

# Briefing *Paper*



## The transition from child to adult health and social care

The journey into adult life is a time of profound psychological and social change – a challenging time for most young people and their families. For young people with disabilities or chronic diseases, important changes in the care they need and in the way that care is provided, often make this transition more difficult. The role of young people in managing their disease or disability is also likely to change. They will often want to take a more active role, independent of their parents, as well as being expected to do so.

Unfortunately, many young people and their families find it difficult to get the support from health and social services which they need at this time. If the services provided fall short of their needs, their health and general well being may suffer, sometimes with serious consequences. For those who plan health and social services, making sure that care is continuous through the transition from child to adult services – referred to hereafter as ‘the transition’ – is an important goal. Continuity of care enhances the effectiveness of the care, as well as minimising uncertainty and distress for young people and their families.

During the transition, young people and their families, and those providing care, are faced with

numerous challenges. These may include, for example, maintaining lines of communication between services and professionals, or the need to help the young person develop as an individual, into someone who can become involved in his or her own care to the maximum. The problems to be solved will vary depending on the types of health and social care needed.

Continuity can break down at several levels. Vital information may be lost during the transition if departments do not transfer records when they should, or if a particular worker who knows the young person does not pass on information at the appropriate time. Indeed, losing contact with a worker with whom the young person and his or her family has built up a significant relationship may have a very important effect on the transition.

In some conditions, the care provided for adults may be less proficient than that which the young person has been used to receiving from children’s services. For example, in cystic fibrosis, adult chest physicians have only recently begun to look after increasing numbers of young adults with this condition, so may not have the desired level of >>

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# Key Findings



specialist clinical expertise. In other conditions, adult services may be tailored more to the needs of the (far more numerous) older people with, for example, diabetes.

Young people and their families may also have to grapple with issues about who provides and funds care, both during and after the transition, and the point at which a young person is ready to transfer to adult services – something which services often define by physical age rather than the person's readiness.

It is impossible to separate young people's experience of the transition from their own physical, social and emotional development. Their relationships with their families and their peers will help to dictate how successfully they negotiate the transition. It may be that informal care – by parents, for example – may be the only level at which a degree of continuity of care is maintained.

Every young person will react in a different way to the changes he or she faces. Many will want to take charge themselves and break free from the control of their families. Others may rebel against their condition and those providing care. The environment in which care is provided can be important: some young people will feel uncomfortable sitting with their parents in a waiting room kitted out with toys; other young adults may feel ill at ease attending appointments on their own in a busy adult clinic. Professionals will have to balance young people's desire and ability to take control, with their safety, the quality of the care they receive and the needs of their families.

The need to consider such diverse concerns makes it paramount that care providers identify the key issues for each particular group of young people and their families, and how best to resolve these. There are some examples of good practice in handling the transition, and there have been some policy initiatives aimed at making it smoother. But the options available to service providers are not well established, nor is there much evidence about whether these options work well.

This briefing paper summarises the findings of a review of current practice<sup>1</sup> relating to continuity of care for young people with chronic illness or disability, during the transition. The review is one of a number of projects on the theme of continuity of care commissioned by the SDO Programme. It provides a starting point to help service providers think about and enhance the care they provide during the transition, having examined a broad range of practices in health, social care and education.

## Review of current practice

The review was conducted by a team from The Florence Nightingale School of Nursing and Midwifery at King's College London, led by Alison While and Angus Forbes. The team has expertise in synthesising evidence of various types while simultaneously assessing its quality. Several members of the team also had previous experience of the transition during their earlier careers. The team set out to find accounts of practices that people working in health and social care settings had developed to help smooth the transition. During the review, it became clear to the team that education was a third and very fruitful area of inquiry.

The research team had three search strategies. First, they looked for published studies that aimed to evaluate such practices. Secondly, they selected five conditions where they expected to find examples of relevant research in published form. These conditions were diabetes, congenital heart disease, learning disabilities, cystic fibrosis and muscular dystrophy. Thirdly, they conducted a survey of key health, social care, education and voluntary sector agencies involved in planning or delivering services for young people in Greater London and Greater Manchester. In undertaking this survey, the team also sought reports (published or unpublished) which provided accounts or evaluations of initiatives directed at young people in the transition. In the event, most of the latter material turned out to be of poor quality; most of the material used in the review came from the first two sources.

The team's next step was to focus on examples of practice and eliminate any solely theoretical accounts of the transition. They examined the details of each practice, and their outcomes, as well as the methods used to examine the practice. Very few reports described randomised controlled trials or experimental studies; the majority were more descriptive in nature

and drew on qualitative work and surveys. All the included studies were assessed and graded depending on the rigour of the methods they had used.

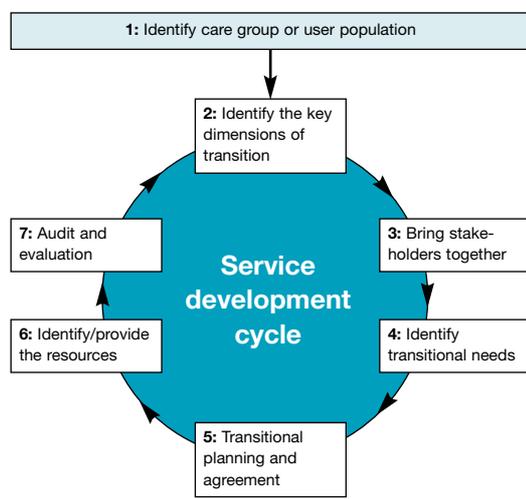
## The menu of practices

The team categorised all the studies, reports and other items of information according to the practices they described. The result was a list of topic areas, each describing various modes of practice (see Table 1). The topics fall under three main headings: services, young people and families. Angus Forbes says this allows anyone to see at a glance the range of different ways that exist of tackling the transition. He acknowledges, of course, that other practices may exist which were outside the scope of the review.

Anyone reading the review can also readily see how many items the team assessed on any particular topic, what types of reports were available, and the team's view of whether the evidence of the published material was strong, moderate or weak. Forbes says: "Overall, the strength of the evidence in most categories was fairly weak, but at least we now have a starting point – a map of the key components of different ways of addressing the transition."

Forbes and his colleagues realised that although the practices they had reviewed varied widely, many of them had core principles in common, which related to the ways in which the practices had evolved and were sustained. They have summarised these principles in a diagram showing the 'framework for service development' (see Figure 1).

**Figure 1:** The framework for service development recommended by the review team. Note that the first step is to identify the user group that the service will be aimed at.



**Table 1:** A summary of the different ways that exist of tackling the transition between child and adult care.

STRUCTURE	SERVICES	OUTCOMES	YOUNG PEOPLE	FAMILIES
<ul style="list-style-type: none"> <li>● Transitional workers.</li> <li>● Transitional teams.</li> <li>● Transitional services.</li> <li>● Developing professional awareness, knowledge &amp; skills.</li> <li>● Provision of information for professionals.</li> <li>● Using continuous services to provide bridge (e.g. primary care).</li> <li>● Intra and inter-organisational (agency) liaison &amp; agreements.</li> <li>● Organisational planning.</li> <li>● Organisational frameworks.</li> <li>● Accessibility and equity.</li> </ul>	<ul style="list-style-type: none"> <li>● Preparation for the transition.</li> <li>● Managing the transitional process.               <ul style="list-style-type: none"> <li>– Assessment (identifying needs other than clinical).</li> <li>– Planning and goal setting.</li> <li>– Review short and long term.</li> </ul> </li> <li>● Case management.</li> <li>● Accountability for process.</li> <li>● A strong therapeutic relationship.</li> <li>● The need for advocacy.</li> <li>● Joint care management.</li> <li>● Flexibility in point of transfer.</li> <li>● Specific communication systems and documentation.</li> <li>● Regular review/audit of service in relation to transition.</li> </ul>	<ul style="list-style-type: none"> <li>● Clinical outcomes improved or maintained.</li> <li>● Young person/family satisfaction (expectations are met).</li> <li>● Young person/family knowledge.</li> <li>● Young person is able to adopt adult roles.</li> <li>● Young person becomes self determining in the management of their condition.</li> <li>● Examining outcomes in the long term.</li> </ul>	<ul style="list-style-type: none"> <li>● Specific services which reflect the lives and needs of young people.</li> <li>● Development of skills for independence in life and in managing their condition.</li> <li>● Development of self determination and autonomy.</li> <li>● Supported psychosocial development in the transition.</li> <li>● Involvement of young people in organising services.</li> <li>● Peer involvement.</li> <li>● Support of young people to develop a new relationship with their parents/carers.</li> <li>● Provision of choices.</li> <li>● Provision of information.</li> <li>● Focus on strengths.</li> </ul>	<ul style="list-style-type: none"> <li>● Support for parents and carers in adjusting to change.</li> <li>● Parental involvement in service planning.</li> <li>● Family-centred approach.</li> <li>● Information for families.</li> </ul>

As the figure shows, the first stage of the cycle is to 'bring stakeholders together'. In other words, planners should bring young people and parents on board, possibly by setting up a joint working party, to work with providers to identify the issues involved in the transition concerned. These issues will not be universally applicable. They could range from young people's desire for adult clinics to have all of their records to hand when they next attend, right through to the need to develop personalised strategies that will allow individuals to develop fully in order to maximise their potential.

Forbes says: "We are not saying that young people should be in charge of the services that they use. The service development framework, or cycle, makes it clear that users should be involved in determining what the transition issues are, and in working out what the best solutions are to these problems."

### Four main models

The team's final piece of analysis allowed them to identify four main models among all the practices they had reviewed (see panel). The models have been derived by blending features from the relevant examples of practice listed in Table 1.

The first three of these models vary in the degree to which they take account of or cater for the young person's personal growth and development (see Figure 2). Thus, the transition will ideally be tailored according to the type of illness or disability experienced by the young person. For example, some conditions will have a minimal impact on the young person's ability to develop naturally. Where, however, the illness or condition limits the child's

potential for growth and development, the individual and his or her family may need extra support to adjust to adult care. The 'trajectories of change' will also vary according to the nature of the condition. For example, the renegotiation of responsibilities that takes place in a family with a teenager with learning difficulties is going to be very different both in rate of change and amount of change to that in a family with a young adult with cystic fibrosis.

The research team stresses that the models that they identified are not mutually exclusive, and that in many circumstances more than one model could be used. They present an analysis of the limitations of their review, and make a list of recommendations relating to continuity of care at the transition, both for those planning services and for those planning research and evaluation on this topic.

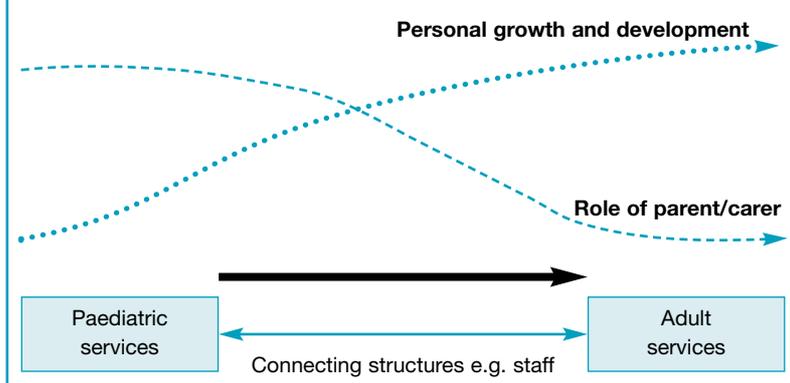
### Does it work?

Those planning services need to know which practices work best. Unfortunately, this review does not tell them. Forbes says: "The research base available was too weak for us to say, categorically, what is good practice and what is bad practice. What we have done is distilled, from a very large volume of material, the core elements of practice that seem to enhance transitional care programmes. We can at least safely conclude that many people have found that these ways of organising such services are helpful."

"The judgement about how useful a practice is will come from your users."

He envisages individual practitioners' looking at the review and deciding whether the practices described would help the constituents whom they serve. "This review provides a key point of reference for health care planners, who will be able to look at the menu of activities related to the transition and consider the four models of care, depending on the needs of the group they are dealing with," Forbes says. "The judgement about how useful a practice is will come from your users. Practitioners who use our service development cycle, shown in Figure 1, will be able to consult the young people and their families. It is they who will say what elements of the service are useful in making the transition a smooth one – and what could be improved."

**Figure 2:** The diagram outlines models 1, 2 and 3 – the direct transition, sequential transition and developmental transition models respectively. In each case, the potential for personal development, its rate and amount, will vary according to the young person's individual needs, and the changing role of his or her family or carer as he or she develops into an adult.



# The Models



## MODEL 1: DIRECT TRANSITION

The emphasis in this model is on good communication and sharing of information. Continuity results when the young person is transferred to adult care safely and efficiently. It does not address aspects of personal growth and development.

Examples of this model within the review included: regular meetings between paediatric and adult consultants to share information on young people prior to transition; good communication between hospital specialists and GPs; ensuring that the necessary referrals and appointments were made for adult services and that these were communicated to the young person; ensuring that non-attendance by young people at adult clinics is monitored and followed up; and the development of shared (paediatric/adult) or client-held records.

“The emphasis in this model is on good communication and sharing of information.”

Used in isolation, this model is probably adequate only where the disease or disability has minimal impact on the young person’s ability to develop naturally. It may also be appropriate where young people’s roles in their care provision are unlikely to change significantly. Otherwise, the researchers suggest that this model should be used in conjunction with either model 2 or model 3.

## MODEL 2: SEQUENTIAL TRANSITION

This model recognises that some special services will have to be provided in order to meet young people’s needs as they grow older.

Examples of this model within the review included: transition clinics or facilities; the

provision of more flexible services either out of hours or at a location more convenient for young people, such as school; and the provision of dedicated professionals or teams responsible for providing services targeted at young people.

The structure of this type of service needs to be distinct from child-orientated care and must allow the young person to rehearse and prepare for adult care. Model 2 services are particularly important when the young person’s role and responsibilities for their care are likely to change significantly. Where possible, the aim should be to assist the young person in becoming an ‘expert’ on his or her condition. This may involve an important redefinition of the family role, with young people being given increased autonomy in making decisions about their care. They may, for example, start attending appointments on their own.

## MODEL 3: DEVELOPMENTAL TRANSITION

This model assumes that young people will need some help in acquiring the skills and support systems they need if they are to use or experience adult care effectively. The model recognises that assistance with general personal development – physically, psychologically and socially – will be required if the individual is to make a smooth transition to adult services. The team found that this model was most common in services for vulnerable young people and those with physical disabilities or learning difficulties, who will require help to become equipped with the skills they need in order to live independently from their families, or, where independence is not achievable, to allow them to access appropriate continuing care that helps them to realise their potential and sustains their quality of life.

Examples of this model within the review included: individualised assessment, planning and training programmes, such as in educational statementing; peer support programmes; the provision of transitional teams and workers to help the young person develop life skills which either promote independent living or maximise potential within continuing care; and strategies such as counselling parents about what level of involvement they should retain as the child grows up.

This model has some affinity with model 2, but is distinct, having an active focus on personal

growth and development throughout the transition. Again, this is likely to involve redefining the family's role in providing care.

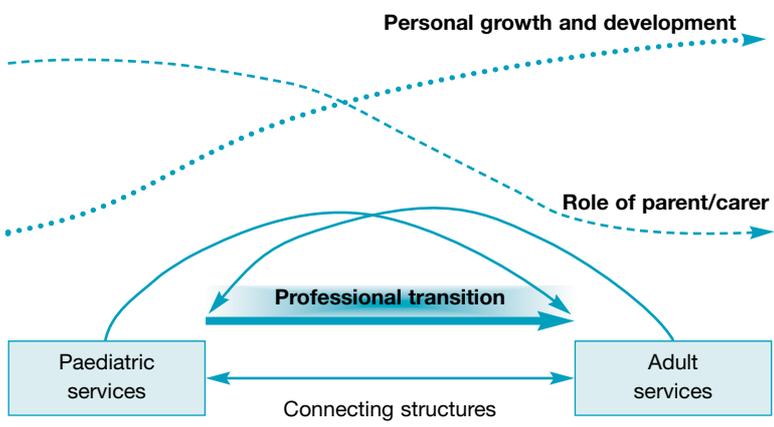
#### MODEL 4: PROFESSIONAL TRANSITION

This model differs from the other three in that its focus is on the professional rather than on the young person. It aims to ensure that the expertise that the young person has benefited from while under the care of children's services continues to be present once he or she comes under the umbrella of the adult service (see Figure 3).

The care of young people with cystic fibrosis provides a good example of how the professional transition model of care can help. A child with cystic fibrosis is cared for up until the age of approximately 18 by a highly specialised paediatric team. At that age, however, the young person is handed on to an adult chest physician, who may not have a special interest in cystic fibrosis. There is a risk that the expertise on cystic fibrosis will remain 'locked' in the paediatric service, with the young person now unable to access it.

The fourth model would ensure that practices were in place to make certain that the necessary skills were transferred between the paediatric and the adult medical teams. For example, during the transition, the paediatric and adult physicians might hold shared clinics, or children might be allocated a member of staff who would follow them for their final year in the paediatric service and for their first year in the adult service.

**Figure 3:** The professional transition model. In this model, the focus is on the health care professional rather than on the patient. It aims to ensure that the expertise that the child has benefited from while under the care of paediatric services continues to be present once he or she comes under the umbrella of the adult service.



## Further Information

### Reference

1. Forbes A, While A, Ullman R, Lewis S, Mathes L, Griffiths P, aided by Ritchie G, Donlan P and Fenwick K. A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability.

The full report, this briefing paper and details of current and future research in this field can be downloaded at [www.sdo.lshtm.ac.uk/continuityofcare.htm](http://www.sdo.lshtm.ac.uk/continuityofcare.htm)

### About the SDO Programme

The SDO R&D Programme is a national research programme managed by the National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (NCCSDO) under contract from the Department of Health's R&D Division.

For further information about the NCCSDO or the SDO Programme visit our website at [www.sdo.lshtm.ac.uk](http://www.sdo.lshtm.ac.uk) or contact:

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