

Transition of care from a paediatric to an adult service

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The starting point

- Early Years & NHSP focus
- Good quality, timely, coordinated services leading to better outcomes
- Adult services improving – waiting times reduced, better hearing aid provision
- What happens in between???




Transition in audiology services

- MCHAS project (2004) firstwave report
- Interviews with 11 sites
- Questionnaires to young people (who had undergone transition) & their families (response of 90)



Key findings (sites)

- 2 sites had written policies
- Age of transition varied (13 -20+ years)
- Lack of continuity between 2 services
- Level of support offered (aid types, assistive devices, counselling, access)



Key findings (service users)

- 30% provided with transition advice / information (mainly spoken)
- ‘I have not been notified or informed of any transition and not been seen for over two years’ (young adult)
- ‘No information given just the next appointment made at the adult dept.’ (parent)



Findings (cont'd)

- 21% rated experience of transition as 'good', 7% as 'very good'
- 'Abandoned after superb care at the child hearing service' (parent)
- 'We felt cut off. There was so much help at school then nothing for years' (parent)
- 'The follow through was non-existent. We started from scratch with a GP referral' (parent)




What was good?

Transition

- 'Still see the same consultant but at a different site. All was explained in detail' (young adult)
- 'They explained everything very clearly' (parent)

Adult services

- 'You get treated like an adult'
- 'Given options to make choices yourself, instead of being talked into what is 'best' for you'



Transition = Change

At a crucial time in the young person's life. Any change can be disruptive

- 'Very little contact. No checks or evaluations since the change'
- 'Very difficult to have to get to the main hospital'
- 'My daughter has to write to the hospital if she requires anything'
- 'We had to find information on services rather than them being provided'
- 'Now have to send aid away for repairs. Takes longer'
- 'I haven't seen a doctor since I joined the adult service. I haven't got a hearing aid as it's broken and I don't know who to contact'



The issues of transition

- Change in approach from regular support & 'hand-holding'
- Lack of continuity – starting again
- Lack of clearly defined pathway / information
- Poor preparation



Transition the new focus

- ECM: Change for children (2004, cross- Government, building on Children Act 2004)
- The Government's aim is for every child, whatever their background or their circumstances, to have the support they need to:
 - Be healthy
 - Stay safe
 - Enjoy and achieve
 - Make a positive contribution
 - Achieve economic well-being
- Aiming high for disabled children (DfES, treasury)
- Disabled young people may face additional challenges in the transition to adulthood. Support at transition to adulthood is vital to enable disabled young people to gain independence, choice and control over the assistance they need, and to achieve their aspirations. However, not all disabled young people are getting the coordinated, intensive support that they need.
- Disabled young people may face more challenges than most in the critical transition to adulthood. The Government will provide £19 million over the CSR period for a Transition Support Programme to help disabled young people and their families benefit from intensive, coordinated support and person centred planning. (May 2007)




Current context

National Service Framework for Children, Young People and Maternity Services (2004), Standard 4.

- 'Young people supported to make the transition to adulthood and to achieve their maximum potential in terms of education, health, development and well-being.
- Young people taking responsibility for their own health and making informed choices and decisions regarding their emotional and social development, and health and well-being both now and in the future.
- Services and staff who are able to respond in a sensitive way which encourages engagement and provides high-quality support for young people.'

- Additionally
 - *Improving the Life Chances of Disabled People*, 2005 Cabinet Office
 - *Removing barriers to achievement: the government's strategy for SEN*, 2004 DfES
 - *Youth Matters/Youth Matters Next Steps*, 2005/6 DfES
 - *Learning for Living and Work*, 2006 Learning and Skills Council (LSC).



Guidance – Transition guide for all services (DCSF, DH, CDC, NCB. 2007)

- “Maintaining good mental and physical health at this crucial time in growing up can greatly affect future life chances and a disabled young person’s ability to participate fully in society. There is a great deal of evidence that young people who are ‘lost’ in the transition to adult health services are more likely to present later with avoidable and treatable complications of their conditions”
- Needs strategic multi-agency agreement
- Needs detailed local pathways
- Suggests ‘Health Action Plans’ which feed into transition reviews (year 9)
- Details responsibilities of health, education & social care professionals, how to be service user focused and Quality Standards



Guidance - Transition: Moving on well (DH, DCSF, 2008)

- “For all young people, the transition from childhood to adulthood involves consolidating identity, achieving independence, establishing adult relationships and finding meaningful occupation. For young people who are sick or disabled, this transition is made more difficult by concerns about whether, how and where their health and social care needs will be met. Many young people feel vague about the transition process because they have not been given the opportunity to discuss it, and families report that they are faced with a ‘cliff edge’ where services fall away when the young person reaches the age of 16”.
- “Crucial to the successful transition of all young people is forward planning based on the needs of the young person and their family, thus instilling confidence in both that their unique needs will be recognised and addressed. Ensuring that children and parents know about the opportunities and choices available and the range of support they may need to access is something which cannot start too early”.
- “Well-planned transition, sensitive to underlying needs, improves health, educational and social outcomes for young people. Good planning that puts the young person at the centre will prepare them and their family for the move to adulthood and transfer to adult healthcare, and early engagement with adult health services and continuing links with the GP reduces the risk of overdependence as young people and families move on from comprehensive children’s services”.



NDCS QS – Audiology specific

- ‘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’.
- An information pack must be provided for young people and their families collated by members of the multiagency team that details the transition process. The pack should contain details of the local adult audiology service, social services, education and careers advisors and other organisations helpful for young deaf people, including contact names and details.
- 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 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.
- All provision of services, support and information relating to transition must be appropriate for the individual needs of young people and their families in terms of age and language levels.
- Transition from paediatric to adult audiology services: Guidelines for professionals working with deaf children and young people NDCS, 2007



Examples of good practice

- Transition pack
- Transition sub-group (part of CHSWG)
- Lead professional
- Links with all other services
- Transition sessions for young people



Conclusions

- You can never start soon enough
- Planning relieves the pressure at a time of lots of pressure
- Information is key
- All your great work will be undone if it ends poorly
- It's less of a drain on adult services to have independent, reliable hearing aid users