

Quality Standards



Transition from paediatric to adult audiology services: Guidelines for professionals working with deaf children and young people

Our vision is of a world without barriers for every deaf child

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Introduction

“Give more information on adult audiology service and give a chance to visit there”
Deaf young person

NDCS’s vision is a world without barriers for every deaf child and young person. NDCS believes in supporting deaf young people appropriately, flexibly and continuously as they move from childhood to adulthood, and empowering deaf children and young people and their families to make informed choices and influence decisions affecting them.

This document is written for professionals in audiology services who are working with deaf children and young people as they move from paediatric to adult audiology services. We know that this journey of change will be different for every deaf young person and suggest that this guidance is useful for working with young people from the age of 14 years. By identifying quality standards that align with national policies, accompanied by practice examples, this document aims to support improvement in audiology practice in services for deaf young people and their families during the transition period.

Under each quality standard we have included a section called ‘How do we know when we have got it right?’. The statements in these sections are based on; *You’re Welcome – Quality criteria for young people friendly health services* (Department of Health, 2011), *Quality of the Patient Experience: Capturing of patient & service user feedback* (Quality Enhancement Tool, 2010), *Quality Standards for Paediatric Audiology Services* (Scottish Government, 2009), and *Quality Standards for Paediatric Audiology Services (Wales)* (Welsh Assembly Government, 2010). The statements are designed to help services understand the types of things that are necessary to meet that standard although the lists are not exhaustive.

“I don’t want to move, I know everyone here in my current service”
Deaf young person

Whilst this guidance focuses on audiology services, we believe that all transition services for deaf young people must be integrated, requiring quality multi-agency working. This will help to ensure that work is not duplicated and that those with key relationships with deaf young people are aware of the range of possible transitional issues that may affect deaf young people at some stage. The principles underpinning this guidance therefore are applicable to all transition services for deaf young people whether they are health, education or social care-sector based.

NDCS first published quality standards in transition between paediatric and adult audiology services in 2005, based on the Department of Health’s Modernising Children’s Hearing Aid Services project (MCHAS, 2000–2005). Since these standards were published a number of projects across the UK have been undertaken in developing transition services, as well as resources developed to support deaf young people during the transition period. However, good quality transition services are not yet widely available. There are several models for good transition and there is no clear evidence that one is superior. This document therefore does not attempt to be prescriptive in terms of what a good transition service looks like. Instead, it aims to bring together the themes identified from the current literature on transition and specific examples of good practice, and to highlight useful resources.

Definition of transition

Transition happens throughout a person's life, from the early years up to adulthood. The process of transition from paediatric to adult audiology services begins when children are being cared for by paediatric services and continues after they have moved to adult services, for as long as is appropriate for that individual (Department for Children, Schools and Families and Department of Health, 2008). Transition should address the holistic needs of the young person, including their physical health, mental health, educational or vocational needs, and social care needs.

Government policy emphasises that this is not solely a matter for healthcare professionals, since long-term conditions also have important educational, social and financial implications. Transition planning should ensure continuity of care for the young person, and that the young person is aware of all of the options open to them. Transition planning in the health service must secure optimal health care for the young person but it is equally important to ensure that their wider needs and their aspirations for their future are at the centre of the planning process.

Transition and deaf young people

Transition coincides with a period of rapidly changing physical, psychological, social and educational development. Young people may be under considerable stress, including exams and moving on to higher education or work. Transition processes need to reflect the wider context of a young person's life at this stage. Additionally, for deaf young people this may be a significant time in terms of identity development. Deaf young people may have different levels of engagement with the audiology service depending on how they are feeling at different times about themselves and their deafness. The Deaf community does not view itself as disabled but instead celebrates its unique language and culture. Peer relationships may take on particular significance and the need to fit in may be very strong at this stage.

“Deafness is a low incidence need. As the majority of deaf children attend mainstream education provision, they may not have opportunities to meet other deaf children. The views of deaf children and young people recorded in the *NDCS Change Your World* survey showed that they highly valued the opportunity to meet and socialise with other deaf children. Providing such opportunities addresses issues of social isolation, low self-esteem and mental health.” (NDCS, 2011)

Around 40% of deaf children have additional needs (Bamford et al, 2004; Guy et al, 2003; Fortnum & Davis, 1997). This can mean that a deaf young person has involvement from a wide range of service providers across health, education and social care. Particular difficulties may arise, for example when the young person's service has been at a specialist children's service or hospital but the adult counterpart is located locally. Sometimes young people find themselves in a situation where adult services simply do not exist when they leave paediatric services (DH and DfES, 2006).

“I'm not sure what will happen at adult service”
Deaf young person

“I am worried because not many other people will know who I am and I am getting used to the people I am working with already”
Deaf young person

“I want to meet older deaf people to see what the future is like – will there be deaf adults at adult service?”

Deaf young person

It is therefore vital that transition services are developed that:

- are sensitive to the individual needs of deaf young people and their families
- take a holistic view of the deaf young person and their family
- help prepare deaf young people for transition and promote independence
- are developed and managed through close cooperation between agencies and professionals involved in the deaf young person’s care.

Current literature and recent projects looking at transition between children’s and adult audiology services identify these key themes:

- involving young people and their families
- access
- working in partnership with other services
- communication and information
- developing independence and preparing for transition.
(NHS Improvement, 2010a)



The transition policy and pathway

“A clear Transition Pathway means that young people, their families and all professionals have clear expectations of the transition process. Transition Pathways have been developed in many different formats, however, the format is not important, as long as the pathway is accessible to young people and their families, and supports professionals across services to understand and deliver those services.” (Council for Disabled Children, 2009)

QSo1

The service has a documented transition pathway and policy that has been developed and agreed with all key stakeholders.

There should be a clear strategic policy which details how the service will work to meet the needs of deaf young people through their transition from the paediatric to the adult audiology service. It should also cover how the paediatric and adult audiology services will support the young person’s transition through other services, such as social care or education. A pathway gives the policy operational detail by mapping out how local services and individuals within them can work most effectively together to support deaf young people and their families.

Transition policy and pathways will vary depending on local circumstances and structures, and crucially on the needs identified locally by deaf young people and their families. However, the policy and pathway should be clear and understandable to all stakeholders including deaf young people, and should identify:

- the named person who is responsible for writing, maintaining and reviewing the transition policy
- all stakeholders, including deaf young people and their families
- timescales for review of the policy as circumstances and needs may change over time
- how flexibility of transition phases and approaches within the policy will be managed to allow for individual needs of deaf young people who may start transition at different ages and work through the transition stage for different lengths of time according to what is appropriate for them and their circumstances
- processes for joined-up multi-agency working
- processes for managing young people in further or higher education living away from home
- how services that are provided are in accordance with the Equality Act 2010 and are easily accessible by people with any form of physical disability or sensory impairment

- the mechanism for identifying a coordinator for young people with a number of different problems requiring input from different teams (often known as a key worker or transition worker). This person will coordinate the young person’s care and provide a holistic overview and integration of their various treatment and management needs. It is important that the young person’s view about who this is is taken into account and negotiated (DH, 2006)
- processes for signposting to other services and relevant information
- confidentiality and consent and safeguarding policies
- mechanisms for identifying and addressing training and development needs (including deaf awareness training, and training for the adult service in the hearing aid technology and software used by the paediatric service) of those working with deaf young people through the transition process
- the processes for reviewing these policies.

“Like transition itself, developing and reviewing a protocol is an ongoing process which needs to be monitored and evaluated regularly.” (DCSF and DH, 2007)

“Access is likely to improve by consulting and involving young people in designing the pathway and continuing to involve them in any changes.” (NHS Improvement, 2010b)

How we did it – NHS Devon and NDCS

NHS Devon and NDCS worked together on an Audiology Improvement Programme pilot project using a multidisciplinary collaborative approach, led by a steering group of a wide range of stakeholders to inform a new model of transition.

The team sought the views of young people through five different focus groups and opportunistic meetings of youth groups. Young people in their area were asked what they wanted with regards to their transition service.

- Young people want to be able to access the service at different stages, not just when the service decides to invite them for an appointment.
- Careful consideration should be given to the timing of transition by taking into account maturity, individual needs and where the young person is educationally.
- The service needed to ensure that there are appropriate methods for young people to get in touch with the service, for example text numbers, email addresses, a website, not just a telephone number.
- Young people felt that reception areas and waiting rooms could often be improved to be more child and young person friendly.
- Staff, including audiologists, need to be deaf aware – not covering their mouth while talking, not talking while looking at a screen (making lipreading difficult), remembering that while the young person is not wearing hearing aids they may not hear you.

- A key worker/named audiologist would make transition for young people easier.
- Phased changes in frequency of appointments between child and adult services would be helpful.
- Where a young person lives away from home whilst in higher or further education, good communication and information about access to the different services (those they access when at home during holiday and those they use during term time) are important.

This feedback from young people was then used to inform the development of a new model for the transition service.

How we did it – Tower Hamlets Community Health Services NHS

Tower Hamlets Community Health Services NHS undertook an Audiology Improvement Programme pilot project. The borough has a high level of ethnic and linguistic diversity and some families have a high level of need and face multiple challenges. Additionally, the adult service was located on a different site to paediatrics. We found that young adults were often lost to follow up once transferred out of the paediatric service. Multidisciplinary meetings were held to map the processes of a new transition pathway, with representatives from audiology, medicine, speech and language therapy, education, social care services and service users (young people and parents) in attendance. We also surveyed the views of individuals who had experienced the existing transition pathway.

The new transition pathway included the following features:

1. a pre-transition protocol specifically aimed at 14 to 16 year olds (school years 9–11) to prepare them for transition and empower them to understand their hearing loss and take part in their own hearing aid care
2. young person's own copy of a 'transition flow chart' mapping their journey from paediatric to adult services
3. a named transition audiologist who works in both paediatric and adult teams with protected regular appointment slots in the adult audiology service
4. an optional one year transition follow up in adult audiology
5. a database of newly transitioned young adults to track their progress and prevent patients being lost to follow up.

How do we know when we have got it right?

- The service has a clear written pathway and policy on transition between the child audiology service and adult audiology service.
- The service is accessible to young people by public transport.
- Appointments are available at times that are convenient for young people to attend.
- Mechanisms exist that allow young people to contact the service directly.
- The service is provided in accordance with the Equality Act 2010. The service is easily accessible by people with any form of physical disability or sensory impairment. Disability support aids are fully functional and freely available to assist service users. Reasonable adjustment is made where required.
- There is reference to the service or trust policy on confidentiality and consent to treatment and the policy is consistent with current national guidance.
- All staff are familiar with the service's confidentiality policy. Processes to ensure regular review of consent and confidentiality policies are in place. The policy supports how staff will work with parents and carers where appropriate whilst respecting the confidentiality of the young person. The policy includes a clear protocol for managing safeguarding concerns and possible breaches of confidentiality.
- Members of staff routinely receive inter-disciplinary training on the issues of confidentiality and consent and issues pertaining to seeing young people without a parent/carer present. Inter-disciplinary training is undertaken in line with local safeguarding children arrangements to ensure that approaches to safeguarding are in line with *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children* (DCSF, 2010).
- The audiology service is delivered in a safe, suitable and young people-friendly environment.
- The reception, waiting area, testing and re/habilitation rooms are accessible and young people-friendly, comfortable and welcoming. There is a range of recreational activities appropriate for young people, for example reading material and multimedia and these are refreshed regularly. In accordance with health and safety regulations, these are maintained and kept in working order.

Further resources

A Transition Guide for All Services: Key information for professionals about the transition process for disabled young people (DCSF and DH, 2007)

Children and Young People's Involvement in Formal Meetings: An extended practical guide (Participation Works Partnership, 2010)

Guidelines for Research with Children and Young People (National Children's Bureau, 2011)

How to Involve Children and Young People with Communication Impairments in Decision Making (Participation Works and National Children's Bureau, 2008)

Pushing the Boundaries: Evidence to support the delivery of good practice in audiology (NHS Improvement, 2010)

Transition Information Network website: www.transitioninfonetwork.org.uk

Transition: Moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability (DCSF and DH, 2008)

TransMap: From theory into practice: The underlying principles in supporting disabled young people in transition to adulthood (Council for Disabled Children, 2009)

Understanding What Matters: A guide to using patient feedback to transform services (DH, 2009)

You're Welcome: Quality criteria for young people friendly health services (DH, 2011)



Involving deaf young people and their families in service development

Services designed and developed with the feedback and involvement of young people are more likely to be relevant to those individuals and to meet their needs. Health, education and social care services have a responsibility to ensure that adequate resources are available to support young people's participation in service development activity such as communication support costs and reimbursement for their time and travel expenses.

“Participation is not about one-off projects. Rather it represents a philosophy of service user involvement which should pervade every aspect of service design and development.” (Royal College of Paediatrics and Child Health, 2010)

QSo2

Deaf young people are routinely consulted in relation to current services and relevant new developments, and they are included in service user satisfaction surveys. The process for doing this is appropriately planned and resourced. This involvement is accessible and meaningful to deaf young people and their families.

Children and young people have the right to be meaningfully involved in all decisions that affect them (The United Nations Convention on the Rights of the Child, 1989). Deaf young people and their families are the experts on their needs and are therefore often in the best position to tell you what they need and how you can meet their needs. It is also important that families of deaf young people are supported in encouraging and empowering their child through transition.

Government policy across the UK emphasises the importance of listening to children, young people and their parents, as well as the involvement of young people in shaping the services they receive and ensuring they access the information they need on these services.

It is often difficult to engage young people in formal adult meetings that may already be in place locally, such as Children's Hearing Services Working Groups (CHSWG). Transition services must plan, cost and provide appropriate training for staff and resources in order to meaningfully involve children and young people on a continuous basis in alternative ways. Services need to plan to deliver involvement exercises periodically using a range of engagement mechanisms.

There are different ways and levels of consulting with young people and their families and involving them in evaluating and developing services. Engagement must be:

- planned and resourced thoroughly
- ongoing and young person-centred
- relevant to young people and their families
- done in a meaningful, flexible and accessible way to individual deaf young people, for example by using appropriate communication support such as qualified BSL interpreters, using media that is widely used by deaf young people, etc.
- clear about how the outcomes will be reviewed and acted upon.

“Effective communication reassures all parties that they are being heard, their contribution is invaluable, informative and important. Effective communication is central to the meaningful participation of children and young people taking into account their diversity, including age, culture, abilities, disabilities, language, experiences, vulnerabilities, and evolving capacities.” (Royal College of Paediatrics and Child Health, 2010)

Evidence suggests that reliance on questionnaires alone is not sufficient. Services need to ask young people how they want to be engaged with and use innovative and technologically appropriate methods.

“To support any young person to participate it is important to be creative to make sure that young people who may sometimes be seen as difficult to reach are engaged with. Advocacy support should be available to those young people who want it, to ensure that they are empowered to have their voices heard, and that they are at the centre of the transition planning process.” (Council for Disabled Children, 2009)

“Services need to ensure that children are using a method of communication which is familiar to them, so that they are given the maximum opportunity to express their views.” (Council for Disabled Children, 2010)

How we did it – NHS Devon and NDCS

Recognising the value of group work and its ability to build young people's confidence to speak out when amongst peers, the NHS Devon and NDCS Audiology Improvement Programme pilot project organised a number of informal focus group sessions for deaf young people. Aware of the fact that some young people feel more able to share their views when facilitated to do so with a peer group, we organised five separate focus groups in different settings. They were held at times that were convenient for the young people and where they wanted to meet. For example, one was held at a bowling alley on a Sunday afternoon, one was held on a weekday evening at a Deaf Children's Society social venue with pizzas provided, and one was held during school time in a hearing resource provision.

We developed a set of guideline questions for the facilitator to discuss with each group or develop according to the needs of the group.

- Are you aware that there is a transitions service from children's audiology services to adult audiology services?
- What does transition mean to you?
- If you think about moving from one service that is geared up for younger people (from babies through to 18) what differences do you think there might be?
- If you think about becoming more independent, leaving school or home, starting work, studying, making more choices for yourself, being more responsible – what do you think might be important for you to know about audiology or hearing aid services that will help you to manage your deafness?
- Are you aware of transitions services for other aspects of your life? If so, what are they and who delivers them to you?
- What information would you like to have to support you when moving to adult audiology services?
- What topics would you like to be covered?
- Who do you think should talk to you about audiology transition?
- When do you think it would be most useful to have this information?
- What is your preferred method of communication?
- How would you like to receive or access audiology transitions information?
- Would you be interested in helping to design some of the information for young people?
- What would you like the audiology transitions service to be called?

How we did it – Tower Hamlets Community Health Services NHS

Tower Hamlets Community Health Services NHS Audiology Improvement Programme pilot project developed a web-based survey to seek the views and suggestions of young adults who had recently transitioned to the adult service in order to test improvements and shape the service according to need and suitability. This was very successful prior to implementing the changes for the pilot project, with a 70% response rate to the questionnaire. The results showed a general satisfaction with the service.

A follow-up online survey resulted in a much lower response rate, so flexibility of approach appears to be very important. We chose to use a web-based survey as we felt that this was accessible to young people, but we are now re-evaluating this approach and are considering offering a choice of online survey or paper survey.

How we did it – Over to You project, NDCS

As part of the NDCS Over to You project (funded by the Department of Health), a one day event was held in Hackney in partnership with Tower Hamlets Community Health Services. A number of young people of a similar age were invited to have their appointment on the same day. As they were waiting for their appointment, there were given the opportunity to meet other deaf children in their peer group. They also visited a separate room which had been set up by NDCS which had a number of different activities planned that the young people could take part in. This was designed to allow them to share their experience of the audiology service and transition. To find out what the young people thought they took part in surveys, focus groups and posted feedback in boxes placed in the waiting rooms.

Young people were asked:

- what does the word transition mean to you?
- have you been told you will be moving to an adult service?
- who told you?
- how do you feel knowing you will be moving?
- do you have any worries about this move?
- do you have any hopes of what your new service will be like?
- what would your ideal service look like? Think about environment (waiting room), staff members, information you get given.

How do we know when we have got it right?

- Deaf young people and their families are routinely consulted on their views and ideas regarding current services and potential developments. The process for doing this is appropriately planned, budgeted for and resourced. This involvement is accessible and meaningful to young people and their families.
- Processes are in place to ensure that the views of young people and their families are included in governance service design and development.
- The service invites and encourages young people and their families to give their opinions of the service offered and whether it met their needs; these are reviewed and acted on as appropriate.
- Young people feel able to approach the service at any time with their concerns and views, not just at consultation sessions.
- User participation in evaluating and developing services is representative of the local population in terms of ethnicity, gender and disability.
- Results of consultations are made available and discussed with deaf young people and their families regularly.
- Young people and their families tell you they feel included.
- Young people and their families tell you they feel fully informed.
- DNA (Did Not Attend) rates for young people using the service are low.

Further resources

For further information on children's policy in each country see:

→ England (Department of Health): www.dh.gov.uk

→ England (Department for Education): www.education.gov.uk

→ Scotland's Commissioner for Children and Young People:
www.sccyp.org.uk

→ Children in Wales: www.childreninwales.org.uk

→ Children in Northern Ireland: www.ci-ni.org.uk

Children and Young People's Involvement in Formal Meetings (Participation Works Partnership, 2010)

Guidelines for Research with Children and Young People (National Children's Bureau, 2011)

Hear By Right: Standards framework for the participation of children and young people (Badham, Bill and Wade, Harry, 2008)

How to Involve Children and Young People with Communication Impairments in Decision Making (Participation Works and National Children's Bureau, 2008)

NHS Improvement: Audiology Improvement Programme project website: www.improvement.nhs.uk/audiology/pilotsites.html

Not Just a Phase: A guide to the participation of children and young people in health services (Royal College of Paediatrics and Child Health, 2010)

Over to You: A report of young deaf people's experiences of audiology (NDCS, 2011)

Participation Network website: www.participationnetwork.org

Pushing the Boundaries: Evidence to support the delivery of good practice in audiology (NHS Improvement, 2010)

Quality of the Patient Experience: Capturing of patient and service user feedback (QET, 2010)

Quality Standards for Paediatric Audiology Services (Scottish Government, 2009)

Quality Standards for Paediatric Audiology Services (Wales) (Welsh Assembly Government, 2010)

Transition Information Network website: www.transitioninfonynetwork.org.uk

Transition: Moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability (DCSF and DH, 2008)

TransMap: From theory into practice: The underlying principles in supporting disabled young people in transition to adulthood (Council for Disabled Children, 2009)

You're Welcome: Quality criteria for young people friendly health services (DH, 2011)



Working in partnership with other services

“Audiology transition for young people needs to integrate with other partners (such as Connexions and education) into the wider transition process where the central focus is the individual. This will help to ensure that the educational, social, psychological and physical health needs of the individual are best met.” (NHS Improvement, 2010)

Local health, education and social care services have a responsibility to ensure they work in partnership to support deaf young people and their families. It is the responsibility of all the services involved to agree and develop policies and strategies for the transition to adult services for deaf young people (see QSo1).

Often there may be other agencies or organisations that are already working with young people around the time of transition. This may include third sector or voluntary agencies that will have a wider role to play in advising teenagers on broader issues around health and education e.g. Connexions, NHS Teen LifeCheck, NDCS, education services, social care services. Multidisciplinary and multi-agency working can help professionals to become aware of the changing needs of deaf young people. This can help to ensure that the necessary support is set in place without delay.

QSo3

The paediatric and adult audiology services maintain positive relationships with one another as well as other local services, such as education, social care and voluntary service providers, to ensure that deaf young people’s holistic needs are met throughout the transition process. These working relationships are built into the transition policy.

There are many benefits of multi-agency and multidisciplinary team working:

- multi-agency working avoids duplication
- interventions are made at the right time and can be assessed regularly to respond to the changing needs of the young person and/or family
- information is shared and communication is improved
- professionals learn from each other and about each other's roles
- training needs can be addressed e.g. staff in adult services are trained in the hearing aid technology and software used by the paediatric service
- the team can provide a supportive knowledgeable framework for making difficult or complex decisions
- parents' knowledge and expertise is valued
- opportunities are created to monitor and evaluate services and offer support in a coordinated and consistent way.

In order to work in an effective multi-agency and multidisciplinary way, teams must have protocols for referrals, and record and share information adhering to local and national guidance on confidentiality and data protection (e.g. in accordance with: *Confidentiality: NHS Code of Practice*, DH, 2003; *Data Protection Act 1998: Guidance for the NHS*, DH, 2011; *Data Protection (Subject Access Modification) (Health) Order 2000*, *Consent – What you have a right to expect: A guide for children and young people*, DH, 2001; *Reference guide to consent and examination and treatment* DH, 2009).

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

“Information about the service is provided to other relevant organisations and to key professionals working with young people.” (DH, 2011)

How we did it – NHS Devon and NDCS

The NHS Devon and NDCS Audiology Improvement Programme pilot project worked hard to establish effective multi-agency working using the following strategies.

- We wrote to all senior leaders in the agencies involved in some way with transitions work with deaf young people, asking for a commitment to engage with our improvement project.
- Once senior endorsement was gained, representatives from each agency were recruited to sit on our steering group.
- We developed a training day initially for Connexions personal advisers on deaf awareness and transition issues for deaf young people. We are now redesigning this to roll out to special educational needs coordinators (known as additional support for learning coordinators in Scotland), personal social health and economic education teachers, and others.
- We developed an information sharing protocol between the audiology service and Careers South West Ltd (formerly Connexions Cornwall & Devon), and permission was given by young people to share their information with other professionals that they had a hearing loss and may need transitional support in this area.
- We developed a partnership arrangement between the Devon Advisory Teaching Service and the audiology service, and invited the transition audiology therapist to transitional reviews starting in Year 9.

How we did it – Addenbrooke's Hospital

Addenbrooke's Hospital in Cambridge formed a Transition Interest Group from the local Children's Hearing Services Working Group (CHSWG). Professionals involved included Teachers of the Deaf, social care professionals, employment advisers and other support workers involved with young people.

The group is now well established and meets every two to three months to discuss any problems that have been encountered in the services, and potential solutions. Positive stories are also shared of young people who are doing well and the things that they have found helpful. The group also works together to organise educational/social events for the young people in the area.

How do we know when we have got it right?

- Information about the service is provided to other relevant organisations and to key professionals working with young people.
- The service has a clear referral pathway for deaf young people with identified emotional and mental health concerns. The pathway includes specialised CAMHS (Child and Adolescent Mental Health Services) input where appropriate.
- Other organisations regularly attend and contribute to transition meetings (representatives from education services, careers, mental health services, etc).

Further resources

NHS Improvement: Audiology Improvement Programme project website:
www.improvement.nhs.uk/audiology/pilotsites.html

Pushing the Boundaries: Evidence to support the delivery of good practice in audiology (NHS Improvement, 2010)

Transition Information Network website: www.transitioninfonetwork.org.uk

Transition: Moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability (DCSF and DH, 2008)

TransMap: From theory into practice: The underlying principles in supporting disabled young people in transition to adulthood (Council for Disabled Children, 2009)

You're Welcome: Quality criteria for young people friendly health services (DH, 2011)



Developing independence and preparing for transition

Evidence suggests that deaf young people with all levels of deafness want or need more information on a range of topics, including accessible information and advice on school and college, health services (e.g. sexual health), youth services and developing confidence. A significant proportion want more information on deafness and technology (NDCS Youth Consultation, 2008).

“Sharing of information between the young person and health professionals involved in their care and treatment is critical to successful transition. Through sharing information, the young person will become more knowledgeable about their condition and their future care can be managed in an open, transparent relationship in which they develop control and are able to make choices regarding their future.” (DCSF and DH, 2008)

It is likely that deaf young people will be ready for beginning transition at different ages and some will require transition support for much longer than others. It is important that the transition service is able to be flexible in meeting the needs of deaf young people. Young people will often be keen to take on responsibility for their own care at the right time for them. As they develop, children and young people need to gain an understanding of their hearing, hearing equipment and their aided abilities. They need to learn how to manage their own devices, learn what resources are available to them and understand how their audiology services operate.

“Set up a preparation period and education programme for the young person and parent: Identification of the necessary skill set to enable the young person to function in the adult clinic. The young person must acquire the knowledge and skills to function in an adult service, largely independent of parents and staff, before they are transferred.” (DH, 2006)

QSo4

An introduction to adult services must be arranged for the young person prior to discharge from the paediatric service. This introduction could be:

- through a group with other young people transitioning at a similar time
- through an individual appointment with the adult service prior to discharge from the paediatric clinic
- through a joint clinic with both the paediatric and adult audiologist present.

During the preparation period arrangements must be made for the young person to be introduced to adult services before they are discharged from the paediatric service at a time that is appropriate for the deaf young person (this is likely to be at a different age for each deaf young person you work with). The way the introduction is carried out will vary depending on:

- local service configuration (whether child and adult services are provided in the same premises or in different locations)
- local needs (based on information gathered from young people's participation)
- the individual young person's and family's needs.

An introduction may be:

- through a group with other young people transitioning at a similar time
- through an individual appointment with the adult service prior to discharge from the paediatric clinic
- through a joint clinic with both the paediatric and adult audiologist present.

How we did it – NHS Devon and NDCS

The young people at the focus groups for the NHS Devon and NDCS Audiology Improvement Programme pilot project discussed some of the issues that they felt inhibited their developing independence. These included:

- lack of deaf awareness in audiology departments. Young people highlighted:
 - receptionists looking at an appointment book rather than at the young person – preventing lipreading
 - names being called out in waiting rooms for appointments when young people are unable to hear i.e. no provision of visual LED systems or flashing system
 - audiologist seeing same young person for years and knowing their method of communication yet not being able to do basic signing such as say hello or how are you
- none of the young people at this focus group having a key worker e.g. a social worker or a Connexions worker supporting their needs around transition. The young people were particularly concerned about needing support to find work
- the need to pay for parking when attending audiology appointments
- not being listened to or perhaps not trusted when making requests for new batteries. There is a need to raise awareness among staff about batteries to ensure staff have a realistic understanding of how long hearing aid and cochlear implant batteries last and a system to cut down the need to visit audiology for new batteries. There is also a need to hold repair clinics for hearing aids outside of school hours
- wanting to be asked if they wanted their parents at appointments or not
- where parents are present at appointments, the need for staff to talk directly to the young person, not their parents
- the need for information on what the young person's responsibilities will be on moving to the adult service (e.g. making their own appointments, etc).

How we did it – Over to You project, NDCS

The NDCS Over to You project included young volunteers. As the areas that the project was working in have high populations of people from black and minority ethnic (BME) backgrounds, we sought to engage with young people from BME backgrounds, resulting in 50% of the volunteers being from BME backgrounds. Volunteers highlighted the positive changes for the deaf children and young people they worked with, and they also told us about what difference the project had made to them personally. They talked about feeling more confident and having more knowledge about audiology in general, and about what deaf children and young people experienced. This was particularly valued by the deaf volunteers:

“I had a lot of negative experiences of audiology services as a deaf child and never got the opportunity to express my views on the service. With Over to You, I wanted to be able to help ensure that deaf children and young people get the opportunity to have their say on how they want audiology services to be delivered and to improve the service.”

“I have gained an awareness of the range of experiences young people have of audiology. I have worked with a range of deaf young people and volunteers.”

How we did it – Addenbrooke’s Hospital

Addenbrooke’s Hospital in Cambridge established a dedicated transition clinic. Young people aged 15 and over are given appointments in the transition clinic at their next review. The appointment letter highlights that transition will be discussed. At the appointment, issues to do with education or employment are discussed (including current place of work/education and subject/job, hearing difficulties in the classroom or workplace, use of FM systems, involvement of specialist education support services, consideration of their hearing needs at college/university, Access to Work scheme, and involvement of any other professionals), and at home/socially (including hearing aid use, social activities, television, music, alarm clock, doorbell, telephone, and obtaining appropriate assistive listening devices).

A transition plan is created with the young person addressing any needs before they will be ready for transfer. For example, do new hearing aids need to be fitted or are they having surgery soon? Do we need to wait until after they have seen other medical professionals or until they finish sixth form? If transfer is not appropriate now then when is it likely to be appropriate? How does the patient feel about the adult service and do we need a gradual transition? Part of the plan is to establish whether the young person would benefit from any group events e.g. a small group appointment or a large conference-style event, and how they would feel about attending them. If they are not keen, then we explore reasons for this and continue to encourage them. We ran a large group event in 2010 and obtained feedback from the young people who attended. The feedback is being used to plan the next event later this year.

Every patient who does not attend the transition clinic is sent a transition-specific ‘Did Not Attend’ letter offering them the opportunity to have another appointment or to have information sent to them if they can’t or don’t want to attend.

In just over a quarter of young people, transition takes longer than the time frame outlined in the local protocol because of chronic health or learning disabilities. These patients often require the support of the paediatric service for longer, benefiting from regular appointments and extra guidance in how to cope with their hearing loss and hearing aids.

How do we know when we have got it right?

- Drop out rates when entering the adult service are low.
- Appointments are available at times that are convenient for young people to attend.
- When attending appointments young people are able to express a preference about:
 - who they are seen by
 - attending with the support of a friend or partner
 - who and how many people are present during the appointment
 - the gender of the member of staff they are seen by
- Young people are routinely offered the opportunity to be seen on their own without the presence of a parent.
- Mechanisms exist that allow young people to contact the service directly.
- This service is provided in accordance with the Equality Act 2010. The service is easily accessible by people with any form of physical disability or sensory impairment. Disability support aids are fully functional and freely available to assist service users. Reasonable adjustment is made where required.
- All deaf young people have an individual transition plan. This will usually include a named key worker or transition worker for each young person who will provide continuity during the transition process.
- The service provides publicity material specifically outlining the transition to adult services. This material is attractive to young people and is presented in a way that is young people-friendly.
- Transition support of deaf young people with complex needs is considered in the context of their cognitive ability and chronological age. This should include assessment of physical, psychological and emotional needs.
- Deaf young people and their families are offered information and advice to facilitate informed decision making.
- Young people must be able to express whether they feel ready for transition and, if not, what additional support they need to feel prepared.
- Young people know who to contact for hearing aid repairs and batteries, etc. throughout the transition period.

Further resources

Children and Young People's Involvement in Formal Meetings: An extended practical guide (Participation Works, 2010)

Information and Advice: For young people aged 12–18 (NDCS, 2011) (can be found at www.ndcs.org.uk/professional_support/our_resources)

Moving On (NDCS, 2008) (can be found at www.ndcs.org.uk/professional_support/our_resources)

NHS Improvement: Audiology Improvement Programme project website: www.improvement.nhs.uk/audiology/pilotsites.html

Other Ways of Speaking: Supporting children and young people who have no speech or whose speech is difficult to understand (The Communication Trust, 2011)

Over to You: A report of young deaf people's experiences of audiology (NDCS, 2011)

Pushing the Boundaries: Evidence to support the delivery of good practice in audiology (NHS Improvement, 2010)

The Buzz website (NDCS website for children and young people): www.ndcsbuzz.org.uk

Transition Information Network website: www.transitioninfonetwork.org.uk

Transition: Moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability (DCSF and DH, 2008)

You're Welcome: Quality criteria for young people friendly health services (DH, 2011)



Communicating with deaf young people

“The development of language and the ability to communicate lies at the heart of a child’s development.” (NDCS, 2011)

Paediatric services play an important role not only in helping young people with complex communication needs and their families, but also their colleagues in adult services, to support successful transitions (McNaughton et al, 2010).

Every deaf child will have different communication preferences, strengths and needs. Deaf children and young people have a diverse range of language preferences. They have rights to an independent interpreter for appointments and should not have to rely on their parents, for example.

Deaf children and young people also have a diverse range of communication strengths, for example:

- better productive spoken language than receptive language skills
- better receptive skills than expressive skills
- the ability to mix and match between visual and aural methods depending on who they are communicating with.

They may also have a range of communication and language needs, for example:

- many deaf children do not have age-appropriate literacy skills
- some acoustic environments are more conducive than others to good communication
- British Sign Language (BSL) may be used at home but not at school.

“There is also a need to ensure that all written and verbal patient information is appropriate for the age and stage of development of children and young people. In that regard it is important that all staff working with children and young people are given the opportunity to develop effective communication skills in working with children and young people.” (Scottish Executive, 2007)

QSo5

All staff who come into contact with deaf young people receive appropriate training on understanding, engaging and communicating with them.

When working with a deaf young person, it is important to establish and use their preferred language and communication methods, which may involve using a qualified interpreter. (NDCS, 2011)

Before starting appointments or meeting with the young person, check with them that they are happy with how the meeting is set up, e.g. if the lighting is ok for lipreading, if the seating layout is suitable, if they can see the faces of other people in the room (i.e. check that faces are not in shadow), etc.

How we did it – NHS Devon and NDCS

After consultation with deaf young people and project stakeholders, NHS Devon and NDCS Audiology Improvement Programme pilot project identified the following:

- if a young person is a BSL user, qualified interpreters should be present at appointments
- young people are often unsure that they are entitled to request communication support
- staff should be aware that they must provide communication support and that hospitals should have a contract with a provider for interpreting services
- when being called into appointments, young people needed a display to tell them it was their turn or for someone to come and tell them (not just having their name called)
- deaf awareness of staff was sometimes an issue and this could make communication difficult (e.g. staff had beards which made lipreading difficult)
- information is needed on what the responsibilities would be for the young person on moving to the adult service (e.g. making their own appointments, etc).

The project is developing a website to improve communication of information based on what young people told us. It should also provide a constant source of information which can be accessed when the young person wants it rather than solely when the transition service physically hands out paper-based information. The website, which will be in English and have BSL video, will cover:

- milestones/change points in young people's lives
- developing identity
- local services
- impact of audiology services
- entitlements e.g. Disability Living Allowance (DLA), access to work, disability support in higher education and out of county
- young people, parent/carers and professionals' areas
- links to other guidance e.g. statutory transition entitlement, and NDCS Quality Standards.

How do we know when we have got it right?

- Deaf young people report that their communication needs are being met before, during and after appointments with the service.
- All staff (including administration staff and reception staff) who come into contact with young people receive appropriate training on deaf awareness, communicating with deaf young people, and understanding and engaging with young people.
- All staff receive appropriate training in equality and human rights issues for them to be able to engage with confidence with a range of young people.
- Appropriate appraisal, supervision and support are offered to staff who provide services for young people to ensure that they are competent to:
 - discuss audiological issues with young people and understand the wider needs of deaf young people
 - work with family and friends in culturally appropriate ways
 - make appropriate referrals when necessary
 - manage sensitive and/or difficult consultations
 - support young people in making their own informed choices.

Further resources

Health Transitions for Youth with Complex Communication Needs: The importance of health literacy and communication strategies (McNaughton D, Balandin S, Kennedy P and Sandmel T) in *Journal of Paediatric Rehabilitation Medicine: An Interdisciplinary Approach* 3 (2010) 311–318

How to Involve Children and Young People with Communication Impairments in Decision Making (Participation Works, 2008)

Over to You: A report of young deaf people's experiences of audiology (NDCS, 2011)

Pushing the Boundaries: Evidence to support the delivery of good practice in audiology (NHS Improvement, 2010)

Quality Standards for Paediatric Audiology Services (Scottish Government, 2009)

Quality Standards for Paediatric Audiology Services (Wales) (Welsh Assembly Government, 2010)

Social Care for Deaf Children and Young People (NDCS, 2011)

Three Way Street: Communicating with children and young people (Triangle, 2009)

Transition: Moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability (DCSF and DH, 2008)

You're Welcome: Quality criteria for young people friendly health services (DH, 2011)

Information

“For the transition process to be truly person-centred, young people must have access to information that helps them understand what happens at transition, how to participate in the planning process, and how to make informed decisions about their future.” (DCSF and DH, 2007)

QSo6

A range of information that meets the needs of the local population must be available and easily accessible to deaf young people and their families throughout the transition period.

A range of up-to-date information must be provided for deaf young people throughout the transition process. Information should include:

- what transition is and what it entails
- contact details for the new service and how to get there (email addresses, telephone numbers, etc.)
- how to access the service (referral/open access clinics/opening times)
- what the changes will be/what the differences are between child and adult services (where service is located, how often appointments will be, what support they can expect from adult service)
- what will happen during appointments
- entitlements (e.g. an interpreter)
- anything they will have to pay for
- new equipment and their choices with regards to equipment
- their own deafness (a portfolio of their deafness and particular hearing needs – particularly useful for when moving to higher education)
- local and national services such as careers services, support groups, voluntary groups, etc.
- where to access up-to-date information on the internet (e.g. latest assistive technology)
- how their information may be shared or disclosed
- who to contact if they have a complaint about the adult service
- the responsibilities of the young person on moving to the adult service (e.g. making their own appointments, etc.)
- who they can contact during the transition process for hearing aid repairs/batteries, etc.
- how to access audiology services whilst away from home (e.g. if in further or higher education away from home).

This information should be attractive to young people and is presented in a way that is young-people friendly. Information must be available to them in appropriate formats and language levels (e.g. for different levels of literacy) that are accessible to deaf young people in line with the Equality Act 2010.

“Improving information accessibility through the use of multimedia such as written leaflets, visual information and the use of technology for example, a website such as NDCS’s the Buzz, and social networking websites.” (NHS Improvement, 2010b)

“Providing the option to view information in British Sign Language or subtitles will appeal to younger audiences allowing them to access information at their own pace, in their chosen language.” (NHS Improvement, 2010b)

Consultation with young people has shown that there is a need to provide accessible information in relation to deafness and technology on:

- the causes of deafness
- the implications of deafness
- how hearing aids and cochlear implants work
- assistive listening devices and environmental aids
- using mainstream technologies with their hearing aids and cochlear implants. (NDCS, 2008, and Wheeler et al, 2007)

This might include:

- website-based information (with subtitling, signing and community language translation as appropriate)
- leaflets or factsheets
- DVDs (with subtitling, signing and community language translation as appropriate)
- reports
- internet forums
- individual support
- face to face discussions.

How we did it – Tower Hamlets Community Health Services NHS

Tower Hamlets Community Health Services NHS Audiology Improvement Programme pilot project developed an information pack which is given to young people at an appropriate appointment at the pre-transition stage. This includes an ‘all you need to know’ adult service information leaflet, a flow chart of their expected transition journey, leaflets from local support services and NDCS publications. It is planned that this information pack will evolve through input from young people and service users. There are also plans to include this information on our departmental website.

How we did it – The Buzz website, NDCS

In 2007, NDCS carried out the UK’s largest ever consultation with deaf children and young people, called Change Your World. We wanted to know what the world looks like to deaf children and young people, what their interests are, fears and concerns and what wider services they wanted from NDCS. Almost 1,500 deaf children and young people aged 9–18 years old took part in the consultation.

Deaf children and young people told us they want to be involved – to participate, lead, volunteer and create information. They expressed the clear wish to have a new website of their own so they can meet other deaf children and young people.

NDCS worked with six schools over a year, including holding focus groups, setting up an advisory panel and doing surveys with the deaf children and young people, to create the Buzz website: www.buzz.org.uk. Young people helped to design and develop the functionality of the site, content and how information and advice should be presented. The 870 Buzz members are testament to how it has engaged young people from the outset of its development.



How do we know when we have got it right?

- Information available is understandable, and in accessible and appropriate formats including:
 - how to access the paediatric and adult audiology services
 - what other deaf services for young people are available locally and how to access them
 - how to make comments, compliments or complaints about the service
- Information is available to deaf young people and their families in their preferred language, which may include using interpreters, providing translations of written material, using language line, etc.
- Information provided by the service is kept accurate and up to date.
- The content and style of the leaflets is appropriate for young people.
- Deaf young people and their families are offered information and advice to facilitate informed decision making.

Further resources

Guide to Producing Health Information for Children and Young People (Patient Information Forum, 2010)

Information and Advice: For young people aged 12–18 (NDCS, 2011)

My Life, My Way: A young person's guide to transition (Welsh Assembly Government, 2010) (for young disabled people)

Pushing the Boundaries: Evidence to support the delivery of good practice in audiology (NHS Improvement, 2010)

Quality Standards for Paediatric Audiology Services (Scottish Government, 2009)

Quality Standards for Paediatric Audiology Services (Wales) (Welsh Assembly Government, 2010)

The Buzz website (NDCS website for deaf children and young people):
www.ndcsbuzz.org.uk

Transition Information Network website: www.transitioninfonetwork.org.uk

Transition: Moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability (DCSF and DH, 2008)

TransMap: From theory into practice: The underlying principles in supporting disabled young people in transition to adulthood (Council for Disabled Children, 2009)

You're Welcome: Quality criteria for young people friendly health services (DH, 2011)

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Council for Disabled Children (2010) *Children's Right to Communicate Their Views and Be Listened To*

Council for Disabled Children (2009) *TransMap: From theory into practice: The underlying principles in supporting disabled young people in transition to adulthood*

Contact a Family and Council for Disabled Children (2004) *Parent Participation Guide, Improving Services for Disabled Children: Professionals guide*

Department for Children, Schools and Families and Department of Health (2008) *Transition: Moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability*

Department for Children, Schools and Families and Department of Health (2007) *A transition guide for all services: Key information for professionals about the transition process for disabled young people*

Department of Health (2011) *You're Welcome: Quality criteria for young people friendly health services*

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www.psych-sci.manchester.ac.uk/mchas/

NDCS (2011) *Social Care for Deaf Children and Young People: A guide to assessment and child protection investigations for social care practitioners*

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NHS Improvement (2010b) *Pushing the Boundaries: Evidence to support the delivery of good practice in audiology*

NHS Improvement: Audiology Improvement Programme project website:
www.improvement.nhs.uk/audiology/pilotsites.html

Quality Enhancement Tool (2010) <http://audiology.globalratingscale.com/>

Royal College of Paediatrics and Child Health (2010) *Not Just a Phase: A guide to the participation of children and young people in health services*

Scottish Executive (2007) *Delivering a Healthy Future: An action framework for children and young people's health in Scotland*

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NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people.

**NDCS Freephone Helpline:
0808 800 8880 (voice and text)**

Email: helpline@ndcs.org.uk

www.ndcs.org.uk

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every deaf child