

Summary Report Audiology Transition Pilot Sites

Summary

There are no national models for Audiology Transition from children's hearing services into adult hearing services, though national standards exist, which were developed by a third sector organisation and launched in 2005 (1). There is also a Children's National Service Framework (2) providing national standards for transition, though there are none specific to hearing impaired or deaf children (2). Work with NHS improvement in three national pilot sites has explored emerging issues of engagement of young adults within the Audiology transition process, across differing service models and in three very different localities. This report recognises that a "one size fits all" model is unlikely to yield optimum engagement of young people, but recognises that there are core principles and learning that have come out of the pilot sites, that are likely to offer benefits to the wider service in terms of improving their transition services, should they wish to adopt these approaches. There are potential QIPP benefits to be realised (see appendix 1)

Key principles:

- Wider stakeholder involvement, with agencies that are already engaging with hearing impaired or deaf young people to support them with other aspects of teenage life. This may include third sector or voluntary agencies, who will have a wider role to play in advising teenagers on broader issues around health and education e.g. Connexions, Teen health check, NDCS, Education, Social Care
- Young people in transition should be regarded as a separate group requiring skilled and sensitive handling from medical (and other) professionals. Neither children's or adults services in their existing current format are consistently adequate or appropriate for young people to secure ongoing engagement and audiological health
- There are some aspects of engaging hearing impaired young people that are specific to this client group however, considering teenage issues and concerns in the round will benefit these young people. This means trying to reach them where they are 'between child and adult' and to consider audiology transition in the wider context of the teenagers life i.e. rapidly changing physical, psychological, social and educational development, as well as transferring into the work environment or higher education
- There are general lessons to be learnt and used from other areas, that are equally relevant to this client group, in terms of engagement strategies with teenagers e.g. Teenage Cancer Trust, Teen Healthcheck
- Ownership of the process by the young people is essential, so that it can be kept relevant, up-to-date and evolve as new issues, media, cultural norms emerge e.g. a multimedia approach, so young people can access the information they require as individuals in a variety of forms when and where they choose to access it.
- Accessibility is key. Young people will not persist in engaging in complex processes to access information much of which is currently placed where providers rather than patients think it should be.

Background

The Audiology Transition pilot sites were selected to represent three varied localities with differing approaches & provision of Audiology support to young adults. NHS Devon is a rural and relatively affluent health economy, with well developed support material and a multi-agency approach to transition. Despite a well developed transition model which met NDCS Quality Standard Criteria, uptake of resources remained low. NHS Tower Hamlets and NHS City & Hackney is an inner London locality, with children's hearing services managed in a bespoke children's centre in the community and adult hearing services housed in three different acute hospital settings across three boroughs. The management structure is separate. The catchment population is culturally diverse and has a high deprivation index. East Lancashire NHS Trust provides children's and adults hearing service in a new community health facility managed under an integrated management structure. Though facilities are new and well-equipped transition between services required a more integrated and systematic approach to ensure consistency of standards by appropriately trained and informed staff. The financial position of this acute provider made service development within existing budgets essential.

Reason for Action

The three pilot sites began work on improving their pathways and services for teenagers in transition. It became apparent that the engagement of young people held special challenges that were common to all sites. To explore these challenges further, sites were brought together in a one day event to consolidate the issues, agree some principles and identify a plan work which would facilitate effective service improvement in Audiology for this client group.

Learning was enhanced by hearing from professionals in Teen Cancer and Teen Life-check who had already explored issues around engagement with young people.

Issues identified

- All sites were keen to gain the views of teenagers / young adults in order to improve their services, however, traditional methods of trying to set up focus groups or gain views through questionnaires, did not prove attractive to this client group and yielded low returns. Tapping into existing forums and focus groups provided better information and online questionnaires did provide some responses.
- There are training needs to be addressed in adult hearing services about how to manage the young adult / teenage population who have specific age- related issues around social and cultural identity, as well as specific communication needs. Knowledge of commonly used hearing aids utilised by this teenage / young adult population need to be understood by those working in adult hearing services, who see this group in transition, to optimise the client's amplification methods.
- Young people with a mild / moderate hearing loss are commonly 'lost in transition' and do not re-enter the service until their hearing deteriorates further or starts to become an issue due to environmental changes e.g. beginning a new job or moving to higher education establishments. It is not clear whether this is because they have a poor experience of adult services or whether their "need to fit in" and be like other teenagers is a strong enough social pressure to stop them wearing their aids. Optimisation of technology for cosmetic

reasons may support the continuation of hearing aid wearing at this time. Manufacturers do not market their aids specifically for this group (paediatric design may appear childlike and adult aids generally do not have the teenage market in mind). Further work would be required in this area to identify the reasons for cessation of wearing aids.

- Transition in audiology services occurs at a time where there are many other life changes occurring for this client group e.g. undertaking exams, starting college, beginning work etc. A 'one size fits all' model is unlikely to work and services need to be bespoke to the individual, considering the developmental capacity as well as broader life issues.
- There are distinct cultures within the hearing impaired and deaf communities and whether deafness is viewed as a disability. Some groups do not view deafness as a disability, but rather as an individual who has different communication needs e.g. British Sign Language (BSL) is as relevant a language as any spoken language that people may choose to use. Other individuals may prefer to undergo surgery such as cochlear implantation in order to restore some hearing function. The transition period is likely to be the point where teenagers and young adults are addressing their individual identities and their views and perspectives need to be considered sensitively.

Potential Approaches

There are approaches and learning from other areas of health and beyond that may yield benefits to transition in Audiology:

- Specific social events / weekends away targeted at young adults where there are "fun" activities arranged, but also access to clinicians and other professionals can be gained on an ad hoc basis. This gives an independent / anonymous adviser where teenagers can ask about queries & issues that they may otherwise not raise. (Teenage Cancer Trust, Centerparcs weekend model)
- Meeting teenagers where they are. Utilise social networking sites such as Facebook, Bebo, etc. to gain teenage views on their condition, anxieties and treatment. These sites will give ownership to the teenagers, but observation of discussion boards etc. can prove an invaluable source of information.
- All media needs to be kept updated / current and relevant to the client group as well as 'easy to access' as this group will generally not make an effort to engage. Video diaries made by teenagers can be very revealing in terms of really seeing the impact of their condition in terms of how it affects their life. (See JimmyTeens TV, Teenage Cancer Trust)
- The need to be "normal" and fit in is a very strong driver for teenagers and they may say one thing to their peers, but hold a different view or wish to access different information when alone or in private. Information, therefore needs to be in a variety of media and accessible when they choose to access it. (Findings from Teen Healthcheck)
- Keep the methods and marketing simple. No elaborate instructions required for websites (an address is fine). Market specifically to the client group, consider teen celebrities etc. (Teen Healthcheck)

Emerging Winning Principles:

Initial findings from pilot site work has revealed the complexities around working with young people, and that traditional methods of engagement used with adult patients are unlikely to yield responses or satisfactory learning to aid service improvement. Further work to facilitate our understanding of why teenagers disengage or stop wearing their hearing aids is needed; however some emerging principles are already apparent when working with this client group.

- Teenagers need bespoke services delivered by professionals trained to treat young people uniquely and holistically
- Introduce Transition services at an earlier age and signpost the changes that will happen with up to date information (leaflets and web pages)
- Remind young people and their parents/carers frequently of the transition arrangements ahead by giving early and repetitive information in a variety of forms
- Involve young people in designing and updating services for teenagers, recognising that using a variety of technology and language (i.e. BSL/sign) will be most successful
- Be flexible, allow young people to transition when it is most appropriate to the individual rather than after a specific birth date
- Establish a valid multi-agency steering group to tackle issues around teenage health care. Ensure deaf awareness, knowledge of signposting and continued training of professionals are frequently reviewed
- Ensure that audiology services are joined up – establish a working group made up of professionals working in both paediatric and adult audiology departments which specifically targets the improvement of the ‘transition period’
- Work with the local Connexions team – they have a statutory obligation to see all teenagers in schools – good communication strategies (flagging any health issues) will enable Personal Advisors to signpost young people back to health care/Audiology support, or to be aware of any special needs in terms of their hearing impairment which may impact on higher education or work placements

Next Steps

- Second Consensus meeting of the Transition sites (7th July 2010) to agree the ongoing testing of the new models from the pilot work
- Agree methods of continued contact between pilot sites to share the ongoing learning during the testing period
- Agree how the learning can be supported and disseminated (NHS Improvement likely to be able to facilitate some telephone support and publication of the work through the eBulletin and NHS Improvement website)
- Reconvene the Transition sites in 6 months to assess the learning from the different models and to clarify the (currently emerging) common themes in Transition - this will include the evaluation of the learning from the new NHS Devon/NDCS model to commence in September 2010; the evaluation of the new Transition Audiologist role being tested in East Lancashire with a view to possible roll out; the evaluation of the ongoing work and model from NHS Tower Hamlets/NHS City & Hackney
- Further discussion with NDCS on the use of *theBuzz* website for national roll-out of general transition information for young people to access with possible hyper-links to information on local audiology services

Further Recommendations

- Further understanding of the expertise needed in using multimedia for engagement of young people
- Further work to explore the mental health issues associated with hearing impaired young people (poorly understood) and how this impacts on audiology care
- Consider information governance issues in the engagement of young people
- Further exploratory work to increase the learning and to provide a better understanding of young peoples views on engagement through the use of:
 1. *Discovery interviews* – will give detailed and anecdotal information
 2. *On-line survey* - targeted to existing groups of young people about what teenagers want e.g. wearing of aids through the teenage years, why they stop wearing their aids, impact of moving to adult services, impact of peer group on hearing impairment/wearing of aids
 3. *On-line survey to parents and carers* - to elicit their views and understanding of the Transition process. From this information we can build a model of how best to work together with families to support young people in moving from dependence to independence
 4. *Learning Diaries* – Audiologists could keep diaries of their experiences with patients using the new models (compared to the old way of working). This could be of particular use with the new roles of Transition Audiologists. It would be useful to elicit the most common ‘themes’ that young people ask for which could help to inform more effective and relevant patient information design

Planned Outcomes of Transition Work

- Collate further evidence to underpin the pilot site transition models
- Identify some winning principles for Audiology Transition for sharing nationally
- Publication of the Audiology work on the Transition from children’s to adult services
- Sharing of the generic learning on Transitions with other partners which could help to shape services for all teenagers from multiple disease areas (paper on emerging principles from Audiology and Cancer already prepared for sharing with Dr Sheila Shribman, National Clinical Director for Children, Young People & Maternity, DH)

References

- (1) *Transition from paediatric to adult audiology services in England, Quality Standards, NDCS (2005)*
- (2) *The National Service Framework for Children, Young People & Maternity Services DH (2004)*

Appendix 1

Potential QIPP Benefits

Quality

- Consistency of treatment across Transition services by removing variation and tailoring to the individual
- Age appropriate delivery of services
- Better trained staff with an increased awareness of style and approaches to teenagers
- Improved patient experience
- Better understanding of the disease facilitating more effective self-management
- Continuous (age appropriate) patient involvement and ownership will keep services relevant, meaningful and up-to-date for teenagers to support their long-term engagement

Innovation

- The delivery of a new bespoke model of age-appropriate care for all teenagers transitioning from children's to adult services
- The model designed could work across organisational boundaries incorporating multi-agency working with health, education and social care to support best outcomes for young people
- The increase in resource required to deliver effective transition services may deliver long-term cost reductions in the wider pathway. Young people need age-appropriate support to help them to move from dependence to independence and to make adult mature choices in their future self-management of their condition

Productivity

- Cost savings from a reduction in DNAs
- There is a potential for a cost saving as some young people will be ready to transfer to adult services at a younger age. Adult services are often more cost effective with less specialist staff required, less frequent appointments, and less time spent on individual appointments

Prevention

- Safeguarding vulnerable children and young adults by supporting their care sensitively, consistently and robustly through to an adult service
- Prevention of young people being 'lost in transition'