant programmes in order to maximise available resources and support for deaf children and their families.

QS The CHSWG must agree policies on providing services to children with complex needs, designing services sensitive to those needs.

Recognition of deafness in children with multiple disabilities is often overlooked. The incidence of deafness amongst people with learning difficulties or other mental difficulties is substantially higher than sensory impairments occurring in other populations (Bond, 2000).

QS There will be financial and organisational implications for services in the development of good quality FFHS to support deaf babies, children and their families. The CHSWG must assess these implications, develop local policy and identify funding to address them.



7. Acknowledgments

We would like to thank the membership of the NDCS Early Years Working Group and all other professionals and parent representatives for their contribution to the development of this document.

8. Appendix I

The NDCS was commissioned by the Department of Health to produce a series of explanatory leaflets to be used as part of the newborn hearing screening programme (NHSP).

There are four leaflets in this series which are outlined below:

- Leaflet 1 **Your baby's hearing screen**
Given to all parents-to-be at 30 weeks pregnancy and again at the time of the screen. It explains what is involved in the screen and why it is important to screen the hearing of babies soon after birth.
- Leaflet 2 **Your baby's follow-up hearing screen**
Given to parents if their baby is referred for a second screen. It explains why the baby may not have passed the first screening test and what will be involved in the follow-up screen.
- Leaflet 3 **Your baby's visit to the audiology clinic**
This is given to parents if their baby is referred after the screening process for full audiological assessment. It explains some of the reasons why a child may be referred and what will happen at the clinic.
- Leaflet 4 **Your baby has a hearing loss**
This booklet is given to parents when their child is identified as deaf. It answers some of the common questions that parents are likely to have at that time. It also offers information about some of the sources of support available.

9. Appendix II

The National Deaf Children's Society - Vision and Values Statement

Purpose

The National Deaf Children's Society (NDCS) is an organisation of families, parents and carers which exists to enable all deaf children and young people to maximise their skills and abilities, and works to facilitate this process by every possible means.

Key values

The NDCS believes that:

- If support is given and positive attitudes are fostered, the challenge of deafness can be a rewarding experience for deaf children and their families.
- Parents and carers should receive clear, balanced support and information as near to their homes as possible.
- Deaf children need to develop fluent language skills in order to understand and influence the world around them, by whichever approach is the most appropriate for the individual.
- The NDCS aims to work with all deaf children and their families and believes that all people are of equal worth.

10. References

- Association of Directors of Social Services (ADSS), British Deaf Association (BDA), Local Government Association (LGA), National Children's Bureau (NCB), National Deaf Children's Society (NDCS) & Royal National Institute for Deaf People (RNID) (2002) *Deaf children: positive practice standards in social services*. (NDCS/RNID).
- Atkinson M, Wilkin A, Stott A & Kinder K (2001) *Multi-agency working: an audit of activity*. National Foundation for Education Research (NFER).
- Baguley D, Davis A & Bamford J (2000) *Principles of family-friendly hearing services for children*. BSA News 29, 35-39.
- Bailey D P (1987) *Collaborative goal setting with families: resolving differences in values and priorities for services*. Topic in Early Childhood Special Education 7 (2).
- Bailey D & Simeonsson R (1988) *Assessing critical events*. In Bailey D & Simeonsson R (eds) 'Family Assessment in Early Intervention', 119-138. Merrill Publishing Co, Ohio.
- Bond D (2000) *Mental health in children who are deaf and have multiple disabilities*. In Hindley P & Kitson N (eds) 'Mental health and deafness', 127-148. Whurr Publishers, London.
- Colorado Department of Education & Colorado Families for Hands and Voices (2000) *The Colorado resources guide for families of children who are deaf/hard of hearing in Colorado*. Hands and Voices.
- Dalzell A (2000) *A needs survey of families with hearing-impaired children*. Master of Science thesis, University of Manchester, UK.
- Davis H (1993) *Counselling parents of children with chronic illness or disability*. British Psychology Society Books.
- Department for Education and Skills (DfES) (1995) *Disability Discrimination Act*. The Stationery Office.
- Department for Education and Skills (DfES) (1996) *Education Act*. The Stationery Office.
- Department for Education and Skills (DfES) (1997) *Excellence for all children: meeting special educational needs*. DfES.
- Department for Education and Skills (DfES) (2001) *Special Educational Needs Code of Practice*. DfES.
- Department of Health (DoH) (1989) *Children Act*. The Stationery Office.
- Department of Health (DoH) (2000) *Framework for the assessment of children in need and their families*. The Stationery Office.
- Department of Health (DoH) (1999) *Health Act*. The Stationery Office.
- DesGeorges J (2000) *Parent participation in systems building*. Available on the Marion Downs National Center for Infant Hearing, Colorado, USA. Website: www.colorado.edu/slhs/mdnc
- Evans R & Robinshaw H (1999) *Service provision for preschool deaf children*. Report to the Nuffield Foundation.
- Gregory S (2001) *Models of deafness and the implications for families of deaf children*. Available on website: deafnessatbirth.org.uk
- Hall D (1996) *Health for all children*. Oxford: OUP (3rd edition).
- Hindley P (2000) *Child and adolescent psychiatry*. In Hindley P & Kitson N (eds) 'Mental health and deafness', 42-74. Whurr Publishers, London.



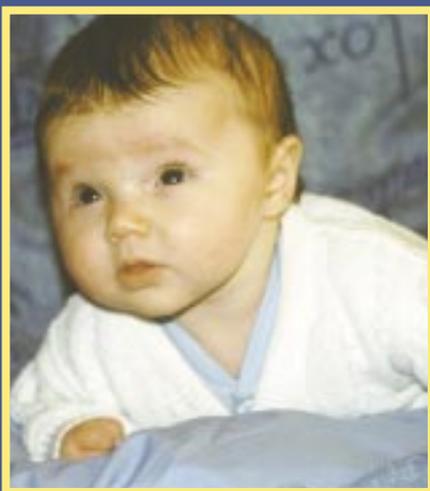
- Leonard A (1999) *Right from the start*. SCOPE.
- McCormick B (1975) *Parent guidance: the needs of families and of the professional worker*. *The Teacher of the Deaf*, 73, 434, 315-330.
- Medwid D & Weston D (1995). *Kid-friendly parenting with deaf and hard of hearing children*. Gallaudet University Press, Washington D.C.
- Mitchell W & Sloper P (2000) *User-friendly information for families with disabled children: a guide to good practice*. Joseph Rowntree Foundation.
- National Deaf Children's Society (NDCS) (2001) *National hearing screening programme leaflets*. NDCS, © Department of Health (DoH).
- National Deaf Children's Society (NDCS) (1999) *Parental survey on late diagnosis*. NDCS.
- National Deaf Children's Society (NDCS) (2000) *Parental survey on UNHS*. NDCS.
- National Deaf Children's Society (NDCS) (1999) *Quality Standards in Education – England*. NDCS.
- National Deaf Children's Society (NDCS) (2000) *Quality Standards in Paediatric Audiology - Guidelines for the early identification and the audiological management of children with hearing loss, Volume IV*. NDCS.
- National Deaf Children's Society (NDCS) – *Vision and Values Statement*. See Appendix II.
- National Deaf Children's Society (NDCS) & British Cochlear Implant Group (BCIG) (1999) *Quality Standards in Paediatric Audiology - Cochlear implants for children, Volume III*. Joint review by NDCS & BCIG.
- National Deaf Children's Society (NDCS) & SENSE (in publication, 2002) *Quality Standards in vision care for deaf children*. NDCS/SENSE.
- Newborn hearing screening programme (NHSP). Website: www.unhs.org.uk
- Royal National Institute for Deaf People (RNID) & National Deaf Children's Society (NDCS) (2000) *Statement of professional competencies*. RNID.
- Shaw J (1973) *Basic counselling*. Stockport Vernon Scott.
- Social Policy Research Unit (2000) *A resource pack: developing a key worker service for families with a disabled child*. University of York.
- Stokes J (1999) *Learning to listen*. In Stokes J (ed) 'Hearing impaired infants - support in the first 18 months' 197-230. Whurr Publishers, London.
- Thameside Community Healthcare NHS Trust (2000) *Sharing the news: good practice, procedures and training for informing parents of a diagnosis of a child's impairment*. Thurrock Community Hospital.
- Yoshinaga-Itano C (1998) *Factors predictive of successful outcomes of deaf and hard-of hearing children of hearing parents*. Available at website: www.colorado.edu/slhs/mdnc/efficacy.html
- Young A M (1999) *The impact of a cultural linguistic model of deafness on hearing parents' adjustment to a deaf child*. *Journal of Social Work Practice*.
- Young A M & Andrews E (2001) *Parents' experience of universal neonatal hearing screening - a critical review of the literature and its implications for the implementation of new UNHS programs*. *Journal of Deaf Studies and Deaf Education*, 6(3).



The National Deaf Children's Society is an organisation of families, parents and carers which exists to enable deaf children and young people to maximise their skills and abilities, and works to facilitate this process by every possible means.

The NDCS is working for all deaf children and young people. The NDCS services include:

- Providing clear, balanced information and advice on many issues relating to childhood deafness
- Advice on audiology, including information on hearing tests, hearing aids and glue ear
- Advice on technology and equipment
- A children's equipment fund (subject to availability)
- An opportunity to try equipment in the home and at school through an equipment loan scheme
- Support with benefit claims and Disability Appeal Tribunals
- Advice and information on education
- Support at Special Educational Needs Tribunals
- The Listening Bus® which travels around the country with the latest technology
- TALK magazine and a wide range of publications for both families and professionals, some in community languages
- The NDCS Helpline, with access to over 100 languages via an interpreter
- Annual technology exhibition for families and professionals
- Annual conference on specific current issues relating to childhood deafness
- A network of regional staff and local contacts providing local support
- Special events for professionals and families of deaf children and young people
- Training and consultancy for professionals



The National Deaf Children's Society

Registered Office: 15 Dufferin Street, London EC1Y 8UR

NDCS Helpline: 020 7250 0123 (voice & text)

Open Mon-Fri 10am-5pm

Switchboard: 020 7490 8656 (voice & text)

Fax: 020 7251 5020

E-mail: ndcs@ndcs.org.uk

Website: www.ndcs.org.uk

Registered Charity No 1016532

ISBN 0 904691 66 7 January 2002



THE NATIONAL
DEAF CHILDREN'S
SOCIETY