



Royal College
of Nursing

Lost in transition

*Moving young people
between child and
adult health services*





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Contents

Introduction	2
Principles of good practice in arranging transitions	3
1. Service provision	3
2. Process and protocols	4
3. Keyworkers' roles in transition	6
4. Education and training	7
5. Young people's involvement	8
The Royal College of Nursing calls for...	9
References	10
Further reading	11

Introduction

Transition [in the context of this document] is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems.
(Blum et al 1993)

Children and young people experience many significant transition points between health care services, as well as those between schools, university and other educational settings. Thirty percent of children and young people also experience transitions in relationships as a result of parental separation, divorce or remarriage. Together, all these transitional phases can have an impact on adherence to therapeutic regimes and retention by supportive health care services.

The journey from adolescence into adulthood is a particularly challenging time for all young people from biological, social and psychological perspectives. For young people with any form of disability, chronic disease or significant mental health problem, this is made even more difficult. As they move between different health care services, they will find significant differences in the expectations, style and culture of these services, while their own care needs will be evolving at the same time (NCCSDO, 2002).

A number of recent position statements and reports from professional bodies identify this as an important area for consideration in caring for children and young people. These include: the Society for Adolescent Medicine (2003), the Royal College of Paediatrics and Child Health (2003), the Royal College of Nursing (2004) and the Welsh Health Circular (WHC(2002) 125), as well as an extensive report from the National Co-ordination Centre for NHS Service Delivery and Organisation which reviews the components of practice that promote continuity in the transition period (NCCSDO, 2002).

Principles of good practice in arranging transitions

1. Service provision

The Royal College of Nursing believes that:

Services need to be flexible and based on the needs of the young person, rather than focused on the needs of the service.

Local services must work together, along with the young people and their families, to plan the transition. This includes working with mental health services where necessary, including child and adolescent mental health services, adult mental health services and emergency inpatient services.

Service providers should examine the way transition services are delivered. Services may need to be re-designed so that they truly meet the needs of this client group. In order to reduce missed appointments, and so that young adults are engaged in their own treatment, services should be accessible and acceptable to these patients. For example, drop-in clinics and online information can make a service more accessible and approachable.

In planning to meet an individual's needs, NHS and social services providers should not overlook services available locally from the voluntary sector.

Transition in mental health services

The upper threshold for accessing Child and Adolescent Mental Health Services (CAMHS) can be different from the entry threshold for Adult Mental Health Services. A young person may be too young for adult services, but cannot access CAMHS because they are too old.

Government policy states that CAMHS should be accessible to young people until their eighteenth birthday. This is a current proxy measure for the Public service agreement (PSA) target of a comprehensive mental health service for children and young people, and is likely to remain so until 2009. However, rather than waiting for national policy changes, transitional services need to be up and running now to help young people in this age group. The Adult Mental Health National Service Framework (NSF) requires services to have a transition protocol. Again, such protocols should be functioning now. The Mental Health Act 2007 requires young people under 18 to be in a suitable environment, subject to their needs.

Recommended standards:

- young people's needs are paramount
- transitional points are set as recommended in the English and Welsh National Service Frameworks. Some flexibility is built in to meet individual needs
- young people can access children and young people's specialist and mental health services, whatever their educational status
- where children and young people are admitted to adult inpatient areas, full consideration is given to child protection issues
- all services use means of access and venues which suit young people, in tertiary, secondary and primary care settings.

Case study: falling between the gaps

Stephen is a 16 year old boy who was referred to a CAMHS provider by his GP, who was concerned about Stephen's mood and the possibility that he might be suffering from depression. The GP identified particular symptoms which warranted referral to CAMHS, including problems with sleep, early morning waking, being tired all of the time and loss of weight, as well as the level of Stephen's alcohol intake and occasional drug misuse. At the time of the referral Stephen was at school, but by the time he was assessed by CAMHS staff six weeks later, he had withdrawn from school.

In the area where Stephen lived there was no commissioned mental health service for 16-18 year olds, unless they were at school. The CAMHS health professional who assessed Stephen was therefore unable to begin a therapeutic relationship with him. The professional felt, however, that the main problems requiring intervention and therapeutic input came from Stephen's alcohol and drug misuse. Fortunately, there was a local substance misuse service which accepted referrals for young people up to age 18 whatever their educational status, and Stephen could access their services.

Had Stephen's mental health problems not been related to substance misuse, he would not have met the criteria for a CAMHS service – and would have to have been referred to adult services. Because there are often marked differences in referral criteria for adult and young people's services, Stephen might then not have been able to access the adult services. This kind of gap in access to service provision means a significant number of young people may not have their mental health needs met.

2. Process and protocols

The Royal College of Nursing believes that:

There should be a shared protocol between children's and adults' services, which is a genuinely shared arrangement, and is properly implemented.

A transition should appear as seamless as possible to the young person.

If possible, the young person should have the opportunity to visit in advance the clinic or team who will take on their care. They should be given time and support to adjust to the transition, and the opportunity to say goodbye to staff and friends connected to the children's service before they leave.

Recommended standards:

- staff are designated within specialities to handle transitions. Such positions must be reallocated when the staff member leaves
 - receiving team or staff member is identified in adult services to welcome and support young people entering their care
 - to ensure effective and seamless transition, each health care area has agreed, accessible and known transitional care arrangements
 - the timing and duration of transition is negotiated with the young person and agreed by all relevant parties
 - care is handed over in a planned and collaborative way, through meetings between at least one key professional from both services and the young person (and their parents/carers if appropriate)
 - services should consider the possibility of adopting a mentoring scheme where a young person who has already undergone the transition may be able to offer help and support to other new arrivals
- a comprehensive written summary of the CAMHS notes is available to the receiving service, with appropriate consent for the receiving service to help provide an overview of past mental health issues
 - preparing the young person for transition includes explanation and, where possible, visits to the new clinic settings. Where young people will be exposed to adult clinical inpatient settings, preparation should include helping young people to understand how some patients may behave, so that they feel less anxious if they encounter difficult or frightening behaviour. In mental health care, preparatory visits are particularly important if the adult service is based in, or close to, adult inpatient settings, or is located in an older, traditional psychiatric hospital, which could be off-putting for a young person. To achieve this, one of the transition meetings could be held in the adult setting
 - when a young person fails to attend appointments, professionals explore why, and if necessary consider different methods of access for them.

Case study: Transition in Salford

In Salford, the paediatric and young person's diabetes team (YPDT) recognise that preparing young people for transition from a paediatric to an adult health care setting plays a vital part a successful outcome. The three NHS trusts there work together to meet the needs of young people with diabetes, and have developed a young people's diabetes service which provides continuity of care for young people with diabetes following transition.

Transition begins when they enter the teenage diabetes clinic at around 13 years old. This clinic is run jointly by the YPDT and paediatric team. The paediatric diabetes specialist nurse (PDSN) is part of both teams, contributing to smooth transition and ensuring continuity of care.

Objectives for transition were based on the Diabetes NSF (2001). The YPDT met these objectives by developing pathways of care for young people which ensure smooth transition. They involved service users in developing these pathways. The pathways include gateways through which young people may move in and out of the service (for example, during pregnancy). The design of the pathways recognises that young people are a vulnerable group undergoing many transitions during this stage of life, and that they need a service which continues to meet their needs into young adulthood.

The service has continued to develop, and its success is due to the collaboration between the paediatric team and YPDT. The consultant, nurse and dietician from the YPDT attend the teenage clinic and get to know young people many years before they move into adult services. Young people are also given a leaflet called Moving on which highlights what to expect from the transition process.

There is no age criteria for transition, but it normally occurs between 16-18 years old. The final decision of when to move rests with the young person, who is involved in all decisions about their care. The team recognises the impact that moving on has on parents/carers as well as the young people, and so also prepares parents for the transition.

Improving links with colleagues from adult services has helped further develop the young people's service and has improved the level of care which young people aged 16-25 receive. A survey of young people who have experienced transition to the young person's service indicated they felt the transition worked well.

3. Key workers' roles in transition

The Royal College of Nursing believes that:

Services should designate a key worker or lead professional to work with a young person, their family and relevant services to plan the transition. Making transition a significant part of a professional's job description will ensure that the transition phase is not overlooked.

Recommended standards:

- transition roles are built into job plans, with role descriptions and selection processes
- all professionals and voluntary organisations are aware of each other's role in transition and the services each offers
- staff in both services are aware of the anxiety that the transition may create for young people and parents, and that sometimes young people's mental health may suffer as a result
- parents or carers will have varying degrees of contact with, and responsibility for, the young person. It is important for key workers to understand this level of contact and also agree appropriate communication channels in collaboration with the parents/carers and the young person. These discussions must include issues of confidentiality
- the young person understands how and when therapeutic contact will come to an end in one service, and agrees this with transition key workers.

Case study: Adolescent nurse specialist in London

The preparation of young people and their families for transition to adult services is more efficient if there is a key worker to co-ordinate the process. One NHS hospital trust in London has appointed an adolescent nurse specialist whose job description includes the role of key co-ordinator for transition and transfer for young people.

Many of these young people have been patients of the paediatric service for many years. They view the transfer to adult services as frightening and have a sense of loss. Making sure that there is time for adequate and sensitive preparation for transfer alleviates their anxiety. Preparation gives the young person and their carers the knowledge and skills - and therefore the confidence - to engage with their new team and negotiate the maze that is adult services.

As transition is a key component of the adolescent nurse specialist's job description, they can allocate time for contact with all the agencies involved in a young person's care. Preparation can include visits to the adult unit to meet staff and look around the ward and outpatient areas, and the nurse can involve parents and carers in the process. The nurse specialist can also help the young person to identify what they feel is important to understand and know about themselves, their illness and the future.

Where there is no member of the team designated as lead and given dedicated time for this crucial service, the handling of the transition to adult services can be very hit and miss. Nurses are often the key professional in making the transition work successfully.

4. Education and training

The Royal College of Nursing believes that:

Services need to be viewed in a new light to ensure they work most effectively for young people.

Children's service models of working are often very different from those of adult services. Children's services generally focus on the child and the family, but adult services tend to focus on the individual and on parts of the body, with little or no reference to the family. So moving from one service to the other can be a very daunting prospect for young people.

All staff should receive training about the needs of the young adult facing transition.

Staff in adult services should be given training in issues relating to young people's developmental and wider social and emotional needs.

Recommended standards:

- adult service colleagues understand young people's issues, needs and risk areas
- transition is included in education and training programmes for both adult services and children and young people's services.

Case study: Transition awareness in South Wales

At one university in South Wales, the pre-registration mental health nursing programme now includes a significant amount of time (six weeks) devoted to child and adolescent mental health issues. This includes half a day devoted to the issues of transition from children's to adult services. There is a post-registration module for a variety of professionals which also includes time to consider transition issues, and a multiprofessional conference also examined transition needs.

These training opportunities, together with the attention the Welsh Assembly Government is giving transition in various strategy documents, show how health services in South Wales are working to raise awareness and improve skills in handling the transition of young people to adult health services.

5. Young people's involvement

The Royal College of Nursing believes that:

Involving young adults in developing services is vital to engaging them with the service and with their own treatment. Involving young people provides valuable information to help with planning and providing accessible and appropriate services.

Guidance is available from YoungMinds, the UK's only national charity committed to improving the mental health and emotional well-being of all children and young people. www.youngminds.org.uk/publications

Providing an acceptable and accessible service can improve adherence to therapeutic regimes and get young people involved in their health care services.

Recommended standards:

- young people are involved in the design of services for them – they take an active role and their recommendations are acted upon
- service staff are aware of, and make a conscious effort to improve, the resilience factors which support good health in young people – for example, parental involvement, and empowering young people
- teaching young people how to cope with the transition is part of the transition process
- people undergoing health transitions should have access to and advice about appropriate support, such as education advice and health education. Some specific organisations such as Connexions in England are available for information and advice to young people on a range of matters.

Case study: A bad experience of transition

“There was hardly any planning when I left the unit. I didn't know where I was going to go, or when. I went to a meeting to talk about leaving. My psychiatrist was there, but there were some other people there who I didn't know. I thought that they were just students or something, but it turned out that one of them was going to be my CPN.”

“I didn't know what was going to happen to me. I had been on the unit for quite a while so I wasn't used to the outside world. I received no practical help to prepare me for living in the community. I didn't even know how to catch a bus!”

“When I was being looked after by CAMHS, the staff encouraged us to think about the future, but the adult services were just there to treat us. It would have been useful to have a special service for young adults, so you can get used to the differences before hand.”

“You may be 18, but if you are developmentally younger, and don't have the support of your family, being moved to an adult ward is even more distressing.”

The Royal College of Nursing calls for:

1. All staff working with young people and young adults to receive specific training to facilitate transition between services
2. Issues of confidentiality between professionals, young people and parents to be discussed and the outcome to be clearly documented
3. Young people to receive support and education to prepare them to cope with transition
4. Each health care area to have an agreed transition policy in place which clearly outlines transitional care arrangements
5. Services to be designed around the needs of young people, rather than on the needs of the service.

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