

FROM THE POND INTO THE SEA

Children's transition to adult health services

Summary

June 2014

SUMMARY

Young people face plenty of challenges when preparing for adult life. For the 40,000 children and young people with complex physical health needs, there are many additional hurdles. In many cases, the health needs of these young people will have been met by the same people who have looked after them for as long as they can remember. However, one of the changes as they reach adulthood is the transfer to an adult environment where they may need to consult several different health teams, therapy teams, and adult social care services.

Over the last two decades, there has been much guidance about this process, often referred to as 'transition'. Of central importance to the coordination of transition is the transition plan. This plan should start at 14 years of age, or even earlier. The guidance sets out

the responsibilities of individual health professionals and the need for a named person as the key coordinator for health. It stresses the importance of good working arrangements between different health and care services.

As part of our review, we spoke to 180 young people, or parents of young people, between the ages of 14 and 25 with complex health needs. We found that the transition process is variable and that previous good practice guidance had not always been implemented. Young people and families are often confused and at times distressed by the lack of information, support, and services available to meet their complex health needs.

It is not acceptable to find, as we did, parents and young people caught up in arguments between children's and adult health services as to where care

should be provided. Or to find that a care service just stops when children's service ends but before the adult service commences. Or to hear from a care worker that transition was well-coordinated, but only because "mother is proactive in coordinating professionals and will actively seek help if needed".



"This report describes a health and social care system that is not working, that is letting down many desperately ill youngsters at a critical time in their lives. We have put the interests of a system that is no longer fit for purpose above the interests of the people it is supposed to serve."

Professor Steve Field, Chief Inspector of Primary Medical Services and Integrated Care



Case study: Peter

Peter's experiences are typical of those faced by many of the young people and families we talked to.

Peter has cerebral palsy. Throughout his childhood, his developing needs presented continuing challenges to Peter and his family. Family life became centred around Peter's needs: physiotherapy, hydrotherapy and hospital visits, both locally and to specialist centres further afield. Because of his complex needs, there is a lot of moving and handling and medical equipment to support him at home. Peter has to be fully supported in his wheelchair; he is registered blind and unable to speak. He is unable to care for himself and relies on his family and carers for all his day-to-day needs.

Peter has a good memory and sense of humour, he recognises those close to him and enjoys going to his special school where he is a day student. Peter enjoys company and responds to questions in his own way using facial expressions and his body language. He enjoys trips out, going to his local church, having a lie-in (school days start at 6.30am) and listening to music.

He needs support from healthcare staff who are competent to feed him through the tube into his stomach, as he cannot eat or drink through his mouth. Breathing problems mean he sometimes needs emergency care and he also needs care from physiotherapists, occupational therapists and speech and language therapists.

Peter had a coordinator for his health needs who was a paediatrician and worked with Peter and his family to ensure that all the specialist health services he needed were available and working together.

When Peter was 14 his parents received a letter that mentioned 'transition' as part of the annual

review that is a mandatory requirement for anyone with a Statement of Special Educational Needs. There was no other information about what transition involved. It came as a surprise to Peter's family, who started to research what this would mean for them. As time went on it seemed that Peter had 'slipped through the net' as he was attending a school outside the local area.

Although Peter's parents arranged meetings with a variety of people, including their local health transitions coordinator and the transitions team manager, it was difficult to ensure that his needs continued to be met during this period. The local service that provided respite stays for Peter had closed. His parents had to meet with various other services and arranged respite from another service themselves.

When he was 15, he had a surgical procedure at a specialist hospital. But by the time of his follow-up appointment he had turned 16, and the hospital's rule was for patients aged 16 and over to be seen in the adult clinic – a very different setting. Peter's local hospital had a more flexible approach and he continued to be seen by children's services up to the age of 19.

Once Peter reached 18, he was no longer under the care of the paediatrician who had coordinated his care throughout his childhood. There was no-one to help coordinate the continuing complex healthcare needs after he reached 18. Peter's parents wrote to their GP to ask for help and they are currently identifying suitable local places for him to attend that will meet his health, social and educational needs.

KEY MESSAGES

Part of the role of children's services or transition teams when caring for young people with complex health needs, as in Peter's case, is to prepare them for the differences they are likely to face at transfer to adult services. The full conclusions and recommendations are set out in the separate full report, but we have four key messages about changes that need to happen to improve the experience of transition for young people and their families.

1 Commissioners must listen to and learn from young people and their families.

The messages from young people and their families are clear. They know what works and they know what goes wrong. Clinical commissioning groups and local authorities must listen and learn from those experiences.

The Children and Families Act and Care Act are an opportunity to get transition right for young people by sharing accurate data, planning ahead and implementing existing best practice guidance for transition.

2 Existing good practice guidance must be followed to ensure young people are properly supported through transition.

There is no excuse for the failure of so many providers and commissioners to follow existing guidance that, if followed, would significantly improve the quality of care during transition. Every young person with complex physical health needs, from age 14 should have:

- A key accountable individual responsible for supporting their move to adult health services.
- A documented transition plan that includes their health needs.
- A communication or 'health passport' to ensure relevant professionals have access to essential information about the young person.
- Health services provided in an appropriate environment that takes account of their

needs without gaps in provision between children's and adult services.

- Training and advice to prepare them and their parents for the transition to adult care, including consent and advocacy.
- Respite and short break facilities available to meet their needs and those of their families.

CQC's inspection models will explicitly look at transition in both children's and adult health services – in hospitals, in primary care and the community – which will be factored into the overall rating. This means that good transition arrangements may raise a provider's rating, and poor practice may reduce it. We may take action in cases where arrangements are so poor that they pose a risk to the quality of care experienced by people who use services.

3 GPs should be more involved, at an earlier stage, in planning for transition.

General practice has a crucial role as the single service that does not change as a result of reaching adulthood. A new enhanced service for general practice is being introduced in 2014/15 to ensure proactive care and personalised care planning for people with complex health and care needs who may be at high risk of unplanned admission to hospital. This will be under the supervision of a named, accountable GP.

The enhanced service has a particular focus on older people, but practices will be expected to consider introducing comparable arrangements for children with complex health and care needs. CQC will be checking how GPs are responding to the needs of young people with complex needs through our inspection and ratings of general practice.

4 Adolescence/young adulthood should be recognised across the health service as an important developmental phase – with NHS England and Health Education England taking a leadership role.

Services should be tailored to meet the needs of this group and include additional recognised training for healthcare staff, such as community nurses, in caring for young adults. Such services should be planned and delivered by staff from all necessary health and care services, who will be required to work together. Care should be provided by staff trained both in the specific needs of young people and how the different services are expected to work together. A named lead must coordinate all care services. This would benefit young people whether their needs involve complex physical care, specialist or mental health care.

We have considered whether there should be distinct young people's services for people aged 14 to 25. This is a credible approach that works well in some mental health services for example. Equally, other good examples of transitional care, such as in renal services and teenage and young people services for cancer, emphasise that flexibility of approach is the key rather than being prescriptive. What works for one 14-year-old may not work for another because of developmental maturity and their resulting needs. What matters most is that

What works for one 14-year-old may not work for another because of developmental maturity and their resulting needs.

services must be integrated, and care coordinated around the individual, with an optimal experience of transition to adult services for those young people who require ongoing health and care in adult life – whatever their age.

WHAT WORKED WELL?

We saw and heard about some examples of good transition arrangements. These were most often in specific health specialties where young people's health needs were predominantly a result of one main condition, for example cardiac, diabetes,

epilepsy or cystic fibrosis services. In these cases, advanced protocols for health transition had been developed, often based on national guidance and benchmarking. Some of the characteristics of these services were:

- **Having consistent staff members who knew about the conditions and the young person's history**
- **Providing adolescent clinics (adolescence is defined as ages 10-19)**
- **Good communication with young people, their parents and each other**
- **Providing good information about what to expect**

We also spoke to, and heard about many hard working, competent professionals who are highly regarded by the young people and the families they care for. We saw examples of children's

community nurses supporting and training young people to take responsibility for their health needs in preparation for adulthood.



"The case manager has been supportive and helpful in helping to understand options available and how to access health care."

WHAT DIDN'T WORK WELL?

From the perspective of many families that we spoke to, transition through health was un-coordinated and often unexpected. For some, it caused great stress and anxiety. One parent summed this transfer to adult services in one sentence:

“From the pond, you are picked up and put in the sea.”

We set out below different elements of good practice, and where this was not being implemented effectively.

1 There should be good planning for transition

We spoke to young people and families as well as the staff involved with providing their health care. We found that transition planning is very variable:

- There was inconsistent and often poor information and preparation from children’s services for young people and their parents about the changes they can expect as they move into adult services. This led to a lack of understanding of the process of transition.
- More worryingly, many of the professionals delivering care also told us that they were not clear about the process. Guidance and protocols for transition were often in place but not always being used, with some professionals unaware of their existence. Many of the commissioning staff that we spoke to acknowledged that there were gaps in the processes. One community nurse told us, when asked if there was a transition pathway, “No, not at all... [we] don’t have clear referral criteria either.”
- When we asked about the transition process, a member of the healthcare team caring for a young person told us “It happens so infrequently, I can’t say how it happens.”
- Some children’s health or therapy services stopped at 16 but there was no adult service available until they were 18. This resulted in essential care being effectively withdrawn.



“I am too scared to think about what will happen. It will probably mean he has to go into residential care. Nobody has talked to me about what happens next.”

“Everybody seems to want to do the right thing, but there seems to be a missing link. No one seems to work together.”



2 There should be a good transition plan in place

We reviewed 103 case records for 14-18-year-olds before transfer to adult services. Eighty per cent did not have a transition plan that included their health needs. We were told that although the guidance made clear that transition plans should be in place, it was difficult to produce them because:

- Integrated care planning was in the early stages of implementation.
- Where there was no equivalent adult service, there was a perception in children’s services

that there was no-one to transfer the young person to, therefore no-one to engage in planning.

- There was a lack of clarity over roles and responsibilities regarding transition.
- There was a lack of engagement between different services. One children’s community team told us that they try to engage with adult health teams but they are always told that “we are not commissioned to do this”.

3 Health passports should be used more widely

We saw some health passports during our review but they were not widely used by those involved in planning with the young person and their family.

- Families and young people told us one of the most frustrating elements of the transfer to adult services was the need to keep repeating the young person’s health needs and history to multiple health teams.

- Although health passports were valued by young people and their families as well as the health and care teams, they were used infrequently. Even where they were in place people acknowledged that an electronic record providing immediate access to young people’s relevant medical history, care needs and wishes was needed as a matter of urgency.



“... as for repetition, I have lost count of the number of forms I have had to fill in time and time again. It is maddening.”

4 There should be a lead professional to support young people and their families through transition

Of the young people and families that we spoke to, 50% said there was no lead professional to support them through transition. Seventy per cent of the health and care staff we spoke to agreed. Families and health and care professionals said that the parents were the main coordinators of care and services. This was mainly because:

- There is a lack of resources and capacity in children's services to manage the existing workload, which is increasing.
- Adult health services are not engaging in transition planning with under-18s because they are not funded to do this.
- GPs are not routinely involved in the care of young people with complex needs as children, but then they have a key role when the young person becomes an adult.

5 Health care settings and services should be responsive to the needs of young people and their families when transferring to adult services

Health and care professionals as well as young people and their families told us that they found adult health care settings and services were not suitable for young people who were transferring to adult services.

- A number of adult health professionals told us they lack experience in supporting young people with complex needs when they first move to adult services.
- Some services that were available from children's community nurses were not available from adult district nurses. This appeared to be partly due to capacity and resources but also different skill and expertise between the two services.
- Some parents had witnessed disagreements in A&E between adult and children's wards, and even intensive care units, about the best place for care to be provided.

6 The needs of parents as carers should be assessed and addressed

Parents told us they felt "abandoned" by health and social care services at this most difficult time.

- There appeared to be a culture of over-reliance on partner agencies to recognise and assess the demands on family members as carers, to follow these up appropriately, and to develop strategies to address their needs. Families reported little concern from health professionals as to their roles as carers and a lack of support or explanation of choices and control over the future.
- Some community children's nurses told us they have had no training in assessing the needs of carers. Despite widespread recognition of the impact of caring for a young person with complex health needs at home, they told us that they don't have the resources to address issues highlighted by carers.



“I was frantic with worry when the funding was turned down, and we had no identified provision. I became ill with anxiety.”

7 Responsibility for funding should be agreed early in the process

Some young people and their families were left without equipment, services, respite care or other requirements during transition, because of failure to agree on responsibility for funding. We were told that:

- Changes in funding from children’s to adult services were not clear and not explained.
- Assessments to allocate funding for continuing health care were often completed by professionals with no previous connection with the young person and their family. This meant that key information was sometimes not available and decisions delayed.
- Although personal budgets can be highly valued by young people and families, some felt ‘left to get on with it’. We were also told that the money from a personal budget was no help if the services were not available to purchase.

CONCLUSIONS AND NEXT STEPS

There was clearly an expectation from commissioning teams in CCGs that professionals across health services for both children and adults would work together to promote effective, timely and well-managed transition. There was little doubt that the majority of individual professionals that we spoke to who work with children and young people were committed to promoting the best possible outcomes. However, their input was often team-specific, task-orientated and responsive, and focused on their own clinical expertise.

In July 2012, the Children and Young People's Health Outcomes Forum published its proposals on how to improve health-related care for children and young people. The Forum's findings in relation to transition were that: "poor transition can lead to frankly disastrous health outcomes for both physical and mental health ... at its worst, poor transition leads to drop-out from medical care for those with a long-term condition, and deterioration in those with disabilities – both leading to unnecessary, costly and often distressing hospital admissions."

From the age of 14, young people with complex health needs, and their families, should be helped to prepare for the differences they will encounter as they become adults, including the differences in the provision of healthcare.

Imminent changes to both the Children and Families Act and the Care Act include specific provisions designed to support more effective transitions to adult services for young people with special educational needs or disability, in health and social care respectively.

The changes to the legislation provide an opportunity to ensure that the wealth of existing information and guidance to support good transition to adult services is at last heeded and implemented.

NHS England, Health Education England, The Department of Health and the Royal College of General Practitioners strongly support the findings of this report and will set out their expectations for how the improvements and recommendations will be delivered.

CQC's inspection models will explicitly look at transition in both children's and adult health services. Key lines of enquiry are included where inspectors will be prompted to look at the arrangements for involving and supporting young people in planning for transition in the primary care and the community health inspection handbooks. What we find will be factored into the overall rating of the service. This means that good transition arrangements may raise a provider's rating, and poor practice may reduce it. We may take action in cases where arrangements are so poor that they pose a risk to the quality of care experienced by people who use services.

In addition, our checks on how providers use the Mental Capacity Act will become a routine part of hospital and care home inspections.

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459

