Transition from paediatric to adult audiology services
Guidelines for professionals working with deaf children and young people
The National Deaf Children’s Society (NDCS) is the only UK organisation solely dedicated to the support of deaf children, young deaf people, their families and the professionals working with them.

NDCS would like to thank the working party and all those who have taken part in the development of these Quality Standards. This document was originally developed from the findings of the Modernising Children’s Hearing Aid Services (MCHAS) team at Manchester University, and good practice case studies are drawn from this work. NDCS is grateful to the support of Professor John Bamford and the MCHAS team, and the services that participated in the first wave studies.

NDCS would like to give particular thanks to the young people and staff who were photographed for this publication.

Quality standards and good practice guidelines: Transition from paediatric to adult audiology services
1. Summary

Growing up is an exciting time, with new chances and choices. But it can also be a stressful and difficult time for many young people with disabilities. This is often because the organisations in their lives do not talk to each other effectively, and they do not involve the young person and their family enough in planning for their future.

Growing up is a key transition point in life and young people should be able to get the support they and their family need unobtrusively and easily. All young people should have equal opportunities in life.

As young deaf people move into adulthood the objectives of the services providing care for them should be:

- to ensure continuity of this care and support for the young person and their family; and
- to provide equality of opportunity in order to enable all deaf young people to participate equally in education, training and employment.

Parents and families also need support during the transition of their sons and daughters into adulthood, as it is often just as daunting a time for them.

Services for young people should be given greater focus and priority. The transfer of young people from child to adult services requires special attention, as it is generally poorly handled. Transition to adulthood and adult services, including integration with health, social care, education and employment services, is an area that all teams involved with the care of deaf children should have provision for.

For young people with long-term conditions, such as deafness, which are less common in childhood than adulthood, the move to adult services often involves quite a shift. In the sheltered environment of a small children’s service they have been ‘special’, but now they are moving into a service with many older patients.

Adult services are likely to offer young people:

- less social support
- less time with clinicians and other staff
- a service that is focussed on the older end of the age range and less able to meet individual needs
- a service where the family may not be included.

Moreover, staff in adult clinics may have little time or interest and few skills in dealing with the more complex needs of adolescents and the issues of their deafness. (Getting the right start: National Service Framework for Children, Standard for Hospital Services, 2003).

2. Introduction

The Modernising Children’s Hearing Aid Services (MCHAS) project was funded by the Department of Health to look at the major issues surrounding audiological provision for children and young people. One area that the project highlighted was the transition from paediatric to adult services. Eleven health sites were involved in this project. Questionnaires were sent to deaf young adults and their parents and interviews were carried out with relevant service providers to find out about experiences of and systems for the transition process. It was clear that this is an area of great concern to young people and their families and that systems currently in place were inadequate. Stories of commercial hearing aids being changed back to cheaper and less appropriate NHS models, poor earmould services, lack of information about FM provision (radio aids) and assistive listening devices, and lack of regular reviews were common.

“If transfer to adult services is handled badly, there is a risk that the young person will ‘drop out' from medical services altogether” (Getting the right start: National Service Framework for Children, Standard for Hospital Services, 2003).

The MCHAS project highlighted that many young adults did in fact fail to attend the adult clinic after transferring from the paediatric service.

However, a very small number of services had introduced specific support for the transition process, and examples of good practice were identified. These, along with input from other services offering specific provision for the transition of young people, and current guidance in educational and health domains, have all contributed to the recommendations made in this document.

2.1 Moving into adult services

Studies have described the problems faced by young people with disabilities and their families when moving through childhood to adulthood services (Pearson et al 1999, Morris 1999, Routledge, 1998).

The key issues raised are:

Poor coordination between the agencies responsible for services for children and adults, leading to dislocating experiences for the young people and their families.

A wide range of agencies are involved with deaf young people and their families, including education, ENT, audiology and social services. Within
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2.2 What should young people expect?

Young people should be able to expect that:

- transition processes place them and their family at the centre of planning for the future, taking proper account of needs and aspirations as the young person defines them.
- the process and stages of transition are explained to them at the right time and in the right way for that person and their family.
- consistent, friendly and informed people are available to provide information and answer questions.
- transition activity is coordinated between all key agencies and professionals, avoiding confusion, duplication and overlap for them and their families.
- transition related work starts well in advance of leaving the paediatric or adolescent service, allowing good preparation and planning with the young person themselves, their family, agencies and workers.
- the adult service they are moving to is interested and capable, with close links to the child service, a well-informed understanding of their developmental needs, and an active participation in their transition process.

Lack of power for young people and their families within planning systems. Young people and families often describe feeling that issues of importance to them are not properly attended to in the period of transition.

There are legal requirements for provision of transition and future plans in the Code of Practice on Special Educational Needs but this provision is likely to be poorer if the young people:

- have significant health care needs
- do not communicate orally
- are from minority ethnic communities (Morris 1999, Pearson et al 1999).

There are no legal requirements for such discussions and plans within a healthcare context, although the National Service Framework (2003) states that:

“Every paediatric and specialty clinic should have a policy on transition to adult services which should be the responsibility of a named person, covering:

- a policy on timing of transfer
- a preparation period and education programme
- a coordinated transfer process
- an interested and capable adult clinical service
- administrative support
- primary health care and social care involvement”

(Getting the right start: National Service Framework for Children, Standard for Hospital Services, 2003)
• access to support, including non-specialist, voluntary and social support is provided. Professionals involved will therefore need to have a good knowledge of these resources and opportunities that may be able to assist young people in pursuit of their goals (see section 5.2).

Many of these needs require multidisciplinary teams with good joined up working practice in place, possibly facilitated by a nominated transition support worker.

3. Transition services

In this document the term ‘transition’ is applied to the move from child or adolescent to adult audiology services. Many of the principles are equally usefully applied to transition between services (for example into another health authority, when a family moves house).

At all times it is important that good quality support and information are available and that services work in a coordinated and joined up way to share as much information as possible.

4. Focus of this document

This document is intended for use by professionals in audiology services (including cochlear implant and BAHA programmes), education, social services and others who work with deaf young people. It will be of importance to both paediatric and adult service providers.

This document uses the words ‘parent’ and ‘family’ to include the child’s carer with parental responsibility. If the child is a ward of court, or in the care of a social services department, appropriate permission must be sought before any medical or surgical procedure takes place.

NDCS uses the word ‘deaf’ to mean the full range of hearing loss. The phrase ‘all deaf children’ includes children with complex needs, ethnic minority children, and children from difficult-to-reach families.

We use the term ‘child’ or ‘children’ to include babies and younger children and ‘young person’ to define older children and young adults.

5. Good practice Quality Standards

This document covers the above issues, highlighting areas of service provision to be considered and ways to support good practice.

5.1 Written Transition Policy

QS01 ‘The audiology, education and social care services must have an agreed written protocol that details the processes of transition for young people between child and adult services. (NDCS QS Paediatric Audiology, In revision 2005)

These policies might be agreed via the local Children’s Hearing Services Working Group (OHSWG) or similar group.

5.1.1 Liaison between sites

From the services surveyed, many did not have a written policy for the transition of their patients, either between paediatric services and adult services or between areas. In some areas this resulted in the patient needing to be re-referred and re-register as a new patient in the adult service. The survey found that many young people, at what might already be an unstable time in their lives, were failing to review the management of their deafness or receive the support to which they are entitled. Both paediatric and adult services therefore need to have written guidance on the transition service they provide, and be aware of the arrangements of the other services. This guidance must be jointly discussed and agreed, so that each is knowledgeable about how the other is organised and which services they offer.

Someone within the team should be designated as the young person’s support, transition or key worker and should know about the services provided outside of the health setting (such as, education and social services) to make sure details of these can also be passed on to the young person and their family (see section 5.4).

5.1.2 Transferral of notes

When a patient transfers, it is expected that their notes will be transferred with them. If this does not happen the young person may be expected to be re-referred and re-register as a new patient and vital information may be lost. This is a waste of the valuable resource where all the information has already been collected about the patient. The patient’s history is crucial, especially in more complex cases.
Copies of paper notes must be transferred to the receiving service. It may be possible to transfer electronic records within organisations (say a hospital with satellite clinics or a health authority) via the patient management system. Sharing of information concerning young people and their families must be done only with their written permission and in accordance with current regulations (e.g., patient confidentiality guidelines and data protection legislation).

5.1.3 Timing of transition
There needs to be agreed guidance on the time young people transfer from services and this guidance should be shared with young people and their families so that they can prepare themselves. This guidance should allow flexibility for individual needs and include information such as who is responsible for young people who stay on in higher/further education.

5.1.4 Higher/further education provision
Young people in higher education often receive patchy services set up in an ad hoc manner. Services must have a policy on who is responsible for these young people. This needs to address a number of points:

• Health and education services need to be aware of the fact that a young person is attending a college or university and where that is situated (i.e., whether the young person is living away from home).
• There needs to be agreement about whether the local education services continue to provide support, in particular with provision of FM systems.
• The local health service needs to decide whether they can continue to provide support for the young person and whether this is practical for the young person and their family. Is it best for them to remain under the care of the paediatric services (possibly up to the age of 21) or to move to the adult services?

A common difficulty is what the young person does if they experience problems with their hearing support (such as their hearing aid breaking) while away from home. Are the services local to the young person’s place of education willing and able to provide support? If so, how is information shared between the two health services? Is service provision split between two providers for term time and holidays? This may be a matter for greater consideration when looking at who finances the care and how many extra cases a service can support from this route.

5.2 Information Pack
It is vital that all information provided is:

• accurate, valid, relevant, up-to-date, timely and understandable
• developmentally, ethically and culturally appropriate.

This is of particular importance when the information is for young people and especially if the young person does not use spoken English as their preferred mode of communication. A range of communication methods should be developed and used, and information should be available in a variety of formats, media and languages (including with subtitles, in BSL and in community languages).

Videos, DVDs and CD-ROMs can be helpful when aiming information at young people. It is important that information is easily accessible and well presented and that it is appropriate to the level of understanding of the young person.

In order to ease the transition process, the young adult and their family must be provided with clear and supportive information in an accessible format at least six months before the transition takes place. This information pack should include the following:

• Information and advice concerning their transfer. This should be provided by the paediatric and adult services jointly and should include contact and clinic details for the adult service. This is especially important if the adult clinics are held at a different venue to the paediatric ones. The information should include address and contact details by phone/minicom/fax/email for the clinic and details of how to get there. As young people will be used to attending the clinic by appointment only, clear details should be included of when and what type of clinics are held and any arrangements for these, such as whether or not an appointment is needed. There should be details of arrangements for management of hearing aids, reviews, earmoulds, assistive devices, outreach clinics and hearing therapy.
• Information about other services that are available to them. This should cover details about local provisions for deaf people such as social services, support groups, and social groups, and what services each of these can provide. There may also be details about career centres and advice and counselling services.
• What changes they will experience with their education service provision. This should state whether or not the service will continue to be
provided to them and if so in what capacity. The young person may have received a high level of support from these services up to this point and so any change needs to be explained clearly. This may introduce the issues discussed below regarding the young person’s responsibilities and how to access support that the education provision may have previously facilitated.

- **Advice about their responsibility as hearing aid wearers** and routine hearing aid maintenance (for example, re-tubing). This should provide all the information a young deaf person needs for good aural health care. This information is likely to include: what to do if a hearing aid stops working; where to get batteries from; information about replacement earmoulds and check-ups; and any other issues to be aware of.

- **Details about the need for good vision monitoring.** Young people identified with a permanent hearing loss should have ophthalmic assessments at key stages of their development. 

5.3 Preparatory Appointment

An initial appointment must be arranged for the young person with the adult audiology service by the paediatric service prior to discharge from the paediatric service.

The information pack detailed above should be provided to the young person before they have their first visit to the adult department. This initial appointment should be facilitated by the paediatric services. By having this first appointment at the adult clinic before the last appointment at the paediatric department, the young person gets the opportunity to clarify any issues or raise any concerns they have about their long term care, in an environment that is familiar to them. The adult department may be at a different location and have different staff to the child department and so arranging this preliminary appointment helps reduce the stress of the situation.

The young person should not leave the paediatric service without an appointment in the adult hearing aid services department being arranged before the transition takes place (i.e. before the final appointment in the paediatric department). This provides a good opportunity for the young person to become acquainted with the new department and service provision.

It is important to remember that a large number of patients are ‘lost’ at times of transition, possibly because it seems very daunting or they do not understand the difference in procedures. It is therefore a time when steps must be taken to make it as facilitative as possible for the young person in order to promote their long-term healthcare.

5.4 Support or Transition Worker

The health and/or multiagency service must designate a member of staff as a support/link or transition worker to provide support for those undergoing the transition between services.

This person will be knowledgeable about local adult audiology, social services, education and careers provision, and other organisations helpful for young deaf people. They will be able to provide, amongst other things, contact names and details. Depending on local policy and skills, this might be a hearing therapist or a social worker for the deaf or a Transition Personal Advisor (TPA) employed by Connexions schemes.
In order to provide the optimal service for deaf children and young people and their families, services must have good provision, support and well-planned procedures for their future care. To put in place good 'transition' services all staff need to play their part. However, to provide the optimum service one person should be a named 'transition worker'. This person:

- helps those undergoing the transition adjust to the change
- acts as an information point, further explaining any information given out by either service and signposting the young person to other services including careers, social services and voluntary organisations
- assists young people in preparing for the service change and offers advice and support throughout and after the process.

This support during transition is especially important for young people with complex needs. Not only might they need more explanation of the process, but they are also likely to be receiving services from even more groups of professionals all of whom need to work in a coordinated way.

5.5 General

5.5.1 Appropriateness of services for young people

It is integral to good service delivery that there is a member of staff available to discuss future long term plans and options with young people and their families. Deafness is a long-term condition and a care plan should be drawn up with the involvement of the young person. This requires staff to be trained to deal with young adults appropriately and to be aware of the issues that working with them may raise. This involves an understanding of the deaf young person, their needs and wishes. It involves treating the young person with respect and explaining issues thoroughly and clearly to them. Some young people may not want, or be in a position to have their families involved. There may be members of their extended family or friends that they would like to attend appointments with them.

For most deaf young adults it is not appropriate to ask them if they have a 'carer' or 'responsible adult' who can act or interpret on their behalf. Alternative facilities must be accessible to allow deaf young adults to make and attend their own appointments with services without relying on the telephone and family members interpreting.

5.5.2 Promoting positive mental health

Around the time of transition young people are often at a vulnerable stage of their development. It is important that staff are aware of the issues of dealing with people at this time of their lives and in particular about how to promote good mental health in deaf young people. This is often best achieved by good quality support services and networks. Therefore it is crucial that staff are aware of these services, be it social services, deaf clubs or voluntary organisations. Staff should be able to offer or refer young people to suitable support.

5.5.3 Involving service users in service planning

To ensure services are suitable for deaf young people and their families, they must be invited to be involved in service planning. Membership of the Children’s Hearing Service Working Group must include services users and parents of deaf children (NDCS Quality Standards: Paediatric Audiology, in revision 2005). Services may want to consider having representatives of the deaf young people as members of the group.
6. Service Audit Performance Checklist

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<th>Question</th>
<th>Yes</th>
<th>In progress</th>
<th>No</th>
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<td>Do you have a written protocol agreed by paediatric and adult services?</td>
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<td>Does it cover the following: (as a minimum)</td>
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<td>• Age at which young people transfer allowing flexibility for individual cases</td>
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<td>• Arrangements for liaison between child and adult services on transition policy (eg CHSWG or other formal group)</td>
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<td>• Transferral of notes from child to adult department</td>
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<td>• Access and self referral systems to adult department</td>
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<tr>
<td>• Services for young adults in further or higher education, both moving IN and OUT of area</td>
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<td>Do you provide written information at least six months before the transition takes place?</td>
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<td>Does the young person have a preliminary appointment in the adult department before the final appointment in the paediatric department?</td>
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<td>Do you have a named transition worker?</td>
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<td>Do staff have training in and information about working with young adults?</td>
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7. Useful contacts

There are few resources that exist which support transition for disabled children from paediatric to adult services and nothing specific to deaf children. The resources detailed below are to be of general support in terms of looking at practice in other areas and finding guidance.

**Transition Information Network**

The Transition Information Network (TIN) was set up “to improve the experience of disabled young people’s transition to adulthood”. They produce a magazine My Future Choices which contains regular updates of resources and have a website:

[www.myfuturechoices.org.uk](http://www.myfuturechoices.org.uk)

**Seven principles for inclusive transition planning**

A Connexions project looked at how services in an area can ensure a coordinated and coherent approach for young people with disabilities at the time of transition. The report identifies principles for all services and can be found at:

[www.connexions.gov.uk/partnerships/publications/connexpubs.index](http://www.connexions.gov.uk/partnerships/publications/connexpubs.index)

**The road ahead**

This project explored information needed by young people with learning disabilities, their parents and supporters at transition. The report is at:


**Responding to, supporting and valuing people**

RSVP runs courses for young people and parents to help them think about transition and the issues involved. More information can be found at:

[www.rsvpconsultancy.co.uk](http://www.rsvpconsultancy.co.uk)

**National Services Framework (NSF)**

The NSF is a 10-year programme intended to stimulate long-term and sustained improvement in children’s health. Setting standards for health and social services for children and young people the NSF aims to ensure fair, high quality and integrated health and social care from pregnancy, right through to adulthood.

[www.dh.gov.uk](http://www.dh.gov.uk)
Improving life chances of disabled people
This report from the Prime Minister’s strategy unit looks at how disabled people can be supported to help themselves. It details how to facilitate a smooth transition into adulthood by removing “cliff edges” in service provision and giving disabled young people access to a more transparent menu of opportunities and choices.
www.strategy.gov.uk/output/page5046

Useful links to pass on

Careers advice and job vacancies:
www.jobcentreplus.gov.uk

University placement details:
www.prospects.ac.uk/links/2

Educational guidance:
www.dfes.gov.uk

Hospital locations and facilities:
www.nhs.uk