

SSC

scottish sensory centre

Scottish standards for deaf children (0-3): Families and professionals working together to improve services



Background

This document is the result of the Scottish Sensory Centre setting up Early Years for Deaf Children discussion groups in various locations in Scotland. One of the groups was looking at Standards and Training.

This group was chaired by Brian Shannan, Educational Audiologist, Fife Sensory Support Service.

Since the start of newborn hearing screening in Scotland in 2005 families have found out that their baby is deaf in the first few weeks of their baby's life. Early intervention has the potential for improving language learning outcomes for deaf children. Currently there is wide variation across Scotland in the way early years teams meet and work. The standards document shows how the early years team should have the family at its centre as part of the team. The document contains a self-audit tool for early years teams to reflect on the extent to which they are family-friendly and offer informed choices. The standards have been produced by a group of professionals, parents and members of the voluntary sector using evidence from research and policy.

Contents

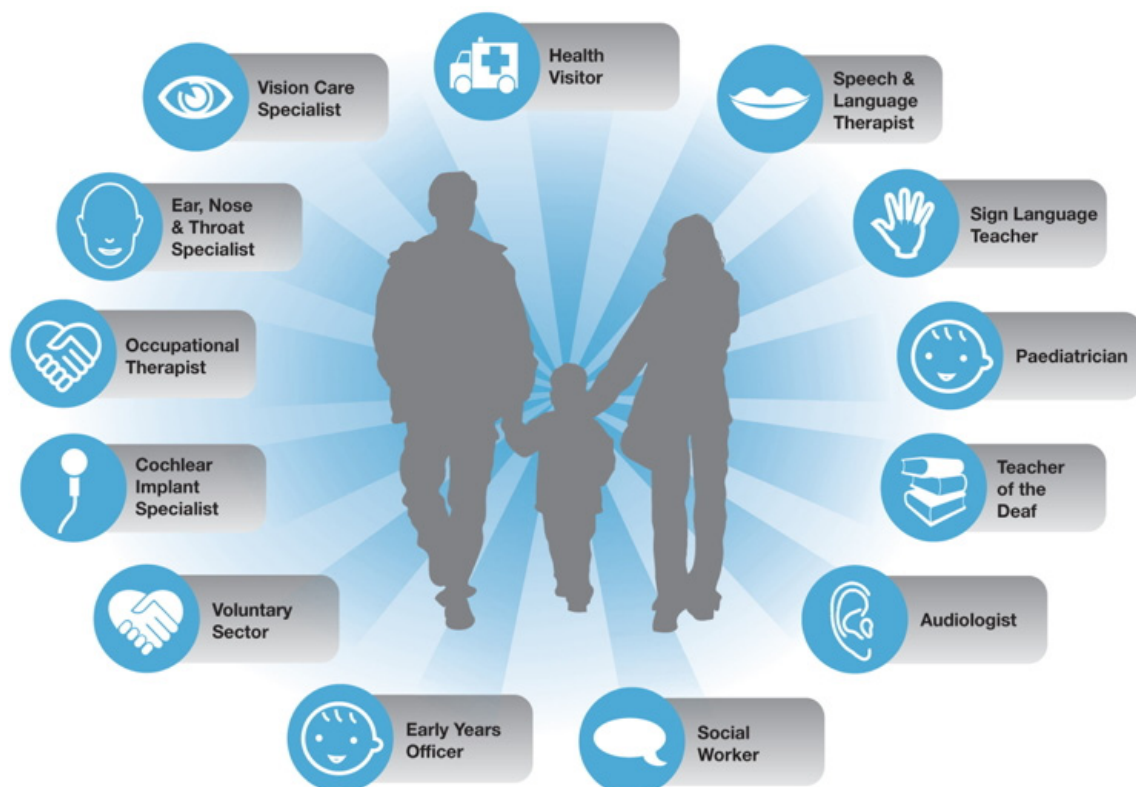
Introduction to Scottish Standards for Deaf Children (0-3): Families and professionals working together to improve services	3
Standard 1: Sharing the News	11
Standard 2: Parents and Professionals Working in Partnership	17
Standard 3: Parents as the Primary Educators	22
Standard 4: Providing Family-Friendly Services	26
Standard 5: Providing Information and Communication with the Family	30
Standard 6: A Positive Attitude Towards Deafness	34
References	38
Useful Organisations	40
Early Years Standards Quality Rating Tools 1-6	43
Appendix 1: Glossary	67
Appendix 2: Completed Family Support Plan	73

Introduction to Scottish Standards for Deaf Children (0-3): Families and professionals working together to improve services

Who are these Standards for?

The **Newborn Hearing Screening Programme** established throughout Scotland aims to identify hearing loss in babies and provide appropriate support at the earliest possible opportunity. Research indicates that the majority of parents with deaf children have no prior experience of deafness in the family and so it is both an unexpected event and a new set of experiences (Bamford et al, 2009). The **Scottish Standards for Deaf Children (0-3) Families and professionals working together to improve services** provide a coherent framework and vision for both parents and professionals supporting deaf children during the crucial early years and in doing so bring the Scottish Government's **Early Years Framework** to life. The standards provide a reference point and **quality rating tool** for benchmarking quality improvement for families as well as all services involved. They place families at the centre of an effective support system and acknowledge that the family is the main stakeholder in ensuring better long-term outcomes for deaf children (*Getting it Right for Every Child*, 2008). Enabling every deaf child to develop into confident and successful individuals by giving each one the best possible start is the bond which glues each standard together. These standards have been developed with the core principles of the UN Convention on the Rights of the Child at their heart.

Many professionals can work in partnership with families during the first few years of life including:



For children with more complex needs there could be a greater number of professionals involved including vision care specialists, physiotherapists and occupational therapists.

The United Nations Convention on Rights of the Child (1989) set out some key principles which have informed Scottish policy about children's rights.

UN Convention on the Rights of the Child

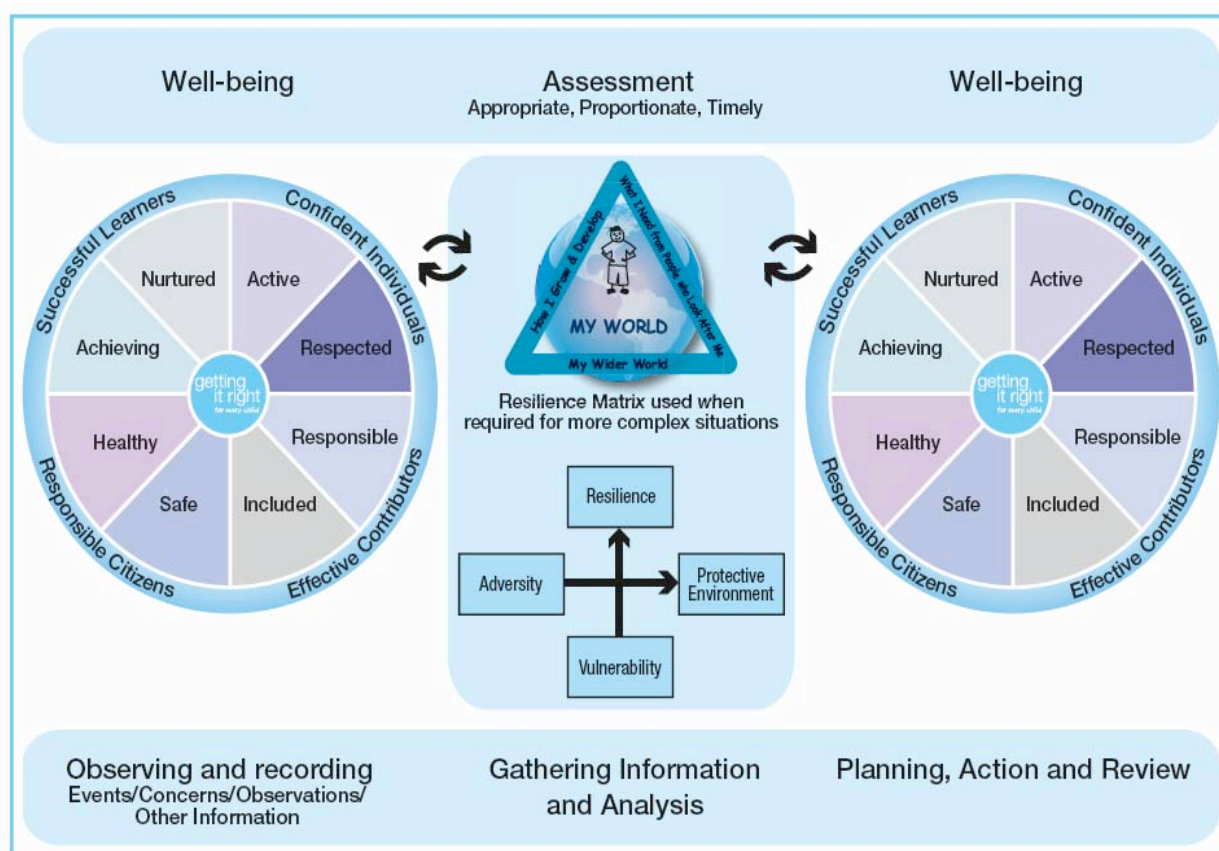
- Children and families are valued and respected at all levels in our society and have the right to have their voices sought, heard and acted upon by all those who support them and who provide services to help them. (Article 12 of UNCRC)
- Children with disabilities and from minority communities have their individual needs recognised and responded to. (Articles 2 & 23)
- Every child fulfils their potential as a successful learner, confident individual, effective contributor and responsible citizen. Every child has access to world class learning and healthcare services that meet their individual needs and which promote resilience and wellbeing. (Articles 24, 28 & 29)

The Early Years Framework & The Scottish Standards

In proposing these national standards we draw attention to common features with the **Early Years Framework** (Scottish Government, 2009) which we believe will lead to best practice being established throughout Scotland for deaf children and their families. These include:

1. The family at the centre of any support as they have a unique understanding of their child.
2. That support should ensure that children, families and communities are able to secure better outcomes themselves. This is demonstrated in our Family Support Plan.
3. That there is a high quality of service and that the standards apply to all types and degrees of deafness.
4. There is equal access throughout Scotland to hearing screening and ongoing early support.
5. That support is coherent.
6. Support is provided by all agencies and that it is coordinated by a named person.
7. Through partnership working and having a named person, services are simplified and streamlined. This approach also produces more effective collaborations.
8. By promoting family-friendly services we provide services that meet the needs of children and families. These services have a focus on engagement and empowerment of children, families and communities.
9. Children's early experiences have a direct influence on the overall life chances as they develop and grow into adulthood. There is a historic cycle of poor attainment for many deaf children which leads to other inequalities in later life. By providing an overall framework for effective early identification and intervention we address the inequalities that lead to cycles of poverty and poorer outcomes.

Underpinning both the Scottish Government Early Years Framework and these quality standards is the **Getting it Right for Every Child** approach and the four key principles of the Scottish Curriculum for Excellence, exemplified in the diagram of the *Getting it Right for Every Child*.



Scottish Standards

These standards are applicable to all services involved with deaf children and their families. There is a growing consensus about what maximises positive outcomes for deaf children and their families. This includes:

- Effective early intervention.
- Parents and professionals working in partnership.
- Empowering families.
- Family-Friendly services.
- Informed choices for families.
- A positive approach to deafness.

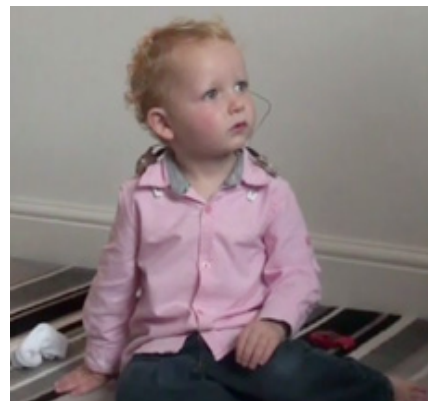
Effective Early Intervention

How the news is shared with the families sets a benchmark for future support. Effective and sensitive family support is essential if positive outcomes are to be achieved from Newborn Hearing Screening. Families should have access to information in a range of formats and have access to a named person so that any questions can be addressed (Moeller, 2000). The need for skilled and experienced staff from a range of agencies to be involved at this time is vital if successful outcomes are to be achieved.

Skilled Professionals Working in Partnership

A family-friendly approach is one of the most effective ways of working with families and deaf children (McDonald et al, 2000). When so many professionals are involved there is a need for all services to work together to provide a seamless service (NDCS, 2000). There is a need for all agencies across Scotland to adopt a family-friendly approach. Family-friendly services have common characteristics including:

- Multi-agency collaboration.
- Services that adopt different approaches to fit the individual circumstances of each family.
- The provision of evidence-based and unbiased information.
- Parents as equal and valued partners.
- An acknowledgement that everyone involved with children and families has an important contribution to make.



Research in the USA also indicates that the close working of health and education services is crucial to reducing stress in families and promoting good **attachment** (Yoshinaga-Itano, 2002).

Empowering Families

The parents are the experts as they know the child better than any professional. As they grow in awareness about the issues of deafness they can become empowered to make informed choices (Knight & Swanwick, 1999). Professionals working with deaf children should have the knowledge and experience of deafness to make them experts in the field. A professional relationship should be seen as a partnership of two experts in which parents should be empowered to choose, re-choose and change their minds (ANZPOD, 2009).

Informed Choices for Families

From the moment that the news is shared with the family onwards, it is the right of the parents to be provided with evidence-based, accurate, unbiased and up-to-date information. 'Informed Choice' means that families can make knowledgeable decisions, which reflect their own culture, values and views (DfES, 2006).

There are three important aspects of informed choice:

- Services and professionals make no value judgements about communication options and this is reflected in strategic decision-making and resourcing (DfES, 2006). Professionals should not make assumptions about the decisions a family will make. All options should be discussed equally.
- Experience is crucial to making informed choices. Having contact with other parents helps families develop their own knowledge and skills.
- Effective communication allows families to understand complex and new information. Providing information in an **appropriate format** in the preferred language at each stage of the process allows families to digest the information in their own time and with other family members.

Family-Friendly Services

Family-friendly services means recognising the diversity of the family and acknowledging that each one has their own experiences and expectations (Knight & Swanwick, 1999). Having a family-friendly service means actively encouraging families to think through the decision-making process, focus on the key issues and evaluate their options. At its core, a family-friendly service works in partnership with families and should be accessible and responsive – when the family cannot go to the service, the service should go to the family. Families deserve continuity and the attitude of professionals should be characterised by active listening (Kennedy, 2000).

Positive Approach to Deafness

The **attachment** between a parent and their baby helps facilitate not only communication but also the emotional wellbeing of the baby. This can be disrupted by the diagnosis of deafness. The process through which parents adjust to the reality of their child's deafness is influenced by how deafness is presented from the very start. The adjustment process is influenced by the view of deafness underlying it (Young, 1999). Therefore, service providers have a duty to ensure that deafness is not presented as only a medical, scientific or deficit issue and that they are positive in their approach to deafness.

The important role of deaf adults is well documented (Young, 1999). Services should engage with **deaf adults** and regard their experience as invaluable.

Where did the standards come from?

To complement the advent of Newborn Hearing Screening programmes throughout the UK, the NDCS produced a set of Early Years Quality Standards in 2002, which are still used by services and parents. The Scottish standards are based on recent changes to legislation which are discussed throughout this document and include an **audit tool** which allows all involved to ensure that ongoing quality improvement is achieved. These standards have been developed in collaboration with a number of agencies at the Scottish Sensory Centre (SSC) and have gone through a period of consultation and review. The standards were available for public consultation on the SSC website. In addition there was discussion with organisations such as British Association of Teachers of the Deaf (BATOD), Heads of Services Forum, Royal College of Speech & Language Therapists (RCSLT) Deaf Special Interest Group, Cochlear Implant Centre at Crosshouse as well as NDCS members and family officers.

How can early years workers use the standards?

The standards are intended to guide early years teams to consider how to set up a multi-agency **early support team** and how to make the service family-friendly. The standards should be used by all agencies working with the family of the deaf child. Throughout the document there is an emphasis on asking parents for their views in a systematic way, including them in all important discussions and giving them information so that they can monitor the development of their deaf child. We hope that early years workers will soon be able to see a difference and that a more even provision emerges between local authorities and health boards.

This document should be used by professionals to undertake their annual audit. The Quality Rating Tool should assist with this process.

How can parents use the standards?

At present standards are variable across Scotland for early years work. By using the following standards parents can see what sort of service they should be getting. They will also be able to see how they can become involved in improving the service, if they want to do this at any stage. Parents can also encourage their local service to carry out an audit using the standards, which they should be actively involved with. Parents can also sit on the local **CHSWG** and can use this document to help improvement to services.

How are the standards organised?

All standards follow a similar format:

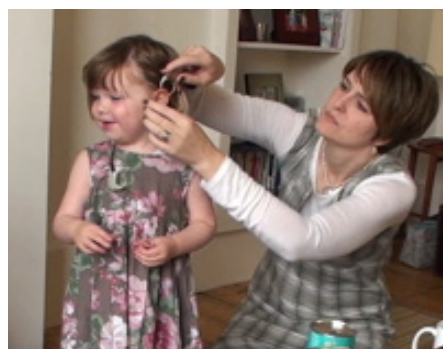
- The standards have a title, which summarises the area on which that standard focuses.
- The order of the standards does not reflect their priority or status. Each standard is of equal importance and each needs to be in place for a family to receive an effective service.
- Each standard has a rationale which provides the reasons why the standard is considered important.
- There are also some reflective questions at the end of each standard. The questions are designed to encourage all involved to reflect on their practice and to recognise what has been successful as well as acknowledge areas for improvement. All involved could develop their own set of reflective questions and so promote reflective practice.
- The rating tool addresses each standard statement.
- Each standard statement has a set of criteria, which details what needs to be achieved for the standard to be reached. Each standard has a different number of criteria. The number of the criteria is not a reflection of priority. There are also a number of examples which indicate when a criterion is not being met. The rating scale is 1 (poor) to 5 (excellent).
- Services and families should use each criterion to demonstrate that the standard has been achieved.

Methods used to Assess Performance

Assessment of performance should be carried out annually. In keeping with the spirit of the document this should be done in conjunction with families and all agencies involved.

Services can use the following means to demonstrate how they achieve the standards:

- Parent surveys.
- Family focus groups.
- Service documentation (information about the service; evidence of staff qualifications, in-service training programmes).
- Interviews with staff.



Definition of Key Terminology

There is a glossary in Appendix 1 which defines common vocabulary used throughout this document. To signpost readers to the glossary the relevant words are set out in a bold font when they first appear. Some of the key terms in this document can be defined in a number of ways and so to provide clarity we have listed them below.

We use the term **deaf** to mean all forms of childhood deafness, including mild, unilateral and temporary losses, such as glue ear. In this document, it is assumed that early years provision of the level described is routinely offered to families of children with a permanent confirmed hearing loss.

We use the term **family** to mean a range of individuals that play an important role in the deaf child's life. This could include the immediate family as well as siblings, grandparents, extended family members and other members of the community such as family friends. We recognise the diversity of a family and acknowledge that each one has their own experiences and expectations as well as dynamics and behaviours (Knight & Swanwick, 1999).



Named person refers to the person from the early support team who has the main contact with the family of the deaf child. This person is sometimes called a link worker or key worker. This will probably be the person the family see most often or who visits the family at home. It could be a speech and language therapist, a teacher of deaf children, an audiologist, educational audiologist or a social worker. The named person should have knowledge of who the key professionals working with the child and family are and how to contact them. The person should also have the ability to introduce families to other families with deaf children and to deaf people.

Before working with families the named person should have skills and additional training in:

- presenting information without bias;
- ability to demonstrate experience in family-friendly practices;
- knowledge and understanding of different communication methods;
- knowledge and understanding of different types of hearing loss;
- ability to work in a team and to coordinate multi-agency teams.

We use the term **Early Support Team** to refer to a group of professionals working in partnership with the parents or carers of the deaf child. The team could include a speech and language therapist, a teacher of deaf children, an audiologist, an educational audiologist, a support worker, deaf mentor, and voluntary worker. The named person is a team member and families are regarded as equal partners in the team. The Early Support Team may also be known as the multi-agency team.

The Early Support Team members have the following skills or receive additional training in:

- Emotional support and counselling skills.
- Providing accurate and unbiased information to families.

- Providing the family and other team members with up-to-date and accurate information. All members should have written copies of all current assessments, test results and reports.
- Monitoring progress of the child's development. This should include early child development as well as language and communication.
- Confidentiality - parents must know to whom information about their child and family is given.
- Deaf awareness training.

Family Support Plan refers to a plan drawn up by the early years team, which includes the family of the deaf baby or child. This plan sets out the priorities of the families, identifies next steps and says who is responsible for doing what. The Family Support Plan can be the same document as the **Individual Management Plan** which the audiologist should draw up.

The Family Support Plan is reviewed at regular intervals and all members of the team should be present. The family must always be present. The review of the plan acknowledges any progress made and identifies future targets. The review of the plan can be the audiologist's **Multi-Agency Support Plan**. A copy of the Family Support Plan is in Appendix 2 of this document.

Acknowledgements

The list of standard statements originate from the NDCS Early Years Quality Standards from 2002. The co-authors of the standards are Brian Shannan, Educational Audiologist, Fife Council, and Rachel O'Neill, Lecturer in Deaf Education, University of Edinburgh. The standards document was developed and edited by the Early Years Group at the Scottish Sensory Centre. This group has worked for two years and the membership has changed over time. The membership includes Jan Savage (NDCS), Frankie McLean (Deaf Action), Ailsa Flett (Fife Council Social Services), Jo White (Queen Margaret University), Lizanne Steenkamp (Queen Margaret University) and Jennifer Nicol (Forth Valley Sensory Centre).



EFFECTIVE EARLY INTERVENTION

Standard 1 Sharing the News

Statement

Getting it right from the start is necessary if improved outcomes are to be achieved for families and deaf children. Receiving the news that their child is deaf is an unexpected event and new set of experiences for the majority of parents. Families should be provided with accurate information on their child's deafness in a timely manner. This should be given by experienced and well-trained professionals who understand the importance of open and sensitive communication. The named person should be involved from the very start (Young & Tattersall, 2005). In addition to the care pathways for audiological assessment, early years support services should be accessible to the family at the earliest opportunity. Seamless services that actively work together provide the key to better outcomes. Families should access these services regardless of level and type of their child's deafness. Also families have a right to have investigations into the possible causes of their child's deafness undertaken in a timely and sensitive manner.

“there is a big delay between us being told she’s deaf and us as parents being accepting that she’s deaf”

Rationale

How the news is shared with the family will influence the bonding process between parent and child as well as determine their understanding and expectation for the future. Parents have a right to be provided with information in a suitable format that they can take with them as a reference and to share with family members (Baguley et al, 2000). During this time deafness should not be presented as only a medical or scientific issue but a positive approach is adopted by all services involved. Services other than health should be involved from the very start (ANZPOD, 2009). Effective and sensitive family support is essential if positive outcomes are to be achieved from Newborn Hearing Screening (Moeller, 2000).



Criteria

In order to ensure that families experience of sharing the news is as transparent and sensitive as possible the following should be established.

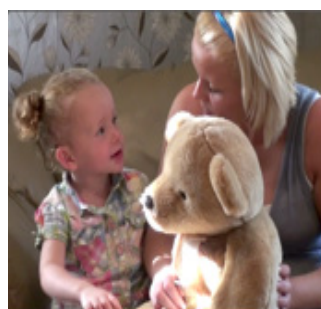
1.1 Families are provided with equal access to audiological services.

1. All families have equal access to newborn hearing screening. There are clearly defined pathways from the screening process to diagnostic assessments and on to engagement with early years teams.
2. Families are made aware of the different assessments their child will go through and the outcomes expected (as in **Quality Standards in Paediatric Audiology**).
3. Families are aware that early identification of deafness together with appropriate support can lead to improved outcomes for children.
4. Families should be able to access early support at any point in the process.
5. Children with more complex needs are referred to the appropriate agencies in a sensitive and timely manner.
6. The care pathways take into account children who pass the screen but are identified as having a risk factor, eg; family history, neonatal intensive care.
7. Children with a unilateral deafness have equal access to services.
8. Services are aware of the impact that glue ear and other conductive losses can have on language acquisition. Therefore, there is a clear pathway for those children to receive equal access to services and a speedy referral to the early support teams.



1.2 Health and audiology services have written guidelines for staff on how to share the news with parents, when and where this should happen and who should tell parents that their child is deaf.

1. Clear guidelines must be developed in partnership with parents on how the news is shared with the family.
2. The guidelines should ensure that families are offered a full explanation of any diagnostic assessments as soon as they are completed.
3. The guidelines should actively promote a seamless liaison between agencies. All agencies should work with a partnership model that has a family-friendly ethos.
4. The guidelines should state that a member of the early support team should be present during the time the news is shared with the family. This person should be the named person in the first instance.

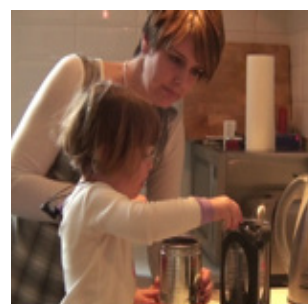
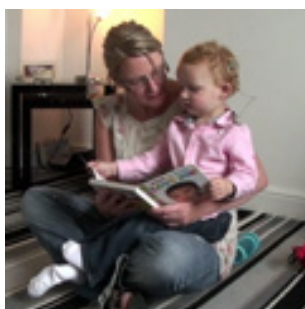
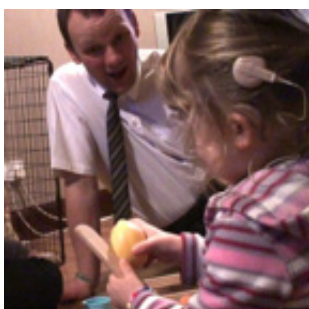


1.3 All services ensure their staff are trained to communicate appropriately, sensitively and effectively with families at all times, particularly at critical times such as sharing the news of deafness.

1. Staff are trained to communicate appropriately, sensitively and effectively with families.
2. Families at the time of sharing the news have time, in an appropriate environment, with an informed professional with skills in supporting families.
3. Families' experiences of 'sharing the news' is positive and provides an opportunity to ask questions and agree the next steps.
4. Families are supported in their planning for sharing the news with the wider family.
5. Families should be given time and not feel consciously or subconsciously that decisions have to be made there and then.

1.4 Parents are given accessible information that they can take away with them. This includes details about who will be contacting them, when this will be and where they can obtain further information and advice and, if they want it, emotional support.

1. Information is provided in a range of formats.
2. Written information is available in English and other community languages.
3. The organisation of an interpreter must also be arranged if the family are unconfident in spoken English.
4. Families are provided with a range of reliable sources including voluntary groups, parent support groups, deaf organisations and internet resources.
5. The professional's role is to provide a wide range of resources including those provided by the voluntary sector and not to make judgements that effectively restrict access or make assumptions about the choices a particular family will make.



1.5 The early years support services are available immediately after deafness is confirmed.

1. Early years support and education services are informed of a child's confirmation of deafness within one working day.
2. The early support team will make contact with the family the day after a referral has been received.
3. The named person from the early support team offers to make a visit at a time convenient to the family; this should ideally be within one week of the initial contact.
4. The family should have a contact number/email/sms for the named person.
5. Services respect parental choice, stage of acceptance, and reflect this in the timing and level of further support.

1.6 Families are offered the opportunity for their deaf child to have aetiological investigations.

1. Aetiological investigations should be comprehensive and comply with national standards (refer to **Quality Standards in Paediatric Audiology**).
2. The aims and possible outcomes of investigations should be discussed with the families.
3. Some parents may decide against investigations and their views should be respected.

Good Practice from Around Scotland

In one area of Scotland there is an Early Support Team that is composed of a specialist speech and language therapist for the deaf, educational audiologist, associate specialist in childcare and the manager of the newborn hearing screening programme. The follow-up diagnostic assessments are arranged at a time when members of the team are available so that when the news is shared at least one member of the team is present in addition to the audiologist. The member of the team present at this time becomes the named person in the first instance. Families receive a follow-up call the next day and a date for a home visit is agreed. At the home visit all parental questions are answered. The family receive a written copy of the home visit and the agreed next steps are clearly outlined.

One hospital in Scotland accepts referrals from parents, schools and speech and language therapists. Concerned parents or anxious teachers are able to contact the audiology department directly.

Family Experiences

It is important for health professionals to have training on how to sensitively break the news, so that experiences for parents in the future is made easier, because it is a time they always remember and if such news is imparted poorly, it can have such a huge and lasting impact of their perception and acceptance of deafness.

(Parent, 2011)

And I think it is probably only after a year really when it was confirmed that she had the hearing loss, and probably even later after that that we as parents accepted it and I think there is – we can talk about it later – there is a big delay between us being told she's deaf and us as parents being accepting that she's deaf.

(Father, 2006)



Reflective Questions

How can I ensure that families are given time to digest information and make choices that suit their individual needs?

What can I do to make sure that I work in an open way with my colleagues and other agencies so that the highest quality of service is maintained?

WORKING TOGETHER IN PARTNERSHIP

Standard 2 Parents and Professionals Working in Partnership

Statement

A key feature of family-centred working is that of partnership. A family of a deaf child may have a number of different professionals working with them each focused on their own particular area of expertise. For deaf children with complex needs, the number of supporting professionals can be very large (McCracken, 2008). Although they may all be working towards the same goal, conflict can arise without proper coordination. Therefore, an essential element of working in partnership is the appointment of a named person who can help facilitate multi-agency collaboration. Parents should be regarded as full members of the team, which should be well coordinated and accessible. Such collaboration requires regular and open communication and team meetings where information can be exchanged (Marshall & Mirenda, 2002).

“Surely there must be a way of sharing information so time isn’t wasted going over the same things time and time again.”

Rationale

Research has shown that families value support that is well coordinated and attuned to their needs (Bamford et al, 2009). The support from early support teams should be coordinated and deliver help when needed. Key to any team is the family. Therefore, the team should have a common goal of raising the parents’ confidence so that they are able to develop strategies to overcome any potential learning and development barriers. The voluntary sector provides a diverse range of services for deaf families and their children (Brown & Remine, 2008). This can include parent support groups, play groups, role models, information and advocacy such as the NDCS Helpline, and regional and local support networks.

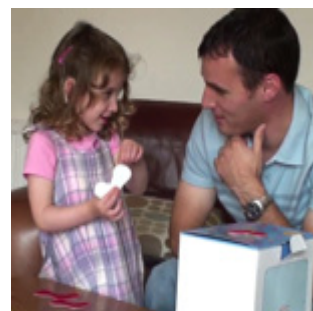


Criteria

In order to ensure that families can have a positive attitude the following should be established.

2.1 All services (health, education and social services) must develop clear written policies 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.

1. Education, health and social services should each have a clear policy on supporting deaf children and their families in the early years.
2. There should also be a joint multi-agency policy which details how services will coordinate and communicate with families in a consistent way.
3. Parents of deaf children must be involved in the development and review of these policies and their views should be actively sought. This should take into account barriers that may prevent their involvement such as child care, timing of meetings, language and culture.
4. This policy should be reviewed every year.



2.2 The multi-disciplinary team includes parents and named individuals from all services supporting the deaf child.

1. Multi-agency teams have well-trained and experienced staff.
2. The service provides convenient meeting times and locations for parent participation.
3. The family of the deaf child must be at the centre of the decision-making process.
4. Membership of the team is flexible and reflects the child's changing needs, eg; speech and language therapy, cochlear implant team, bone anchored hearing specialists, sign language teacher etc.
5. Under the terms of the Children (Scotland) Act 1995, colleagues in social services must be informed when a child is identified as being deaf, and should be represented on the multi-agency team.

2.3 The early years support team has agreed protocols for referrals, recording and sharing information, as well as planning, delivering and reviewing support to families and assessing deaf children.

1. The consent of parents is sought in relation to the sharing of reports and information between professionals.
2. Parents know who holds information about their deaf child.
3. Services should allow adequate staff time to collaborate on joint working and planning.
4. Services engage in multi-disciplinary training to develop good working relationships and good communication between agencies.
5. Reflective practice is encouraged using the quality rating tool in this document.
6. Health, education and social services should work together to share local data on the number of deaf children in their area. This will allow services to plan for appropriate resources to be available for their support.

2.4 There is a named person responsible for coordinating the early years support services in partnership with the family.

1. There is a named person responsible for coordinating the early years support services for the family, even though the responsibility for early years support may need to be shared.
2. The family is informed about how they can contact the named person and another person in the team if the named person is not available.
3. The named person is accessible to the family all year round.
4. The family's named person has specific training in working with pre-school age deaf children and their families and is knowledgeable about the rights of the parent and child.
5. The family's named person has knowledge of local and national services for deaf children and how to access them.
6. The named person also has 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.
7. The named person should be present at the time of sharing the news.

2.5 The voluntary sector is recognised as a key member of the multi-disciplinary team supporting a deaf child and their family.

1. Parents should be provided with early information on services offered by the voluntary sector and how to access them.
2. Statutory service providers should liaise with voluntary sector representatives as valued members of the multi-disciplinary team supporting families of deaf children.
3. Membership of the **CHSWG** includes service 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 involves all those represented, including parents.

Good Practice from Around Scotland

In one area the Audiology Department, Speech and Language Therapy Service and Sensory Support Service have each developed a written policy on working with children from birth to three. In addition to this the various professionals in partnership with parents have a written policy for the Early Support Team. In this policy it clearly states the roles and responsibility of team members.



Family Experiences

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 of a deaf child)

The support we received from the voluntary sector in our experience was crucial in acceptance of deafness and empowering us as 'new' parents.

(Parent, NDCS, 2011)



Reflective Questions

How can we improve our way of working with families to ensure that they are appropriately involved in discussions and decisions that affect them?

How can the team aim to ensure a coordinated approach to gathering information so as to avoid parents having to repeat information more than once?

EMPOWERING FAMILIES

Standard 3 Parents as the Primary Educators

Statement

The family are the specialists when it comes to their child, and have the most direct influence on their child in the early years. Families are key to enabling their deaf child to become confident young people who can communicate well and contribute to society. Although professionals are knowledgeable about deafness, it is only the family that fully appreciate the culture and values that are appropriate to them. The active engagement of the family provides the Early Support Team with motivation and direction. Parents and the deaf child should be at the heart of all decision-making if better outcomes are to be achieved. Barriers to the family being fully involved should be identified and overcome. Any sustainable partnership must have at its core the capacity not only to develop a family's knowledge about their child's deafness but the skills to make them independent decision-makers on their child's behalf (Marschark, 2007).

“everyone gets together every six months and says what they have been doing and puts some targets together for the next six months”

Rationale

A culture of engaging with families and respecting them as equal partners needs to be embedded in the services that work with all families of deaf children (Brown & Nott, 2006). 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 (Baguley & Bamford, 2000). Families spend the most time with their deaf child, and are best placed to develop opinions on their progress. It is commonly accepted that successful support for a deaf child will only occur when parents are empowered with skills, knowledge and confidence as valued and equal partners in the Early Support Team (Eleweke et al, 2008). We should work towards age equivalent language outcomes for all deaf children, whether the language chosen by the family is speech (Nicholas & Geers, 2007) or sign language.



Criteria

In order to ensure that families are at the centre of partnership working and that they are empowered to be confident decision-makers the following should be established.

3.1 The early years support team in partnership with parents draws up a Family Support Plan for each deaf child.

1. Parents are involved in deciding the content of their family support plan (Appendix 2).
2. Such plans detail: the aims of the support, level of support, agencies involved, when and how the support will be delivered, by whom, the role of the family and when it will be reviewed.



3.2 Parents play a central role in developing the language and communication of their deaf child. They also support the monitoring of their deaf child's progress.

1. Early years support teams provide parents with guidance on developing communication with their deaf child at home through play and other day-to-day activities.
2. Early years support teams provide parents with support and encouragement to develop their skills to play an active role in monitoring their child's development.
3. All assessments have a clear set of aims and outcomes which are used to benefit the deaf child and their family.
4. Professionals give parents full information as to the purpose and nature of any assessment and tests.
5. Parents receive a copy of results, reports and next steps in an appropriate format as well as information about how the results will be used.
6. Professionals are well trained in assessment approaches and have the skills to share the results in an open and collaborative manner.

3.3 Children have a right to be fluent in a language by the age of five.

1. Language and communication development is a collaborative process which depends on the relationship between the child and their parents. Therefore, the attachment between parent and child should be nurtured by all professionals involved.
2. The role of the professional is to encourage families to focus on the wider issue of communication and language development.
3. In the absence of additional needs, a deaf child has the capacity to achieve age appropriate language and communication skills.
4. Families should play a central role in monitoring their child's language development. Professionals should work in partnership with families to ensure age appropriate language by age of five and provide guidance to families on how to monitor communication development.
5. The role of the professional is to make families aware of the milestones and timelines associated with language development. When progress is not happening at an appropriate pace there should be a review to ensure that intervention can be changed or modified. Open and meaningful dialogue about a child's progress should be encouraged at any time.
6. Any child who is not reaching language milestones appropriately is assessed as soon as it is practical to try and identify or exclude an additional language problem.
7. Not all deaf children acquire the language originally chosen by the family. In order to achieve age appropriate language, the prospect of using two languages simultaneously or changing language approaches should be discussed with the family.

Good Practice from Around Scotland

In one area of Scotland the Family Support Plan is used with all families under the age of three. The educational audiologist attends the planning meeting as do all other professionals involved. To allow both parents to attend, the meetings are sometimes held in the late afternoon/early evening. The meetings generally take place in the family home and they decided who the plan will be shared with. Families are listened to and they provide valuable information on where the child is at. They also set their own priorities and next steps. The plan is reviewed every three months.

Family Experiences

I think when I was new to this [assessment], I can remember being very confused about it: "Why are you here? What is this PRESCAT for?" I genuinely did not know what a PRESCAT meeting was for, and I was invited along to this thing in the Psychological Services building, and I remember thinking, why? So it is a meeting, basically about education. So before you are getting to school, I think our son had his first one at 11 months, so you are under their watch. And it is actually very nice: everyone gets together every six months and says what they have been doing and puts some targets together for the next six months. And then once he was in mainstream nursery we started on this thing called an IEP, which is the Individual Education Programme, which is much more formal because when he was 2 it was all about is he going to build bricks! (NDCS, 2009)

We started talking and signing about emotions very early in Sam's life. Probably from sort of three months old, so if we were looking at a story on a video or signing a book I would introduce emotion, expressions. You know, "is the teddy bear sad?" Or you know, "why is the teddy bear sad?" So Sam now at least has a real range of emotions and emotion is part of his vocabulary, and he will try and experiment with his cross voice and his angry voice, and he will sign that at the same time. So I really feel that he can express his emotions. (Parenting a Deaf Child)



Reflective Questions

What can I do to ensure that the plans developed in partnership with the family are flexible and reflect the changing needs of the family?

How can I develop my skills in active listening?

FAMILY-FRIENDLY SERVICES

Standard 4 Providing Family-Friendly Services

Statement

All services working as part of the Early Support Team promote family-friendly services. Family-friendly services embrace the diversity of the family and acknowledge that each one has their own experiences, confidence and expectations. Family-friendly services regard parents not only as equal partners within a multi-disciplinary team (Watkin, 2002) but as the final arbiters regarding the needs and priorities for their child (Baguley et al, 2000). Professionals may be expert on the issue of deafness but the parent is the expert on the child. Family-friendly services recognise that services should develop the confidence and independence of families as it allows them to remain in control, make choices appropriate to their values and circumstances as well as better manage their child's support needs. Family-friendly services recognise that how services are delivered to families is as important as what is delivered.

*“Sorry,
hold on
a wee
minute,
what
does that
mean?”*

Therefore, a key feature of family-friendly services is the empowering of families by providing flexible access to services, continuity of care, open communication in an appropriate language, active listening and through all services putting the family in the driving seat (Baguley et al, 2000).

Rationale

Families have the right to be respected and regarded as the central member of an early support team.

There needs to be an active partnership with parents which should be characterised by listening.

All families are different and so services should be individualised and responsive to the needs of each family (Young & Tattersall, 2005; Young, 2002). Families have a right to expect that staff from every service are well trained, experienced and has appropriate skills in working with families.

An approach dominated by professional support can result in high dependency with families only feeling confident to make decisions or problem solve when supported by professionals (GIRFEC, 2008). How parents view their own expertise is important, as it will colour how confident they see themselves at bringing up their deaf baby (ANZPOD, 2009).



Criteria

In order to ensure that families can become confident decision makers the following should be established.

4.1 All service providers are aware of the principles of Family-Friendly Services and have written local guidelines based on these principles.

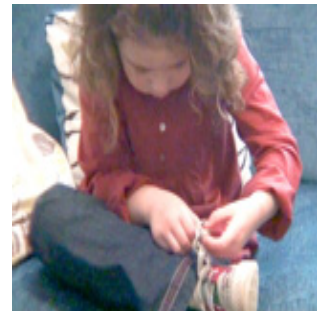
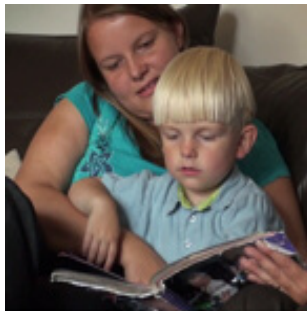
1. Families are actively involved in developing guidelines for working with families of deaf children.
2. The guidelines should recognise that all families are different.
3. The guidelines should state that families and professionals should work in partnership and there should be partnership between the agencies.
4. Families have a right to accurate and comprehensive information.
5. The attitude of the professionals should be characterised by listening.
6. The family-professional dialogue should be undertaken in appropriate language.
7. The guidelines have a written statement about inclusion, diversity and informed choice.
8. The guidelines are in a format which is accessible to parents and demonstrate flexibility to the needs of each child and family.
9. Services must be flexible and available at times that suit families, such as at evenings and weekends.

4.2 Service providers carry out an annual audit to evaluate the effectiveness and family-friendliness of their services, as well as identifying and implementing changes to improve their services.

1. An audit of services demonstrates that the views and experiences of parents are included.
2. The audit process incorporates parents' views of their child and family's needs.
3. Findings from the audit and any service development plans should be transparent and in a format accessible to families.
4. The early support team uses the quality rating tool contained within this document to facilitate this.

4.3 Family-Friendly Services plan for periods of transition in partnership with the family.

1. Education authorities must begin to gather information and views from any professional who has been working with a deaf child at least 6 months before they are due to enter formal pre-school provision.
2. Parents must be fully involved and engaged in this process, and everyone in the early years team as well as the nursery staff should be clear about the learning objectives of the deaf child.
3. Parents must be given information about their rights under the Education (Additional Support for Learning) Acts 2004 and 2009 in accessible formats.



Good Practice from Around Scotland

In one area of Scotland families receive many of the services they require in a location designed to suit their needs. During the first few months a child can need a number of impressions taken for ear moulds. It is not always possible for the families to attend the hospital where parking can be difficult. Also other siblings may need to be collected from school or have after school activities. To support this, the audiologist and educational audiologist make joint visits where ear mould impressions are taken and any other difficulties the family are experiencing are addressed. This allows for joined up working in a manner that suits each family's needs.

Family Experiences

So a lot of them speak in a kind of jargon that they know, but you are not aware of so a lot of the time you could be maybe sitting there and if you are not the type of person to come forward and say “Sorry, hold on a wee minute, what does that mean?” Then it would bypass you and you would not know what they meant by it ... Basically when they are speaking if they could speak a bit – maybe not clearer, but more in layman terms, rather than medical terms, that would be easier.

(NDCS, 2009)



Reflective Questions

How can I use my knowledge and understanding of family-friendly services to plan and produce better outcomes for families of deaf babies?

INFORMED CHOICE FOR FAMILIES

Standard 5 Providing Information and Communication with the Family

Statement

Families have a right to accessible and intelligible information about their deaf child. Information provided to the families in all areas should be evidenced-based, comprehensive and unbiased (Young, 2002). The information provided to families should not only develop their knowledge but also enhance their skills in making decisions that are appropriate to their family and their individual needs. Although families vary in their strengths, needs and capacities they each still have a right to be provided with informed choice. Effective communication is important as it allows families to comprehend complex topics and arrive at decisions that are appropriate for them. Informed choice is an evolving framework that should be flexible and allow the families to review and change their mind. Professionals should not make assumptions about the choices families will make (Eleweke et al, 2008).

“for families to see independent deaf adults could give optimism and alternatives”

Rationale

Families are the only people who fully understand the values and culture that are relevant to their child. The professionals' role is not to influence the decisions families make by promoting one choice over another (Bamford et al, 2009). Instead families should be given time and comprehensive information in an appropriate format. This could include verbal, written, digital and/or video. By providing information in this way it allows the wider family members to be involved, helps generate further questions and is a useful reference point for the future. An Informed Choice approach does not restrict information to options which are available in a given locality, nor does it allow personal views or beliefs to influence the giving of information. Information should be repeated as this helps parents comprehend and retain information (Young, 2002).

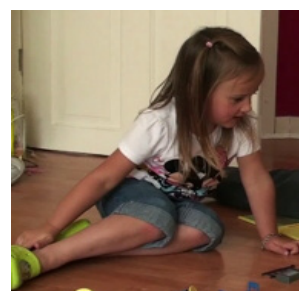
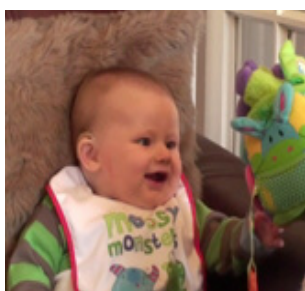


Criteria

In order to ensure that families can become confident decision makers and have access to comprehensive, unbiased and evidence-based information the following should be established.

5.1 All services involved in supporting a deaf child and their family adopt, and actively promote, a policy of informed choice.

1. Families are provided with comprehensive, accurate, unbiased, evidence-based information about all choices they make for their child.
2. Information is provided in a range of formats to suit each individual family's needs, including community languages.
3. The role of the professional is to assist families in making decisions appropriate for them. Families should be encouraged to focus on the key issues and evaluate all their options.
4. Services make no value judgements about one option over another and this is reflected in their strategic decision making and resource allocation.
5. Families are supported to reach decisions in ways that are sensitive to their individual strengths, resources, needs and experience.
6. Informed Choice is not seen as a one-off decision but as an ongoing process which should be capable of responding to changing circumstances.



5.2 Communication with families.

1. The role of the professional is to actively listen to families and allow them to make informed choices.
2. Professionals should not pre-judge the decisions that families will make. Each family should be treated individually and have access to all options.
3. At no stage on the family's journey should they feel pressurised into making decisions. Families must be given time to research and reflect the decisions appropriate to them.
4. Service providers adopt open and flexible policies that effectively endorse a range of possibilities and communicate all of these possibilities to families.
5. Families' decisions are respected and upheld by those working with them.

5.3 Access to other parents.

1. Families bring an insight and experience different from that provided by professionals. Therefore, to ensure informed choice families should be able to meet other parents of deaf children.
2. Families should have access to a wide range of families with different views and experiences.
3. Families should have access to family mentors provided by the voluntary sector such as the NDCS.

5.4 Access to deaf role models.

1. Deaf adults and children bring personal experience and insight. Therefore, to provide informed choice, services offer families opportunities to meet with deaf adults who have been trained to work with families of very young deaf children.
2. Services provide the opportunity for deaf children to regularly meet peers who are also deaf.
3. Families should have access to a wide range of deaf role models with different views and experiences.



Good Practice from Around Scotland

In one area of Scotland a toddler group has been set up so families with children with any degree of deafness can get to their events because the authority pays for taxi transport. In addition there are annual parties where families get together, again with taxi transport. There is also a sign language class for the family and friends.

Family Experiences

Having recently met a Deaf adult (BSL-user), I would have loved to have met her in the early days. I think signing is rarely given as an option. In the era of implants, oral seems to be the default position, unless there are 42 additional difficulties but for families to see independent deaf adults could give optimism and alternatives. (Parent, NDCS, 2011)

We actually do sign language as well, we have just started doing it. ... My husband and I go to it, and our daughter does the children's one, and her big sister does the older children's one. [we are working on her speech but] the way we see it, at the end of the day, if she takes her hearing aids out she is a deaf child, there is no ifs or buts ... With the sign language, if the mainstream school does not work when she is older then we can send her to another school, either a deaf school or a school that has a deaf base in it and then she will be mixing with deaf children ... and it means that when she is older – if it is in place, it is there, and if she doesn't want to use it, she does not have to. It is like another language really. (Parent, NDCS, 2009)



Reflective Questions

How can I provide families with a range of opportunities and experience to ensure that they can make informed decisions?

POSITIVE ABOUT DEAFNESS

Standard 6 A Positive Attitude Towards Deafness

Statement

How professionals present deafness will impact on the bonding process between parent and child as well as influence expectations for the future. Services should ensure that deafness is not presented as only a medical or scientific issue and that they are positive in their approach to deafness and its culture. The Informed Choice approach encourages Early Years professionals to positively support the choices parents make and not to make assumptions about their viewpoint (Young, 1999). An important guiding principle should be the development of a positive relationship with and positive attitude towards their child's deafness, and for the child themselves to develop a positive self image and ownership of their own deafness. It is also important that the extended family are supported to develop a positive attitude towards the child's deafness.

"I now think what was there to worry about?"

Rationale

There are many different ways of thinking about deafness. Three particularly well-developed ways have differences between them which Early Years professionals need to be aware of. The medical viewpoint, the social barriers viewpoint and the cultural viewpoint all have justification and are valid ways of thinking about deafness, whether the parents are deaf or hearing. However, it is important for Early Years staff to reflect on their own training and the influences which have shaped their attitudes to deafness to ensure that this does not bias the advice and support offered to families (Young, 2002).

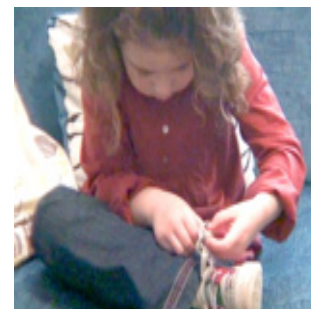


Criteria

In order to ensure that families can have a positive attitude, the following should be established.

6.1 All early years support workers have received training enabling them to communicate positively about deafness. This training includes information on the different views of deafness and on how these different ways of understanding deafness can impact upon the deaf child and their family.

1. Professionals show a positive attitude about deafness and to the range of choices which parents make for their child.
2. All staff in contact with families of deaf children undertake deaf awareness training.
3. All staff have personal experience of interacting with a wide range of deaf adults as well as children.
4. Staff are aware of the perceptions of deafness within different cultural communities, and reflect this in the family support plan.

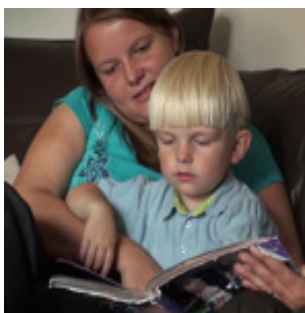


6.2 Professionals working with the deaf child and their family provide unbiased and accurate information on all communication methods.

1. Professionals stress the importance of language development rather than a specific mode of communication. Language development is a collaborative process with great emphasis being placed on the relationship between the child and their brothers, sisters, friends and important adults.
2. All communication methods are discussed with the family. Families should be advised that there are no 'wrong' choices and the 'right' choices are those that work best for the child and the family.
3. Professionals respect and reflect on parental opinion about the effectiveness of support their child is receiving.
4. Parents are aware of their right to request an assessment of their child's additional support for learning needs by the local authority at any time.

6.3 Services offer families opportunities to meet with deaf adults who have been trained to work with families of very young deaf children, as well as opportunities for deaf children to access peers who are also deaf.

1. Deaf adults and children bring personal experience and insight. Therefore, to provide informed choice, services offer families opportunities to meet with deaf adults who have been trained to work with families of very young deaf children.
2. Services provide the opportunity for deaf children to regularly meet peers who are also deaf.
3. Families should have access to a wide range of deaf role models with different views and experiences.



Good Practice from Around Scotland

In one area of Scotland families are routinely introduced to deaf children and their families. Families are given the contact details of a number of families who have made different choices (cochlear implant, hearing aids, signing and oral). The families are also provided with access to deaf adults who will make a home visit, if required.

Family Experiences

I found out Tracy was deaf from birth. She was profoundly deaf. My feeling was it was alright because I'd been brought up signing and having Deaf people in my family. It was harder on Tracy's mum because she didn't know about signing. My mum was the only deaf person she'd met.

(Parent of a deaf family, 2011)

We don't really know any deaf people but now going to weekends with deaf children and meeting deaf children and meeting other people I now think what was there to worry about?

(Parent of a deaf child, 2011)



Reflective Questions

When working with a family of a deaf child how can I ensure that my own beliefs and values are not imparted to the family, either consciously or subconsciously?

How can I ensure that my approach to deafness facilitates natural interaction where parents are relaxed and enjoy their child?

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Young A & Tattersall H (2005) Parents' of deaf children evaluative accounts of the process and practice of universal newborn hearing screening. **Journal of Deaf Studies and Deaf Education** 10(2), 134-145.

Useful organisations

British Deaf Association (BDA)

British Deaf Association Scotland
1st Floor, Central Chambers
Suite 58
93 Hope Street
Glasgow
G2 6LD
Telephone: 0141 248 5554
Fax: 0141 248 5565

Deaf Action

Head Office
49 Albany Street
Edinburgh
EH1 3QY
Telephone: 0131 556 3128
Textphone: 0131 557 0419
Fax: 0131 557 8283
SMS: 07775 620757
Videophone: 82.71.100.121

Deaf Connections

100 Norfolk Street
Glasgow
G5 9EJ
Scotland
Telephone: 0141 420 1759
Fax: 0141 429 6860

Deafblind Scotland

21 Alexandra Avenue
Lenzie
Glasgow
East Dunbartonshire
G66 5BG
Telephone: 0141 777 6111
Fax: 0141 775 3311

DeafVision

Dumfries and Galloway Development Worker
The Hub
Friar's Vennel
Dumfries
DG1 2RL
Call or text: 07985382129

Enquire

Children in Scotland
5 Shandwick Place
Edinburgh
EH2 4RG
Telephone: 0845 123 2303
Text relay: 18001 0845 123 2303
Fax: 0131 228 9852
Email: info@enquire.org.uk
Website: enquire.org.uk

NDCS Scotland

Second Floor
Empire House
131 West Nile Street
Glasgow
G1 2RX
Telephone: 0141 354 7850
Fax: 0141 331 2780

To access support from your local family officer, or for free impartial advice on any aspect of childhood deafness, contact the NDCS Helpline: 0808 800 8880

Local Deaf Children's Societies:

For details of local groups of parents of deaf children meeting in your area contact the NDCS Scotland office using the details above.

RNID Action on Hearing Loss

RNID Scotland
Empire House, 131 West Nile Street, Glasgow, G1 2RX
Telephone: 0141 341 5330
Textphone: 0141 341 5347
Fax: 0141 354 0176

Scottish Cochlear Implant Programme

Crosshouse Hospital
Kilmarnock
KA2 OBE
Telephone: 01563 827323
Fax: 01563 827507
Text: 07824598277
Email: cochlear.implant@aaaht.scot.nhs.uk
Website: www.sciponline.co.uk

Scottish Council on Deafness (SCOD)

Scottish Council on Deafness
Central Chambers Suite 62
(1st Floor)
93 Hope Street
Glasgow G2 6LD
Telephone: 0141 248 2474
Textphone: 0141 248 2477 and 1854
Fax: 0141 248 2479

Scottish Sensory Centre

Contact for information or appointment:
Monday to Friday 9.30 am-4.00 pm
Telephone: 0131 651 6501
Textphone: 0131 651 6067
Fax: 0131 651 6502
Email: sscmail@ed.ac.uk
Website: <http://www.ssc.education.ed.ac.uk>

Sense Scotland

43 Middlesex Street
Kinning Park
Glasgow
G41 1EE
Telephone: 0141 429 0294
Textphone: 0141 418 7170
Fax: 0141 429 0295

West Scotland Deaf Children's Society

281a Central Chambers
93 Hope Street
Glasgow
G2 6LD
Telephone (Voice and Text): 0141 243 2958
Fax: 0141 243 2203
Email: wsdcs@btconnect.com

EFFECTIVE EARLY INTERVENTION

1.1 Standard - Families are provided with equal access to audiological services.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>There is no locally agreed policy or written pathway for multi agency involvement.</p> <p>There is no evidence of time spent with parents preparing them for the assessment.</p> <p>Information is not provided to families about the range of professionals they can contact for more information, pre or post diagnosis.</p> <p>There is no evidence of later (post birth) diagnoses accessing the early years service, and no evidence of self referrals from concerned parents.</p> <p>There is no evidence of early years services supporting children with a unilateral loss or those with glue ear.</p>	<p>All families have equal opportunity to have their child screened. There are clearly pathways from the screening process to diagnostic assessments and on to engagement with early support teams.</p> <p>The pathways and associated policy should make clear that parents are made aware of the purpose of the assessments being undertaken.</p> <p>Families are able to access early intervention at any point in the process.</p> <p>The care pathways take into account children who pass the screen but are identified as having a risk factor.</p> <p>A policy should provide equal access to children with a unilateral loss and those with glue ear.</p>		
Next Steps		People Responsible	

1.2 Standard - Health and audiology services have written guidelines for staff on how to share the news with parents, when and where this should happen and who should tell parents that their child is deaf.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>There are no written guidelines regarding communicating the news.</p> <p>There is no policy that states who the staff involved are, the timing and the location.</p> <p>There has been no family involvement in producing written guidelines regarding sharing the news.</p>	<p>There are written guidelines regarding sharing the news. This policy includes specific reference to the staff involved, the timing and location. Families and staff are aware of this document and use it as a working document.</p> <p>The guidelines should state that a member of the early support team should be present during the time the news is shared with the family. This person should be the named person in the first instance.</p> <p>Families have contributed to the written guidelines regarding sharing the news.</p>		
Next Steps		People Responsible	

1.3 Standard - All services 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.				
Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence	
<p>All staff involved in sharing the news are not fully qualified and have no experience of working with deaf children (0-3) and families.</p> <p>All staff involved in sharing the news have no additional postgraduate qualifications in working with deaf children and families (0-3).</p> <p>All staff involved in sharing the news do not have a CPD portfolio that demonstrates ongoing training in working with deaf children and families (0-3).</p>	<p>All staff involved in sharing the news are fully qualified with at least two years experience of working with deaf children (0-3) and families.</p> <p>All staff involved in sharing the news have additional postgraduate qualifications in working with deaf children and families (0-3).</p> <p>All staff involved in sharing the news have a CPD portfolio that demonstrates ongoing training in working with deaf children and families (0-3).</p> <p>Staff who are involved in sharing the news can work effectively in BSL and/or with interpreters.</p>			
Next Steps		People Responsible		

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

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>Families are not given a copy of any hearing assessments in an appropriate format which detail their child's deafness.</p> <p>Families are not provided with an information pack.</p> <p>Families are not given information about the role of the named person.</p> <p>Families are not provided with information on the various agencies involved.</p>	<p>Families are given a copy of any hearing assessments (within 7 days) in an appropriate format which detail their child's deafness.</p> <p>Families are provided with an information pack which will include information on; deafness; contact details of local and national organisations; websites from organisations that provide balanced and unbiased information. The importance of developing a fluent language by age five is also included.</p> <p>Families are given information about the role of the named person.</p> <p>Families are provided with information on the various agencies involved. This will include information on their role in the initial assessment process as well as with ongoing support.</p>		
Next Steps		People Responsible	

1.5 Standard - The early years support services are available immediately after deafness is confirmed.				
Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence	
There is not an agreed policy for written referrals to the early support team.	<p>There is an agreed policy for written referrals to the early support team. This should specify that a referral should be made within one day of the family being informed regarding the confirmation of deafness.</p> <p>The named person from the early support team will make a visit at a time convenient to the family; this should ideally be within one week of the initial contact.</p> <p>The family should have a contact details (phone number/email/SMS) for the named person.</p>			
Next Steps		People Responsible		

1.6 Standard - Families are offered the opportunity for their deaf child to have aetiological investigations. These investigations are carried out in accordance with local protocols based on nationally agreed standards.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>No aetiological investigations are offered to the family.</p>	<p>Families are offered the opportunity for their child to have aetiological investigations. These should comply with national standards.</p> <p>The aims and possible outcomes of investigations should be discussed with the families.</p> <p>The doctor should provide parents with accurate and unbiased information so that they can make an informed decision. The final choice lies with the parents.</p> <p>Some parents may decide against investigations and their views should be respected.</p>		
Next Steps		People Responsible	

WORKING TOGETHER IN PARTNERSHIP

2.1 Standard - All services (health, education and social services) must develop clear written policies 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.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>There is no policy about working with families.</p> <p>Or if there is a policy, it has been drawn up by professionals without involving families.</p> <p>If there is a policy, it is kept in files in professionals' offices.</p>	<p>All services have a policy statement that demonstrates a commitment to providing a high quality integrated service for families and children from birth to three years.</p> <p>All service policies and practices are developed in partnership with families.</p> <p>The statement should state how the service/professionals will work in partnership with families and other services.</p> <p>There is a specific mechanism in place that allows for an annual review of the joint policy. This should include a review both at an individual service level and multi-agency level.</p> <p>The policy documents are in a variety of formats which are accessible to parents.</p>		
Next Steps		People Responsible	

2.2 Standard - The multi-disciplinary team includes parents and named individuals from all services supporting the deaf child.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>The multi-agency team have no regular meetings.</p> <p>The multi-agency team have limited or no training opportunities.</p> <p>The team has no formal policy setting out the roles and responsibilities of the team members.</p> <p>The family member is not regularly invited to or does not attend the team meetings.</p> <p>The family member does not consult or represent local groups and reflect their opinion.</p>	<p>The multi-agency team have regular meetings (at least 4 a year).</p> <p>The multi-agency team have regular training in order to develop good relationships between agencies.</p> <p>The team has a policy setting out the roles and responsibilities of the team members.</p> <p>The family member is recognised in the policy and through their involvement in the meetings as a valued and equal member of the team.</p> <p>The family member consults or represents local groups and reflect their opinion.</p>		
Next Steps		People Responsible	

2.3 Standard - The early years support team has agreed protocols for referrals, recording and sharing information, as well as planning, delivering and reviewing support to families and assessing deaf children.				
Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence	
<p>There is no policy for receiving referrals (from practitioners or self-referring parents).</p> <p>All agencies do not allow staff time to collaborate on joint working and planning.</p> <p>Planning does not recognise the shared skills of staff and results in excessive workloads.</p> <p>There is no multi-agency planning. Families are not involved in creating multi-agency plans.</p> <p>Multi-agency working, planning and practice does not reflect current guidance, research, and established good practice.</p> <p>Next Steps</p>	<p>There is clear policy and practice for receiving referrals (from practitioners or self-referring parents).</p> <p>All agencies involved allow staff time to collaborate on joint working and planning.</p> <p>Planning should promote shared skills and minimise workload. Multi-agency planning identifies family strengths, needs and decisions that is sensitive and acknowledges family diversity.</p> <p>The family is involved in developing any multi-agency plans.</p> <p>Multi-agency working, planning and practice reflect current guidance, research, and established good practice.</p>			People Responsible

2.4 Standard - There is a named person responsible for coordinating the early years support services in partnership with the family.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>The family is not given information in an appropriate format about the role of the named person.</p> <p>The family does not have the contact details of the named person (phone number/email/SMS).</p> <p>The named person does not attend all the family support plan meetings and does not assist in the coordination of services.</p> <p>The named person is given no time, training and support by agencies involved.</p> <p>The named person is not evaluated annually.</p>	<p>The family is given information in an appropriate format about the role of the named person. This should include what the named person can and cannot do.</p> <p>The family has the contact details of the named person (phone number/email/SMS).</p> <p>The named person attends all the family support plan meetings and assists in the coordination of services.</p> <p>The named person is given time, training and support by all agencies so as to ensure they perform their role effectively.</p> <p>The named person is evaluated annually and all team members, including the family contribute to this evaluation.</p>		
Next Steps		People Responsible	

2.5 Standard - The voluntary sector is recognised as a key member of the multi-disciplinary team supporting a deaf child and their family.				
Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence	
<p>Parents are not given any information about voluntary organisations who can support them.</p> <p>Professionals have little or no contact with the voluntary sector and do not have access to resources developed by voluntary organisations.</p> <p>There is no voluntary sector representation on local CHSWGs or equivalent.</p>	<p>Parents are routinely given information about local and national voluntary organisations who can support them.</p> <p>Professionals have regular contact with the voluntary sector and have access to resources developed by voluntary organisations</p> <p>There is regular representation of the voluntary sector on the local CHSWG.</p>			
Next Steps		People Responsible		

EMPOWERING FAMILIES

3.1 Standard - The early years support team draws up a Family Support Plan for each deaf child.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>There is no Family Support Plan to support the family and the deaf child.</p> <p>Families have limited input in determining the current priorities within the Family Support Plan.</p> <p>The families do not decide who this will be shared with.</p> <p>The Family Support Plan does not specify how the targets will be supported and the roles of personnel involved. It also does not specify when the plan will be reviewed.</p>	<p>Families in conjunction with the early support team draw up a Family Support Plan to support the family and the deaf child.</p> <p>Families, with support from professionals, determine the current priorities within the plan. The families decide who this will be shared with.</p> <p>The plan incorporates joint and shared assessment practices and acknowledges the child's needs, strengths and weaknesses and allows these to be built on and developed.</p> <p>The Family Support Plan specifies how the targets will be supported and the roles of personnel involved. It also specifies when the plan will be reviewed.</p>		
Next Steps		People Responsible	

3.2 Standard - Parents play a central role in developing the language and communication of their deaf child. They also support the monitoring of their deaf child's progress.				
Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence	
<p>Parents do not have any information about assessment tools.</p> <p>Members of the early years team do not routinely give information about assessment to parents.</p> <p>Parents do not have information about the purposes of assessments or what they involve.</p>	<p>Parents are provided with an Early Support Monitoring Protocol and are made aware of how to use it.</p> <p>The early years team regularly provides accessible training events for parents of deaf children in the 0-3 age group, both informally in parents' houses and more formally.</p> <p>Parents are provided with a written explanation of any assessments undertaken with their child.</p> <p>This information is in an accessible format for parents and they can look it up independently e.g. on a website or in a booklet.</p>			
Next Steps		People Responsible		

3.3 Standard - Children have a right to be fluent in a language by the age of five.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>Professionals do not make families aware of the milestones associated with their child's language development.</p> <p>Staff are not trained in presenting information about communication without bias. There is no discussion about the options available if the child does not develop the family's chosen language at an appropriate pace or level.</p> <p>There are no provisions that ensure discussion about a child's progress is an ongoing process.</p> <p>All staff are not trained in supporting family to monitor and assess their child's progress.</p>	<p>Professionals make families aware of the milestones associated with their child's language development.</p> <p>Staff are trained in presenting information about communication without bias. This should include a discussion about the options available if the child does not develop the family's chosen language at an appropriate pace or level.</p> <p>Services develop provision that ensure discussion about a child's progress is an ongoing process. It is a collaborative process involving the family and professionals as equal partners.</p> <p>All staff are trained in supporting the family to monitor and assess their child's progress.</p>		
Next Steps		People Responsible	

FAMILY-FRIENDLY SERVICES

4.1 Standard - All service providers are aware of the principles of Family-Friendly Services and have written local guidelines based on these principles.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>Families are not aware of any guidelines for working with families of deaf children.</p> <p>Families have not been involved in checking the Family-Friendly Services guidelines.</p> <p>The guidelines do not have a written statement about inclusion, diversity and informed choice.</p> <p>Family-Friendly Services guidelines are in a single format which might not suit the needs of all parents.</p>	<p>Families have been actively involved in creating written guidelines for working with families of deaf children.</p> <p>Families have been actively involved in checking how effective the Family-Friendly Services guidelines are.</p> <p>The guidelines have a written statement about inclusion, diversity and informed choice.</p> <p>Family-Friendly Services guidelines are in a format which is accessible to parents and demonstrate flexibility to the needs of each child and family.</p>		
Next Steps		People Responsible	

4.2 Standard - Service providers carry out an annual audit to evaluate the effectiveness and family-friendliness of their service, as well as identifying and implementing changes to improve service provision.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>The family-friendly services guidelines do not include information about how it will be reviewed.</p> <p>If the review exists it does not contribute to the service development plan.</p> <p>The family-friendly services audit has no criteria for evaluating service provision.</p> <p>Findings from the audit and any service development plans are inaccessible to families.</p> <p>If there has been an audit, it is not clear how the information has been gathered.</p>	<p>The family-friendly services guidelines specifies that an annual audit is undertaken using this document at both individual service level and multi-agency level.</p> <p>Each audit should contribute to the service development plan with specific priorities, actions and named practitioners responsible.</p> <p>The audit has specific criteria for evaluating service provision.</p> <p>An audit of services demonstrates that the views and experiences of parents are included.</p> <p>The audit process incorporates parents' views of their child and family's needs.</p>		
Next Steps		People Responsible	

4.3 Standard - Family-friendly services plan for periods of transition in partnership with the family.				
Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence	
<p>No pre-school assessment meeting takes place.</p> <p>Professionals are not aware of the requirements of the ASL Act to identify and support pre-3 disabled children.</p> <p>No deaf children have their additional support for learning needs assessed.</p> <p>Parents are not made aware of the range of pre-school provision on offer within their local area and beyond.</p>	<p>Pre-school assessment meetings are established in good time and update meetings held regularly, involving parents.</p> <p>Professionals are fully aware of their obligations to work in partnership with other agencies and develop support plans and strategies for pre-3s, with reference to the Supporting Children's Learning Code of Practice.</p> <p>IEPs and CSPs are considered as options for deaf children, and parents are made fully aware of the legal status of these plans. Where a school or nursery decides not to open such a plan, this is explained to the family.</p>			
Next Steps		People Responsible		

INFORMED CHOICE FOR FAMILIES

5.1 Standard - All services involved in supporting a deaf child and their family adopt, and actively promote, a policy of informed choice.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>Parents have no understanding of 'informed choice' and are provided with no information about the full range of communication options open to their child.</p> <p>The skills base of the professionals prefers one form of communication over another.</p> <p>Parents are not supported to develop the skills to support progress with their child's language and communication, whatever the method.</p>	<p>Parents know what the principles of informed choice are and are provided with information about the full range of communication options open to their child.</p> <p>The skills base of the professionals available to work with the families is of equal level in all communication options. Professionals working with signing children should be qualified to Signature Level 3 or equivalent, as a minimum.</p> <p>Professionals working with deaf children should have Higher English and/or a relevant qualification (degree/postgraduate qualification).</p> <p>Parents are fully supported to develop the skills to support progress with their child's language and communication, whatever the method. Parents are encouraged to review the choices they have made.</p>		
Next Steps		People Responsible	

5.2 Standard - Communication with families.				
Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence	
<p>Service providers do not adopt open and flexible policies that effectively endorse a range of possibilities and communicate all of these possibilities to families.</p> <p>There is no policy to provide guidance on communication and listening.</p>	<p>Service providers adopt open and flexible policies that effectively endorse a range of possibilities and communicate all of these possibilities to families.</p> <p>All services have policies that clearly state the following:</p> <ul style="list-style-type: none"> a) That professionals should not pressurise families to make decisions. b) That family decisions should be respected. <p>Professionals are encouraged to listen to families.</p>			
Next Steps		People Responsible		

5.3 Standard - Access to other parents.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>Services do not provide all families with information on local voluntary and parent groups.</p> <p>Services do not provide the opportunity for families to meet.</p> <p>Families do not have access to a wide range of families with different views and experiences.</p> <p>Families do not have access to family mentors provided by the voluntary sector such as the NDCS.</p>	<p>Services provide all families with information on local voluntary and parent groups.</p> <p>Services provide the opportunity for families to meet.</p> <p>Families should have access to a wide range of families with different views and experiences.</p> <p>Families should have access to family mentors provided by the voluntary sector such as the NDCS.</p>		
Next Steps		People Responsible	

5.4 Standard - Access to deaf role models.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>Service does not offer any opportunities for families of deaf children to be introduced to deaf adults.</p> <p>Service does not offer any opportunities for deaf children to meet other deaf children.</p>	<p>Early Support Teams have a bank of deaf adults, who use a wide range of communication methodologies and have a wide variety of degrees of hearing loss, and who have received training, readily available to meet with families of young deaf children, and actively arrange introductory sessions.</p> <p>Services for deaf children facilitate opportunities for deaf children throughout the local authority area to meet and play with other deaf children in an informal setting.</p> <p>Service refers families to local and national voluntary sector agencies to facilitate introduction and interaction with other families.</p>		
Next Steps		People Responsible	

POSITIVE ABOUT DEAFNESS

6.1 Standard - All early years support workers have received training enabling them to communicate positively about deafness. This training includes information on the different viewpoints of deafness and on how these different ways of understanding deafness can impact upon the deaf child and their family.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>Staff hold one of these viewpoints as predominant and have not reflected on the range of viewpoints about deafness.</p> <p>Staff prioritise one viewpoint in discussions with families of deaf children.</p>	<p>All staff working in the Early Support Team have had training about the three viewpoints of deafness.</p> <p>The training includes the opportunity to reflect on the professionals' own development and the impact the different viewpoints often has on families of deaf children.</p> <p>When working with families of young deaf children, staff will show positive attitudes about deafness and to the range of choices which parents make for their child.</p>		
Next Steps		People Responsible	

6.2 Standard - Professionals working with the deaf child and their family provide unbiased and accurate information on all communication methods.				
Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence	
<p>Parents are only informed about a limited range of communication methods – generally the ones which are most readily available in the local authority.</p> <p>Parents are encouraged to make a commitment to just one approach early on in their child's development.</p>	<p>Professionals give unbiased and accurate information about ways in which deaf children can use speech, BSL, SSE, gesture and home languages.</p> <p>Bilingualism and multilingualism are valued by Early Support Team and the cognitive advantages are understood.</p> <p>Parents know they do not have to make one irrevocable choice about communication methods.</p>			
Next Steps		People Responsible		

6.3 Standard - Services offer families opportunities to meet with deaf adults who have been trained to work with families of very young deaf children, as well as opportunities for deaf children to access peers who are also deaf.

Score 1 No elements of the quality statement criteria are met (or not evident)	Score 5 Fully compliant with good to best practice as indicated by quality statement criteria	Evidence	Self-assessment score based on evidence
<p>Parents are only informed about a limited range of communication methods – generally the ones which are most readily available in the local authority.</p>	<p>Professionals give unbiased and accurate information about ways in which deaf children can use speech, BSL, SSE, gesture and home languages.</p> <p>Bilingualism and multilingualism are valued by Early Years staff and the cognitive advantages are understood.</p>		
Next Steps		People Responsible	

Appendix 1: Glossary

Appropriate format – providing information in a variety of formats allows families to access information in their preferred mode of communication. It also allows families to refer to it at a time of their own choosing. Formats could include written, verbal, digital and/or video/DVD.

ASL Act – the Additional Support for Learning Act (2004), which was amended in 2009. The Act sets out the Scottish approach to how schools should work with pupils who have additional needs.
<http://enquire.org.uk/>

Aetiological investigations – finding out why a child is deaf. Parents often want to know this, although it is not always possible to discover the reason.

Attachment – the strong bond between parent and baby which encourages a healthy and happy start in life.

Audit tool – a method that a work team can use to measure their level of success. The team gathers evidence from its work to decide on how good their services are. Parents and professionals may also be involved in auditing services in other local authorities.

British Sign Language (BSL) – the language of the Deaf community in the UK. BSL is a visual gestural language with its own grammatical rules, different from English. There are approximately 100,000 Deaf BSL users in the UK.

CHSWG – Pronounced ‘chizzywig’. Children’s Hearing Services Working Group. A development set up by the Health Service to receive comments and feedback from parents and deaf young people themselves about audiology services. Voluntary organisations are often also on these groups.
<http://www.scotland.gov.uk/Publications/2009/01/23140147/11>

Cognitive advantages of bilingualism and multilingualism – most children in the world use more than one language. There are well-documented advantages in having more than one language. But to develop more than one language, children have regular contact with adults and children who are using that language. Deaf children have just as much potential to be bilingual or multilingual as any other child.
<http://www.bilingualism-matters.org.uk/>

Communication methodologies – different ways deaf children use to communicate. For example, using speech (sometimes called an oral method), using British Sign Language, using Sign Supported English which is talking and signing at the same time, or using a more basic sign system such as Makaton or Signalong.

Community languages – are languages which are used by different communities, sometimes in the same local area to each other, for example Polish, Punjabi, British Sign Language, Cantonese.

Conductive losses – deafness caused by a problem in the middle ear. It may not be as severe as inner ear deafness, but can still affect educational outcomes significantly.

CPD portfolio – a record of continuing professional development which shows recent training courses attended.

Criteria – these points give details about how the standard is to be achieved.

Curriculum for Excellence – From 2010 Scottish schools have been following a new curriculum which aims to produce confident and independent young people. It provides a coherent, more flexible and enriched experience for children aged 3 to 18, wherever they are educated.

<http://www.ltscotland.org.uk/understandingthecurriculum/whatiscurriculumforexcellence/index.asp>

Deaf – means all forms of childhood deafness, including mild, unilateral and temporary losses, such as glue ear. In this document, it is assumed that early years provision of the level described is routinely offered to families of children with a permanent confirmed hearing loss.

Deaf awareness training – this is training usually taught by deaf people themselves which outlines the experiences deaf people face in everyday life and work. This training is useful even for qualified teachers of deaf children, for example to improve their understanding of how to work with a sign language interpreter or different ways to communicate by phone with a deaf person.

Deaf role model – a deaf adult, who may use speech or sign or both, who gets to know the family with a deaf baby or participates in early years activities with families. This role could be paid or voluntary depending on the local area.

Diagnostic assessments – tests which give more information than the simple pass/refer outcome of the screening test. For example in the first few months a deaf baby's life there will be an attempt to find out what the baby can hear at different frequencies.

Early intervention – now that deaf babies are identified in the first few weeks and months of life, the early years team starts to work with the family much earlier too. The intervention is focused on the family's needs and could be home visits, phone calls, emails, SMS, provision of specialist childcare etc. Members of the early years team who work with families in this way could be speech and language therapists, teachers of deaf children, educational audiologists, audiologists or support workers.

Early Support Team – refer to a group of professionals working in partnership with the parents or carers of the deaf child. The team could include a speech and language therapist, a teacher of deaf children, an audiologist, an educational audiologist, a support worker, deaf mentor, and voluntary worker. The named person is a team member and families are regarded as equal partners in the team. The early support team may also be known as the multi-agency team.

The Early Support Team members have the following skills or receive additional training in:

- Emotional support and counselling skills.
- Providing accurate and unbiased information to families.
- Providing the family and other team members with up-to-date and accurate information. All members should have written copies of all current assessments, test results and reports.
- Monitoring progress of the child's development. This should include early child development as well as language and communication.
- Confidentiality - parents must know to whom information about their child and family is given.
- Deaf awareness training.

Early Years Framework – the Government's policy guidance on Early Years work launched in 2009.

<http://www.scotland.gov.uk/Publications/2009/01/13095148/0>

Educational audiologist – a teacher of deaf children who has received additional training in audiology. The educational audiologist works closely with the health service audiologist, with other teachers of deaf children and with parents. Not every local authority has one.

Family – means a range of individuals that play an important role in the deaf child's life. This could include the immediate family as well as siblings, grandparents, extended family members and other members of the community such as family friends.

Family mentor – a volunteer from a voluntary organisation who has regular contact with a family. This person should have a CRB check and have had some training in their role. The mentor could be deaf or hearing and in some cases may also be the parent of a deaf child or young person.

Family Support Plan – refers to a plan drawn up by the early years team, which includes the family of the deaf baby or child. This plan sets out the priorities of the families, identifies next steps and says who is responsible for doing what. The Family Support Plan can be the same document as the **Individual Management Plan** which the audiologist should draw up.

Getting it Right for Every Child (GIRFEC) – a Scottish policy which sets out ways agencies such as health, education and social services should work much more closely together and communicate better to support children more effectively.

<http://www.scotland.gov.uk/Topics/People/Young-People/childrenservices/girfec/programme-overview>

Glue ear – temporary deafness caused by fluid or pus building up in the middle ear. This can be a fluctuating hearing loss and may impact on the development of spoken language.

Informed choice – before families make decisions about the services they would like their child to have, they need all the facts. Informed choice is a way of thinking which was first used in the health service. It means that professionals working with families of deaf children should set out all the options and not favour one particular approach. This is a new way of working for some professionals, who in the past would have recommended one particular approach.

IEPs and CSPs – Individual Educational Plans and Coordinated Support Plans. An IEP sets out support at a nursery or school level for a child with additional support needs. Some children will also need a CSP, which involves several agencies. Different local authorities sometimes have other names for the IEP. There is debate about how many deaf children get or need a CSP.

Inclusion – the approach suggests that schools need to change to meet the needs of all their pupils, and that usually a child with a disability should attend their local school. This principle underlies Scottish legislation, eg; the ASL Act. There is debate about what the term means for deaf children, particularly for those who use sign language.

Monitoring Protocol – a detailed checklist which parents can fill in with other members of the Early Support Team about their deaf child's progress with spoken and signed language, play and other developmental milestones. It is available for download at: <http://www.education.gov.uk/childrenandyoungpeople/sen/earlysupport>

Multi-agency teams – a team with staff from several professional backgrounds or departments such as health, education and social services. See Early Support Team.

Named person – refers the person from the Early Support Team who has the main contact with the family of the deaf child. This person is sometimes called a link worker or key worker. This will probably be the person the family see most often or who visits the family at home. It could be a speech and language therapist, a teacher of deaf children, an audiologist, educational audiologist or a social worker. The named person should have knowledge of who the key professionals working with the child and family are and how to contact them. He/she should also have the ability to introduce families to other families with deaf children and to deaf people.

Before working with families the named person should have skills and additional training in:

- presenting information without bias;
- ability to demonstrate experience in family-friendly practices;
- knowledge and understanding of different communication methods;
- knowledge and understanding of different types of hearing loss;
- ability to work in a team and to coordinate multi-agency teams.

National Deaf Children's Society – a UK-wide association of parents of deaf children. It has local groups run by parents and provides information and advice to parents and professionals who work with deaf children. <http://www.ndcs.org.uk/>

Newborn Hearing Screening Programme (NHSP) – from 2004 all Scottish babies have been screened with a hearing test in the first week of life. In Scotland the test that is used will depend on the area that you live.

Paediatric – about children. A Paediatrician is a doctor who works with children.

Protocols – ways of working which are set down in steps so that everyone knows about them and knows what to do in different situations.

Quality Rating Tool – the part of this document which is set out as a grid with column headings 1 and 5. The examples under column 1 show poor practice and 5 show excellent practice. Early Support Teams can use these examples to help them judge how good their own service is.

Quality Standards in Paediatric Audiology – this document outlines the way audiology departments are expected to work with the families of deaf children. Parents are sometimes involved in auditing services using these standards.
<http://www.scotland.gov.uk/Publications/2009/04/27115728/0>

Rationale – this section gives the reasons why we think the standard is needed.

Referral – the official notification that a new deaf baby or child is diagnosed. An audiologist in the Health Service may make a referral to the early years team and from this point the team will work with parents to discuss what services are needed. Referrals are always written.

Scottish Sensory Centre (SSC) – funded by the Scottish Government and based at the Moray House School of Education in the University of Edinburgh. It provides training and support for teachers of deaf and teachers of visually impaired children, parents and the young people themselves.
<http://www.ssc.education.ed.ac.uk/>

Sharing the news – after the screening test and the further diagnostic assessments, then the results are given to the parents by members of the early support team.

Signature level 3 or equivalent – a recognised level of sign language fluency which professionals working with deaf children who sign should aim for. It is approximately the same level as a Higher.

Single Outcome Agreements – since 2007 in Scotland local authorities have had individual agreements with the Government to show how they will improve services.
<http://www.scotland.gov.uk/Topics/Government/local-government/SOA>

Statutory service providers – organisations funded by the government which provide services such as health, education etc.

Supporting Children's Learning Code of Practice – guidance aimed mainly at teachers about how to implement the ASL Act. (Revised 2010).
<http://www.scotland.gov.uk/Publications/2010/08/11140218/0>

Teacher of the deaf – a qualified teacher who has undergone further training to specialise in working with deaf children aged 3-18. Some teachers of deaf children have had further training in work with the 0-3 age group and their families.

Unilateral deafness – deafness in one ear only. Usually these children learn spoken language at the expected age, but they will probably find it difficult to hear in noisy surroundings.

Views of deafness – a way of thinking about deafness. Different groups of people hold different perspectives on deafness. Doctors and health service staff have often seen deafness as something which needs to be cured – a medical model. A social model of disability suggests that deaf people have an impairment and that society needs to change to give better access for deaf citizens. A cultural model of deafness sees deaf people who use sign language as a minority community. Most people who work with deaf people or who are deaf themselves are influenced by several of these approaches at the same time.

Voluntary sector – organisations which are not funded directly by the Government but which provide help to families of deaf children, for example NDCS, BDA, RNID.

Appendix 2: Example Family Support Plan

Family Support Plan for Grace

This plan was written on 20/01/11

This plan was discussed and agreed by the following people. Everyone agreed to work towards the next steps in this plan.

This plan should not be shared with anyone other than the people listed without asking the family first.

Name	Title	Phone Numbers
John and Mary	(Parents)	
Brian Shannan	(Educational Audiologist)	
Jean Boyle	(Speech and Language Therapist)	
Brady Hall	Audiologist	
Alan McGee	Teacher of the deaf	

The family consents to this plan being shared with the following people:

Health Visitor
Paediatrician
Sensory Support Service
Audiology Department Victoria and Albert Hospital

Review of the Plan

We expect the plan to be reviewed on the 10th March, 2011, at 3.30pm.

Support Provided:

Jean Boyle (Speech and Language Therapist) will visit the home once a fortnight.
Alan McGee (Teacher of the deaf) will visit the nursery once a fortnight

Audiological Information:

Grace has had two hearing aids since September. The family notice a difference when they are worn. The family had a lot of trouble at the start getting the hearing aids in place but Grace is much happier now.

Recent aided testing at the hospital (11 January 2011) indicated that hearing levels are within speech ranges (40 dB across all frequencies).

Grace will be reviewed at the hospital in March 2011. A morning appointment has been suggested.

Family Support Plan for Grace

Where we are now?

1. Grace is wearing both hearing aids a minimum of 6 hours a day. She is aware of environmental sounds and is also responding to mum and dad's voice.
2. Her attention skills are developing extremely well and this allows her to copy sounds and signs exceptionally well.
3. Dad has enrolled in a BSL 1 class and has just passed his first assessment.
4. Mum and Dad are using the listening books provided by Jean everyday.
5. Toilet training is now going well and is less of an issue. There may be ideas and advice coming from the school nurse very soon to help with toilet training.

Our priorities are now

Having a bit more structured approach to listening activities would be very useful.
Getting some support with signing at home would be helpful for mum.

We also discussed the following:

1. The importance of enjoying Grace as a daughter. Natural play between family members should be encouraged. Although some structured activities are suggested these should not take over everyday life and communication.
2. Keeping communication as natural as possible was encouraged by all.

Any further questions or comments?

When will Grace's vocalisation change? When will she say some words?

Jean said that a child's response to listening is different, but the expectation would be well within the year.

The family were encouraged to use the Early Support Monitoring Protocol to assess Grace's overall development. If there were any areas where progress is not as quick as everyone would like then we could review what we were doing.

The family asked about the outcome of the aetiological investigations. It was agreed the family would phone Dr Reid.

Agreed priorities or next steps	Actions	Who will do what?
Remember communication in its broadest sense. That communication involves all the family	Grace will learn to link gesture and sign with what she hears.	John and Mary should continue to use sign, gesture, symbols and spoken words when communicating with Grace. Jean will continue to model good practice on her visits. Alan will share the same approaches with the nursery.
Continue to discourage use of her dummy.	The dummy will impact on Grace's speech development. It was agreed that this should be discouraged.	John and Mary will work towards the dummy being used less by Grace. The long term aim is for the dummy to be removed permanently.
Checklist of awareness for sounds.	Point out sounds to Grace in the expectation she will become aware of these sounds. These will be recorded in the sounds book provided by Jean.	John and Mary will use the checklist to monitor Grace's listening development. Mum and Dad will also use the Early Monitoring Protocols to evaluate Grace's development in the broadest sense.
Continue with listening activities	Sound of long duration compared to short duration. Initially with drums or other musical instruments. Then trying speech sounds.	Alan will play sound games - starting with drum beats of different lengths. Moving onto sounds of different syllable lengths, eg; baa vs baa baa vs baa baa baa. Alan will teach signs for listening including loud, quiet. Mum and Dad will continue the good practice modelled by Alan and Liz.

For more information and additional copies of this book please contact:

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