

Transition to Adulthood for Young People with Complex Needs and Long-Term Conditions – A Case Study

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Summary

This article looks at the complexities of the transition process in England and how the agencies may struggle to meet the needs of those individual young people who have complex needs and are living into adulthood. Katie is an example of how transition can become complicated by the timing of the deterioration of a condition and the change to an expected pathway. The article shows the need for a careful interpretation of guidelines.

Introduction

Children with complex needs are increasingly living into adulthood, outgrowing their paediatric needs and requiring a range of health services as adults (Transition: getting it right for young people, DH 2006). This has led to paediatricians and other child health professionals needing to pass their involvement with these young people to adult services that are not historically set up in the same way as children's services. It has led to complications for these young people in transition from childhood to adulthood in England because there is not an equivalent doctor with the same holistic approach as the community paediatrician in adult services. The young people and their families find themselves having to access a range of services rather than a one-stop-shop for co-ordination of their healthcare. This article looks at why confusion arises during the transition period and why it can prove even more complicated when a young person becomes disabled or their condition worsens during the transition period.

Before describing the experience of Katie and her family, the following is a discussion of key aspects of transition under the headings:

1. Education legislation
2. The transition process
3. Transition pathways
4. Information collecting
5. Funding issues
6. Continuing care

1. Education legislation

Legislation regarding school health provision has resulted in the provision of a community paediatric system closely linked to a young person's education (Special Educational Needs and Disability Act 2001). The intention is that a child is able to access education with medical evidence to provide treatment that will ensure that the child is able to make maximum progress. This can vary from one local authority to

another as can the decision to provide a statement of educational need. Some health resources are provided within the school budget, sometimes referred to as 'school action' or 'school action plus', rather than being the responsibility of the special educational needs department of the local authority when a statement of educational needs is raised. These school-resourced children may have health-related conditions which require extra equipment or services to meet their needs which the school would have to provide rather than the educational department. Throughout the child's school career, health interventions may be provided by the school doctor, the child's general practitioner (GP), the community paediatrician as well as by a range of specialist services which may come from a variety of hospitals and paediatric services in this country and elsewhere (as the internet opens the possibility of consultation worldwide).

2. The transition process

Because of the complexity of involved child health services that may have developed through-out the child's life, the passage of these children from child to adult health services has led to confusion regarding when specific child health services end and when adult health services take over. Some paediatric services are provided through the school health service, either directly from school resources or as a result of a child having a statement of educational need. These school-provided services may change when the child moves to another school or education authority and will end when the child leaves school entirely, thus ending the statement of educational need. School does not end at the same age for each child and therefore the statement of educational need may end at different ages for different children. A young person may therefore have a child health service that ends at 16 years when local education authority end a statement of educational need, or, if they continue in a post-sixteen placement (at school, either locally or in an out-of-area specialist provision) they may continue with child health services until they leave at 18 or 19 years.

Apart from the health services that are legally provided as part of the statement of educational need, there is no uniform age that specific health services change over from child to adult healthcare (Transition: moving on well, DH & DfES 2008). This can add to confusion because different Primary Care Trusts may change over at different times as they choose to fund their services differently, and because consultant paediatricians may choose to hand over to adult colleagues at different times depending on what adult services are available or unavailable. For parents of a young person with disabilities, it can be a time when structures that have been in place to support the young person and their family change in the expectation that the young person will become increasingly independent. For

professionals working with the young person and their family it involves a handover of reports, information and the end of what may have been a longstanding provision of children's services. For the young person it should mean that they are able to do what all young people do – separate from childhood with the hopes and dreams of achieving their full potential as an adult.

For young people who have been receiving services for the larger part of their childhood because of a condition that has affected their health, the process towards transition should be gradual. The formal process documented in the Special Educational Needs Code of Practice (2001) begins in year 9 at school and runs alongside the statement of educational need until the statement ends. The statutory educational input continues for all to the age of 16 years or year 11 (SEN Code of Practice, DCSF 2001). Some young people, usually with severe or profound disabilities, continue in local or residential specialist education for another two or three years, after which until this year, the Learning Skills Council (LSC) took over funding a college educational placement if reports (co-ordinated through the Connexions service) were acceptable. The LSC merged back into the local education authority in April 2010 and the implications for this are as yet still in the change process.

3. Transition pathways

There are various routes that young people with disabilities take through children's services. Children will be allocated geographically to an area, and a postcode can make the difference between services that are, or are not, provided. They are likely to be allocated a community paediatrician who will cover particular educational establishments or their disability may have required the services of the children's mental health services which may take them via a different route. They may be referred to a variety of paediatric services in the acute sector either within their geographical area or to a specialist at a centre of excellence, chosen by family or the local paediatric service.

4. Information collecting

On the basis of these and other services, the range of appointments can be widespread with a vast accumulation of notes and correspondence, which are not always linked together. A child's GP should receive correspondence and reports when the child is seen by other paediatric services. However, the expertise may not be with the GP if there is a network of community and school paediatricians who undertake the co-ordination of the specialist services during the course of the child's life. Information sent to GPs, although filed, may not be acted upon unless a specific request is made to do so or the parent makes an appointment with the GP for the child. This would increase the number of appointments that a parent needs to make

for the child and so is unlikely to occur regularly. Files kept on children are not necessarily passed into adult services. Health or other assessments linked to school may not even pass from one school to another and are reliant on summarised reports between school and college when statements of educational need come to an end. Agencies may have different rules about file-sharing, either with other agencies or between child and adult services. Adult services are often reluctant to wade through the files kept on children and, unless previously having worked in children's services, would not necessarily know of their existence or how to access them.

5. Funding issues

There is no agreed definition of a 'young person' or a 'young adult' in the UK. This can lead to services within and between agencies ending at different times and confusion when trying to negotiate a path for a young person who has not required services until they have reached their transition years. The issue of funding is a factor highlighted as a consideration when young people require services either within or between agencies. Services that are likely to continue over into adulthood also require agreement that a chosen placement will not be withdrawn as a result of funding when that changeover takes place.

6. Continuing care

The health service has a process called 'continuing care' to decide whether a need should be specifically health funded. The documentation originally set up to negotiate on these continuing care decisions was intended to ease the path for people, usually elderly, leaving hospital – to determine whether they continued to require NHS care or were able to be looked after with a social care package in the community. Failure to come to these decisions meant that there were people in hospital who no longer needed acute care and were ready for long-term care (either provided in a care environment or with trained nursing staff wherever that took place). An adult deemed to have a primary need for healthcare is assessed in terms of the nature of the condition, the intensity of the needs, the complexity of the condition and the unpredictability of the condition. A person meeting the criteria could be wholly or part-funded by health services. The level that is referred to as 'Category 1' requires the NHS to pay for all aspects of a person's care and is not means tested on a person's income once applied.

As there was no equivalent process for young people under 18 years, the adult continuing care criteria was used to apply to funding decisions about young people with complex needs. This is where confusion arose because in some areas, total funding by health care was interpreted as health care taking on total responsibility for all aspects of health and social care. They were wrongly assessed as meeting 'Category 1'.

For some of these young people this meant that the local authority withdrew their involvement as they no longer had to account for money spent on these individuals – meaning a withdrawal of expertise as well as funding as care management was expected to take place through the continuing care department. It also meant that for those young people who were regarded as the most complex, nurses and therapists had to take on the health and social care role and negotiate with commissioners in the same care management capacity as social workers but without having social work training.

Increasingly, where budgets become more restricted, managers become less inclined to offer anything but the absolute basic necessities, and sometimes this occurs without the wider picture of family need being taken into consideration. A young person who seemingly meets the continuing care criteria of Category 1 would have their health needs met but health services will not pay for educational needs. Nor will health services fund care for siblings or the rest of the family. Needs not directly involving the person meeting the continuing care criteria specifically are pointed back in the direction of social care for their own assessments. This results in a change of approach for families who have previously had a holistic multi-agency approach applied to their circumstances.

When a young person becomes disabled as a result of their condition worsening during the transition period, the timing of the new disabling event can be crucial. The last thing a parent is thinking when their son or daughter has a cerebral bleed resulting in a cerebro-vascular accident, a road traffic accident or is fighting for life after a mugging is that they should continue the statement of educational need after the age of 16. If the statement lapses, however, and the young person is post-16, the local education authority is not obliged to reassess the individual for the reinstatement of the statement of educational need.

Katie's story

Katie's story is an example of how transition can become complicated when a deterioration of a condition comes during the change to an expected pathway – and how it can be further complicated by the application of the continuing care criteria.

Katie has Moyamoya syndrome. This condition involves abnormalities in the blood vessels within the brain and cerebral cavity. For Katie, this resulted in an intra-ventricular bleed that left her with the effects of a cerebro-vascular accident. This happened after she had left school in year 11 and was awaiting her placement at a local college. She had functioned with a moderate learning disability up to this point and had a statement of educational need. She had attended

a local school as a day pupil for young people with moderate learning disabilities.

Her health crisis led to her requiring intensive care where her prognosis was given as critical and poor. Her condition stabilised enough for her to move to a hospice near home. She stabilised further and could be moved back into home with a care team who were funded through a continuing care assessment because of her poor prognosis. This assessment for continuing care was during Katie's childhood, however, and although health were responsible for her provision of health care, she could not be classified as meeting continuing care Category 1 because she had not reached adulthood.

The team of health professionals who had worked towards stabilising Katie's health realised they needed to involve transition and adult services as she was just 16 when the condition occurred. The team needed guidance in which professionals they needed to involve as she progressed into adulthood.

When I first became involved, as her health needs had stabilised, there was more time to focus on her mental health needs and on stimulation of her cognitive functioning. Her parents had been through an extreme grieving process. They had given up work as Katie had needed their undivided attention in hospital and now they were physically and emotionally exhausted.

Social care had decided that they would not allocate a social worker from the specialist disabilities team during the course of Katie's illness in hospital, nor now that she was at home because she was allocated a continuing care package involving trained nursing staff (due to her poor prognosis). An attempt was made to re-engage the children's disabilities team through a transition social worker in view of Katie's age but it was found there could not be an involvement unless there was a case-holding social worker in the children's team. A further attempt to request allocation was also refused on the basis that Katie's needs were health based and there was no role for a social worker.

The information that was given to me by team members working with Katie was that they had been told by the social services disabilities team that social care would not become involved because of the extent of her continuing health care needs. The implication was that if continuing care became involved, *all* of Katie's care would be healthcare managed as well as health funded. This, however, does not apply to a young person under 18 for whom the term *continuing care* relates only to specific aspects of healthcare and not to *all* health and social care. The National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care (2009) emerged from the Department

of Health after Katie turned 18 stating that all services should work together for a child or young person so that the best outcome is achieved.

The transition meetings progressed attended predominantly by health personnel and the process of moving the young lady from child to adult *health* services was, essentially, achieved. However, it became obvious during this process that Katie needed mental stimulation and a re-engagement with education now that her health was stabilised. Because she had left school in the academic year before her health assault took place, her statement of educational need had expired. When I approached the local authority education department in the October of that year, having taken advice from the Connexions service, they came to the decision that they would not reassess her because her statement had ended and she was now post-16. They felt a college placement would be the appropriate route for her. They stated that she was now the responsibility of the Learning Skills Council (LSC). We approached the LSC, again using our Connexions contact, and tried to establish what would be needed to enable a placement to be made available that provided the expertise needed. We were told that the placement had to be officially approved by the LSC.

Katie's parents did not want a residential placement. After a local trawl, an independent day school that specialised in children and young people with complex needs and physical conditions felt they could meet Katie's needs and agreed to assess her. Unfortunately the school was not an LSC-approved placement but, with advice from the LSC, the follow-on college for the group of educational establishments the school belonged to agreed to oversee the placement. After a delay which was probably related to the unusual circumstances of Katie's predicament, the assessment took place at this school and they, with the overseeing college stated that they could meet her needs. We assembled all of the documentation as requested by the LSC and ultimately passed this to them. Unfortunately, a change in LSC personnel occurred. A new officer reviewed the paperwork and the response to this submission was that as Katie met Category 1 criteria for continuing health care, she was deemed to have no educational needs. The LSC would therefore not be funding the educational side of the placement. This was again a misinterpretation of the application for the continuing care criteria for a young person under the age of 18.

This information was relayed back to the continuing care team. The decision there was that health would agree to pay the health component but not what they considered to be the educational part of the placement. After some liaison with the education department, the continuing care team agreed to pay for an educational psychology assessment to try to provide

the LSC with the information it needed to agree that Katie would benefit from educational input.

The whole process of trying to provide Katie with cognitive stimulation she may have benefited from had she been allocated a sixth form placement in an appropriate college establishment, took eighteen months from Katie's health deterioration. There was no positive conclusion to these efforts as, when Katie turned 18, she was assessed as meeting the adult Category 1 'fully funded' continuing care status by the health service and, because of this, the education department decided that her needs were now most definitely entirely health based.

Katie and her family now

Health personnel in children's services are now no longer involved with Katie and adult services have provided day services at two centres – but she has not had the family's preferred option of an educational placement. Katie's health is still stable, she is now 20, but she has been three years without the educational placement that could have been available if funding had been agreed. Had she not deteriorated at the age of 16 when her statement of educational need had lapsed and had she been allowed the expertise of education and social care to work alongside the health-provided services, she and her family would have benefited from the support that they so badly needed to cope with their emotional turmoil.

Thankfully, Katie has survived the illness and is at home – but with many more needs than before. All her activities of daily living need assistance and her parents have to learn, without the much needed educational expertise, how to work with Katie to develop and extend the cognitive function she still has. They have to find out about such things as wheelchair-accessible social events and family entitlements without the aid of a specialist disability social worker as well as coping with their own feelings of how this has affected them as a family.

Some lessons

There are several learning points for professionals from this family's experience:

1. To use and develop professional expertise in transition so that details of the transition process are followed. It is then likely that there would be fewer omissions and misunderstandings by one or more agencies that can endanger the smooth progress towards adulthood.
2. To maintain the multi-agency focus on a young person with complex needs.
3. To work to maintain all links with agencies already involved with a child until it is obvious that they are no longer likely to be needed. This especially includes:

- The need to maintain a statement of educational need
- To include the educational department in the progress of the transition to enable an amendment to the original documentation rather than creating a new statement if the original has been allowed to lapse.

Subsequent to this case study:

1. The Learning Skills Council has now been dissolved and the funding that was managed by this agency is now allocated to the local authority through:
 - i. The Young People's Learning Agency.
 - ii. The Skills Funding Agency.
2. The Continuing Care Guidelines have been published for young people under 18 with an emphasis on the multi-agency approach, even if the young person is assessed to require full funding by health.

References

1. Transition: getting it right for young people DH (2006) http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132145
2. Special Educational Needs and Disability Act 2001 <http://www.legislation.gov.uk/ukpga/2001/10/contents>
3. Transition: moving on well DH & DCSF (2008) http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592
4. SEN Code of Practice DCSF (2001) <http://www.teachernet.gov.uk/doc/3724/SENCodeofPractice.pdf>
5. A Transition Guide for All Services DH & DCSF (2007)
6. The National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care DH (2009)

Useful websites

Transition: How to find your way through. Good Practice Guide. Dimensions (2007)

http://www.dimensions-uk.org/Filestore/Transitions/Good_practice_guide_Dimensions.pdf

LSC Funding Guidance: Learner Eligibility Guidance (2008)

http://readingroom.lsc.gov.uk/lsc/National/LSC-P-NAT-080079_LearnerEligibilityGuidance.pdf

NHS Continuing Care Decision Support Tool (2009)

http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/DH_073912

National Framework for Children and Young People's Continuing Care (2010)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114784

The Young People's Learning Agency

www.ypla.gov.uk

The Skills Funding Agency

www.skillsfundingagency.bis.gov.uk

To learn about Moyamoya syndrome (or Moya Moya disease) go to:

http://www.cafamily.org.uk/medicalinformation/conditions/azlistings/m41_4.html

Contact

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