



Action for Sick Children Scotland works for the best quality of healthcare to be provided for all children and young people at times of illness. We are pleased to provide a submission to the Health and Sport Committee for its meeting on 4 March 2014 looking at the transition between paediatric and adult services in the NHS.

In our view the key actions that lead to successful transitions are as follows:

- Transition is a process not an event and it is best if preparation starts early. Some young people attend transition clinics from age 14 where they are supported jointly by paediatric and adult professionals until final transition to adult services at 16 years or later. Allowing patients/families the time to transition gradually is important. Preparation can start as early as time of diagnosis.
- Transition is likely to be more successful if NHS Boards have a clear transition policy setting out the principles of transition from paediatric to adult healthcare.
- It is likely to be more successful where transition pathways exist for specific conditions and when more than one condition exists, transition pathways for both conditions need to be integrated. Pathways should be person centred and tailored to the individual young person who should be involved in its development and agree milestones.
- It is vital that patients and families know the key person responsible for supporting them through transition. The Royal College of Physicians of Edinburgh (RCPE) project, 'Think Transition: Developing the essential link between paediatric and adult care' (2009) showed that it is vital for patient and family to know that someone familiar with their history will be with them through the process into the adult system.
- Young people often leave school during the transition to adult health services so good communication between health, education and social services (if appropriate) in line with GIRFEC principles can support good transition.

ASCS believes that barriers to successful transitions are that:

- Often there is no equivalent adult service for young people. Young people with complex healthcare needs often attend several clinical specialities which may be placed in different localities in the adult system. This needs effective planning and communication between specialties and a lead person.
- Adult services are largely speciality led, so tend not to have a holistic view of the young person's needs.
- Many adult health professionals are not prepared for the needs of young people especially those with multiple problems. They will not have received training in how to care for young people undergoing transition at a time of great physical and emotional change. We are not aware of specialist nurse training for transition and our understanding is that there is currently no specialist nurse for adolescents in Scotland
- Staying in an adult ward can be frightening and bewildering for young people who may be beside elderly, very ill people. The environment is often inappropriate. ASCS's 2012-13 Parental Access and Family Facilities Survey of NHS wards admitting children, <http://www.ascscotland.org.uk/default.asp?page=19> shows that education provision and recreation facilities for young people are unavailable in adult wards and visiting for parents is restricted. Education should not be seen as a paediatric issue. Young people in adult wards should be supported in their educational needs. Their social and emotional needs should also be addressed.
- Information in adult services is often generic, aimed at adults and not tailored for young people.

The effectiveness of existing professional guidelines and patient pathways:

- The RCPE 'Think Transition' Report mentioned earlier outlines core principles for transition, makes recommendations and describes pathways for young people in remote and rural areas and for some specific diseases. The Scottish Government Report, 'Better Health, Better Care, Hospital Services for Young People in Scotland' (2009) contains a range of recommendations and guidelines on transition. The Managed Clinical Networks have developed transition pathways. ASCS supports the recommendations in these reports. Where guidelines can be implemented they will improve young people's experience of transition, but when resources are required for implementation they often cannot be given priority due to lack of funding.
- In 2011, NHS National Services Scotland, following its 'Transition: Make it Happen' conference, convened a short life working group on which ASCS participated. This resulted in the development of recommendations on best transition practice. We recommend that these are now integrated with current Scottish Government policy and legislation eg the Children and Young People Bill. These would then assist Boards to implement best practice.

The Scottish Government and NHS Boards could do the following to promote and bring about better transition services:

- Each NHS Board should appoint someone with a main remit to oversee transition policies and practices across paediatric and adult services – a champion for transition. This should be a senior post appropriately funded and resourced.
- Boards do not need to have the same transition policies but they should be led by an overarching Scottish Government policy. The transition approach should be flexible and welcome the young person as a young adult but also include parents as experts in the physical and in some cases the psychological needs of their young person.
- Implementation of Transition Guidance and Pathways is key and Scottish Government should monitor Boards' progress.
- Appropriate integrated IT systems need to be in place across paediatric and adult services to allow easy access to patient medical history which could help to smooth the process of transition.
- Boards should ensure that all health professionals caring for young people are appropriately trained. This includes professionals in adult services and paediatric services. Those in paediatric services will be trained to work with younger children but not all will be trained to work with young people.
- Boards need to ensure they are prepared to care for young people with conditions that are 'new' to adult services such as severe neurodisability, inherited metabolic disorders, rare endocrine disorders that in the past would have resulted in the death of the child within paediatric services. Provision of age appropriate palliative and hospice care is also needed.
- Appropriate care in a suitable environment for young people should be provided in paediatric and adult services. The European Association for the Welfare of Children in Hospital (EACH) Charter should be promoted and implemented in adult focused wards which admit young people.
- Education should not be seen as a 'paediatric issue'. Young people in adult wards must be supported in their educational needs.
- Boards need to have systems in place for paediatric and adult services to work together.
- Youth services should be offered before and after transition as part of the team around the young person.
- There should be information available in adult services tailored for young people and which takes account of their specific needs.
- NHS Boards should be encouraged to work in partnership with third sector and other organisations which offer self management support to children and young people. Developing self management skills at an early age will support young people through transition into adult health services.
- Scottish Government/NHS could consider undertaking a survey of young people and carers with different conditions one or two years after their move into adult services to find out about their experience of transition and identify areas in the adult service that need to be adjusted to optimise the care of these young adults.

