Transition to adult hearing services:
National Deaf Children’s Society briefing

This briefing sets out some of the challenges that deaf young people face in moving to adult hearing services. It highlights a number of resources that audiology services may find helpful in their work to support young people in transition.

Definition of transition:

"Transition can be defined as a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems."1

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 in health services 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.

Challenges described by deaf young people and their families during transition:

- Up to 40% of deaf young people will have one or more additional health needs. These conditions may interact and impact on other aspects of their lives.
- Young people with complex disability may have particular problems when there is no equivalent adult service able or willing to take on their long term health care and medical supervision.
- Deaf young people are often used to seeing the same small audiology team who know them well and may see a doctor regularly.
- Deaf young people often describe problem with communication when they move clinics, both one-to-one with clinicians and when attempting make appointments.
- Severe/profound hearing loss from childhood is a rare occurrence in an adult clinic and deaf young people may feel that staff don't fully understand their particular needs.
- Deaf young people are often confused by the differences between children's and adult services. For example why do they need to change hearing aids simply because the adult service uses different models, why does their hearing aid prescription change, why do they need to see a GP for ear syringing when they have always had microsuction at the clinic before, why can they no longer call or email their audiologist directly with a problem but need to go through a general hospital booking system, and understanding open repair clinics when they are used to ringing up and collecting a replacement hearing aid ready programmed when needed?
- Some deaf young people are unable to make appointments themselves using a telephone only booking system and resent needing to ask another person to make appointments for them.
- Deaf young people are often confused by the differences between services in different areas such as when they live away from home during higher or further education.
- Deaf young people are frustrated by needing to repeat their story each time they see someone new and there are particular challenges when notes aren't transferred between services.
- Deaf young people describe feeling very uncomfortable in general waiting areas with elderly patients.

• Deaf young people vary enormously in their development and readiness to move on to adult services. They welcome flexible transfer ages and being fully involved in the decision when to change.
• Deaf young people have been left with no service provider when the children's service ended at 16 and their new adult service didn't take them until they were 18.

What deaf young people and their families welcome:

• Flexible transfer ages taking into account the young person’s needs and wishes. In education the formal transition planning process starts at 14 and it may be appropriate to begin discussing audiology transition around the same time.
• Support in acquiring the knowledge and skills needed to navigate and make best use of adult hearing aid services.
• Holistic information on all aspects of health, educational/vocational and social needs into adulthood.
• Being given the opportunity to foster independence by talking to them directly and maybe without the parent present.
• Being able to take more control and increasing self-management.
• Having a named person/transition worker they can contact with any problems.
• Not being talked to like a child and feeling that clinicians are talking to their parents instead.

Implementing transition services:

• Poorly planned transition from children’s to adult health services can be associated with increased risk of non-adherence to treatment and loss to follow-up, which can have serious consequences for the young person.
• Successful transition planning and programmes are crucially dependent on collaboration between children’s and adult services as well as engaging with young people to fully understand what they need and expect from the process.
• Transition should be viewed as a process and not as a single event and needs to be flexible enough for individual needs to be met.
• Staff working with young people should balance the need of the young person for privacy and confidentiality, and their wish to take increasing responsibility for their own health care, with the need for their parents to have sufficient information to provide the support that young people often require.
• There are several models for good transition and there is no clear evidence that one is superior.

Useful NDCS resources

• Commissioning audiology services for young adults
  A leaflet for those responsible for commissioning audiology services for teenagers and young adults, in particular those who have grown up with congenital or acquired permanent childhood hearing impairment (PCHI). It highlights the key differences between paediatric and adult audiology care, and the main challenges deaf young people meet when transitioning between services.

• Quality Standards: Transition from paediatric to adult audiology services

Visit the National Deaf Children’s Society to access a wider range of other resources for professionals working with deaf children.