

FROM THE POND INTO THE SEA

Children's transition to adult health services

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FOREWORD

I was frustrated and upset when I read this report, though unfortunately I was not surprised. It is not about incompetent doctors, uncaring nurses or remote social workers; on the contrary the vast majority of them are highly competent, care deeply and desperately want to help. No, 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. The system is fragmented, confusing, sometimes frightening and desperately difficult to navigate. Too often instead of helping young people and their parents it adds to their despair. It need not be like this.

As we set out to understand the experiences of these young people and their families we saw some wonderful examples of good transition planning, especially in specific health specialities (cardiac, diabetes or cystic fibrosis services). This shows it can be done.

There is plenty of guidance on what makes for good transition planning and good commissioning of care. But we found a significant shortfall between policy and practice. For young people, their families – and sometimes the staff caring for them – this creates confusion and frustration. Even worse, young people can find themselves without essential care or equipment because of the different ways services are provided, or while funding arrangements are resolved.

In 2013 the Government asked organisations to pledge to do everything they can to improve the care of children and young people, and the Care Quality Commission (CQC) was happy to sign up to this. One of the five shared ambitions in that pledge was that services will be joined-up and care will be coordinated around the individual – to ensure the best possible experience of transition to adult services for those young people who need ongoing care.

However, through this review it has become clear to us that a system-wide change is needed to achieve a joined-up approach. Each part of the system, at every level, needs to work together. I hope that, together, the changes that the Care Act 2014 has made and the recommendations contained in this report will achieve the change and improvement that has been clearly needed for a long time.

Planning must start early, and funding responsibilities should be clear. Adult and children's services should work together and information must be shared routinely so that young people and their parents don't waste precious time repeating information about their health. Young people must not fall in the gap between children's and adult services.

Medical advances and better care mean that more children with serious illnesses and disabilities are surviving into adulthood. There is a powerful argument to make sure that now, more than ever, care for these young people is integrated and coordinated around their needs and the needs of their families. We believe there needs to be an urgent review of how these services are commissioned, and that commissioners must listen more effectively to young people and their families and deliver better, more effective, joined-up services.

During this review we have listened to and learned from children and young people, and we pledge to involve them in our inspections. When we find good and outstanding care, we will celebrate it. We will encourage improvement where we find it is needed and we will not hold back when we find inadequate care that is not meeting the needs of our children and young people.

A handwritten signature in black ink, appearing to read 'Steve Field', with a horizontal line underneath.

Professor Steve Field

Chief Inspector of Primary Medical Services and Integrated Care

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. 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 services

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

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.

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.

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



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.

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INTRODUCTION

In England, it is estimated that there are more than 40,000 children and young people (aged 0-18) living with a life-threatening illness.¹ The life-limiting or life-threatening category of illnesses includes more than 300 different conditions. The young people with these conditions often need complicated therapy and treatment packages that are distressing and time consuming. Both their condition and the therapy and treatment can limit the opportunities available to them, and affect their family life.

New developments in medicine and health care mean that treatment for many children with complex health needs has improved. This means that the number of these young people who become adults is growing every year. A recent study commissioned by Together for Short Lives and published in September 2013 estimates there are 55,721 young adults (aged 18-40) currently living with life limiting conditions in England.² It also shows that the numbers are increasing over time. These figures clearly indicate that we need to increase the availability of services that provide care and support for this group of young people, to ensure that the quality of that extended life is everything a person can reasonably expect it to be. This will include services to manage their symptoms and make life as comfortable as possible (palliative care). We also need suitable and effective arrangements for their education, social care and other support systems.

All children need preparation for adult life; some will face more challenges than others. Children with complex physical health needs will need to overcome additional challenges and all involved with their development will have a lot to learn about what adult life will mean for them.

CQC has given priority to strengthening its focus on children and young people and promoting stronger partnership working. We therefore carried out this review to improve our understanding of how well different care services work together during transition from children's to adult health services. We did this through reviewing the care experience of young people with complex health needs. There is a lot of variation in practice in supporting young people from children's to adult health services. Young people with complex health needs are particularly vulnerable as they have a high level of dependence on health care and there are usually a number of providers involved in delivering their care. Ensuring a successful transition to adult services depends not only on individual providers of care, but the effectiveness with which providers and commissioners (those who buy services) work together.

Over the last two decades, much guidance has been published about the planning process for the move from children's health services to adult services, often referred to as 'transition'. These guidance documents all agree that the process should start at 14 years of age, or even earlier.



“This [transition] is a major milestone and the impact of this was not properly shared. We had to learn about the process from another parent; that is sad. Our best source of information is other parents – things should not be like this. It falls on us as parents to instigate all that happens. We have been on tenterhooks for the past four years; nothing has happened, but the process is supposed to be going on.”

Transition is defined in the Department of Health’s 2006 publication *Transition: getting it right for young people*³ as “a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems.”

This period should be used to prepare them and their families for the handover of care to adult services. The period of transition is a process where a young person’s health and social needs should be regularly reviewed and assessed. It is a time that is recognised as one of increased risk. Young people move from the ‘safe’ environment of paediatric teams, who generally coordinate all their health service requirements, to a very different adult environment where they may need to consult several different health teams, therapy teams, and adult social care services.

Transition is only one aspect of developmentally appropriate care for young people. To get transition right, services need to consider whether the rest of the care is developmentally

appropriate. At the same time, these young people are experiencing all the other changes that this age group goes through as they approach adulthood, including the need to establish their own identity. Many of them are dependent on their parents, carers and health services for some or all of their day-to-day personal and health needs. They rely on this support network to help them meet and talk to friends, to use equipment and provide adaptations to help them fulfill their aspirations and hopes for the future. These young people and their families face continuous challenge in their everyday life.

Those providing health and other services should not be adding to those challenges.

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.⁴ 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

* The Children and Young People’s Health Outcomes Strategy was launched by the Secretary of State for Health in January 2012, by establishing a Forum composed of individuals with a wide range of expertise and a shared commitment to improving health care for children and young people.

... 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.”

As a result, a number of organisations made a commitment to work on improving the experience and outcomes of transition to adult services for children and young people. For example, the Royal College of General Practitioners has committed to developing plans to improve the experience of transition by 2014. The National Institute for Health and Care Excellence is currently developing guidance on transition. NHS England is developing a service specification for transition for specialised services.

There are imminent changes as a result of both the Children and Families Act 2014 and the Care Act 2014. These 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.

At CQC we began a programme of ‘themed’ work to look at the transition arrangements for young people with complex health needs. As the regulator for health and adult social care, CQC has an opportunity, together with other parts of the health care system, including the Department of Health, to drive improvement in the outcomes for young people in this area.

As this report shows, a successful transition to adult services does not only depend on the care provided by individual people. It also relies on how effectively those who provide services and those who buy or ‘commission’ them work together.

CQC’s regulatory powers in respect of this programme enable us to look at leadership and commissioning. This means we can try to identify why some services work well together to support young people through transition and try to find

out the reasons why others do not. This will provide a basis for health and other services to learn from our findings.

This report details what we found. It highlights the challenges that young people and their parents and carers face – despite the availability of guidance for good practice for professionals that has been developed over the past 20 years.

How we carried out the programme

The focus for this themed review was the arrangements for the transition of children with complex health needs from children’s to adult services. There is no agreed definition of ‘complex health needs’ among policy makers or professionals; it can include children who have physical disabilities, special educational needs, or life-limiting or life-threatening conditions. In this themed inspection, we included young people between the ages of 14 and 25 who:

- were receiving a children’s continuing care package
- had life-limiting or life-threatening conditions
- received care from three or more multi-disciplinary health professionals as a result of long term or chronic conditions.

The themed review did not focus on the experience of young people whose primary diagnosis is a mental health condition or learning disability. However, we did include young people with these conditions if they also had complex physical health needs.

The young people and families who provided information for this programme were living with a wide range of long-term health conditions that resulted in complex needs. These ranged from the need for highly specialist experts in rare neurological conditions, to speech and language therapists and continence nurses, to specialist ventilation teams that support young people with breathing difficulties. In many cases

the young people themselves were not able to communicate verbally because of their physical condition or learning disability. We therefore used different ways to communicate with them, as well as talking to their parents.

We approached 100 clinical commissioning groups (CCGs) to help us find young people, aged between 14 and 25, with complex physical health needs. From the anonymised information, we selected a sample of 19 areas to visit across England. We also inspected 23 services that were registered with CQC, who provide care for young people during and following the period of transition to adult services. These included residential care homes and colleges, short break services, home care services and hospices.

The purpose of our visits to CCG areas and inspections of services was to:

- Meet with young people, their parents, family or carers.
- Meet with people in teams that provided care to the young people who met our criteria.
- Review records to evaluate the process of transition ('case tracking').
- Speak with people in organisations that are responsible for commissioning services for young people before and during transition.
- Encourage CCGs and care providers to ask young people, their parents, family or carer to tell CQC about their experiences of transition on our website, if they were unable to meet us in person.

We collected information about:

- The pathway and process of transition.
- How effectively the different services worked together (multi-disciplinary working).
- How young people and their families were involved in planning for the transition.
- Training and skills of staff.
- People's experience after the transfer to adult services.

To gather experiences from more people, we also:

- Held focus groups with young people, their families and carers in Birmingham, Bristol, London, Salford and York.
- Offered telephone interviews with our Experts by Experience, people in our involvement team or inspectors.
- Developed an online web form for those unable to meet or speak to us.

We spoke with:

- 58 young people between the ages of 14 and 25:
 - 53% before transition, and
 - 47% after transition.
- 124 family members, parents or carers. Of these,
 - 55% were parents of young people who were still receiving children's services (pre-transition), and
 - 45% were parents of 18 to 25 year olds who were post-transition.

We also talked to:

- 437 multi-disciplinary team members
- 78 commissioners and managers of services.

We used case tracking to look at the transition process for 199 young people who met our criteria for this review, of which:

- 103 were pre-transition
- 96 had transitioned to adult services.

Where we identified concerns about the transition process for young people that we had either spoken to or whose records we case tracked, we raised these concerns with the appropriate provider, commissioner and/or local authority.

40,000

In England, there are more than 40,000 children and young people under 18 who are living with a life-threatening illness or life-limiting condition.

55,000

There are also 55,000 young adults (aged 18-40) living with a life-threatening illness or life-limiting condition.

300

There are more than 300 different life-limiting conditions or life-threatening illnesses, such as cystic fibrosis, muscular dystrophy, severe cerebral palsy and certain types of cancer.

This report

In this report, we have changed all names and other information that could identify a person, to maintain confidentiality.

While CQC carried out this work, the Children and Young People's Health Outcomes Forum asked the National Network of Parent Carer Forums (NNPCF)* to look at *"What good integrated care should look like in transition, and how that can be measured from the perspective of parent carers of disabled children across a broad range of disability/impairment."*

The NNPCF was asked to develop ways to measure people's experience (patient-reported experience measures, or PREMs) and outcomes (patient-reported outcome measures, or PROMs). These are designed specifically to measure patients' experience of health care and to identify the impact of care on patients. As parents of young people with complex health needs, the NNPCF group is well-placed to describe the experiences and outcomes that young people and their families should expect.

The NNPCF published its report *What Good Integrated Care Looks Like in Transition* in August 2013.⁵ We have included the NNPCF's experience and outcome measures in this report, as a framework on which to report on the findings from our themed programme of work.

* The National Network of Parent Carer Forums is made up of all the parent carer forums across England. Each forum is a group of parents and carers of disabled children and children with SEN who work strategically with local authorities, education, health and other providers to make sure the services they plan and deliver meet the needs of disabled children and families. www.nnpcf.org.uk

1 THE TRANSITION PROCESS

“You have to fight for everything”

Key findings

- The information and preparation provided by children’s services to young people and their parents about the changes they can expect as they move into adult services is inconsistent and often poor.
- The process of transition was not clear or well understood by young people, their families or carers.
- Nor was it well understood by some professionals delivering the care.
- Guidance and protocols for transition were often in place but were not always being used, and some professionals were unaware of their existence.
- The system feels fragmented and parents and young people have to tell their story repeatedly to numerous professionals across health and social care.
- Parents told us that they were the main coordinator of care as there was often no lead professional to support young people and families during transition. This was confirmed by many care professionals.
- The process of transition has rarely begun in accordance with guidance at age 14.

NNPCF measure of experience

We understand the process, we know who is involved and we know what is expected of all professionals and within what timescales.

We found very few young people and families who understood the transition process. Very few knew what to expect from the different professionals involved. One parent summed up the views and feelings of a number of people that we spoke to:

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

More worryingly, many professionals told us they were unclear about the transition process. We saw that most areas have a strategy and a formal agreement to plan and work together across children’s and adult services. This provides a framework for the transition pathway to adult health services. However, in most cases these were not being fully used in practice. In some cases the staff providing the care were unaware of any agreed frameworks. In one area, we saw a copy of the transition protocol and pathway to explain how the local transition arrangements worked. But most multi-disciplinary health professionals that we talked to were unaware of it. One member of staff said, “It’s fair to say that there is not an overarching transition strategy.”

In most areas, it is the local authority and educational establishments who are the key drivers in the preparation and planning of transition. This may or may not include the health arrangements.

However, we found that there is often nothing to trigger transition arrangements for those young people with complex health needs who do not attend a special school. For some young people with health complexities but no statement of special educational needs (SEN), and who fall below the threshold of continuing



“The move from school to adult services was the biggest change in her life and all the people who knew her disappeared. There was a new key worker, new social worker. It all happened at once. But the social worker followed through. It’s a shame it has to change at all. I was kept informed. She moved from one home to another – I was fighting her corner, wouldn’t allow for her needs not to be met. [She’s] in a lovely home now.” **Parent**

care needs, there is often no planning for transition at all. Even for those young people that we found did have a transition plan, the preparation for transferring to adult health services was inconsistent and uncoordinated.

Protocols and pathways

We did see some examples of good transition arrangements. These were more often in specific health specialties for example, cardiac, diabetes and cystic fibrosis services, where advanced protocols for health transition had been developed often based on national guidance and benchmarking (see the section on specialist hospitals).

Professionals from children's health and social care services voiced their concerns around both the lack of clarity for the process of handover to adult services and the availability of appropriate services to effectively map the care that they provide to young people after the age of 18. Not all areas we visited had continuing care assessment teams. In those that didn't, the assessments were carried out by the children's community nursing team. In some cases we were told this was as an 'add on' to their current roles, and meant that they struggled to fit this extra work in to their already full workload. A member of the multi-disciplinary team at one CCG told us that they "try to be proactive" and very few young people "pop up" that they didn't already know about, but it was still an issue.

Some children's services reported that they were reluctant to refer young people to adult services. They were both uncertain whether there was a pathway to follow and concerned about the appropriateness of available services. This was reflected in the feedback from families. Some of them reported experiences of a service or support just stopping completely. Many families told us about the negative impact of a late assessment and lack of services on the family unit. Young people and their parents often have to find out about choices and support available to them once they reach 18. Members of health and other multi-disciplinary teams told us that limited resources and capacity in services had restricted how they implemented good transition planning protocols and pathways.

When we tracked the case records of some young people, we referred one case back to senior managers at the CCG, as it had 'slipped through the net'. For this young person, there was no evidence that any transition or continuing healthcare (CHC) processes had been followed. One family told us that they felt everything had been left to the last minute. Nobody had considered the time needed for the young person to adjust to a new setting and new team of carers. Their parents also needed to be able to spend time preparing their other children for the changes and the possible emotional impact on them of moving their sibling. The parents told us they felt their lives were on hold and they couldn't plan anything. In some cases, families told us that some activity around individual transition arrangements appeared to be happening as a result of CQC's visit to the area: "Once the letter from CQC arrived, professionals were in touch and promising all sorts."



Case study: Matthew

Matthew is 21 and has congenital muscular dystrophy. He transferred to adult services when he was 18. The transition therapy team was very supportive at an early stage, which helped his transition. There were regular planning meetings to discuss the handover of care across several different agencies and care providers. Matthew was supported to be the driving force to develop a database of his equipment needs, to plan his holiday and pursue his hobbies.

The team worked hard to support Matthew with his needs. However, there was no documented transition plan and the Continuing Healthcare review

was significantly overdue. The lead transition nurse told us that that Matthew “nearly fell through the net”. He was at mainstream school and didn’t qualify for special educational needs (SEN), which is often the trigger for starting the transition process. Luckily his community occupational therapist brought Matthew to the attention of the transition nurse.

Despite the work of individuals supporting Matthew, they were quick to tell us that his mum was the ‘lynchpin’ in the care package and raised concerns that arrangements ‘would fall apart’ without her. There is no lead for healthcare provision.

NNPCF measure of experience

The right professionals are involved at the right time during the process.

Roles and responsibilities

We heard many reports from multi-disciplinary teams, young people and parents about a lack of clarity over roles and expectations. This was both in written policies and in practice. Some professionals told us that this confusion is a direct result of the lack of local transition guidance and pathways. We found there was no associated, clearly defined expectation of the roles and responsibilities of health professionals.

We found that attendance by health professionals at transition planning meetings was patchy. Some said this was because of pressures on capacity and resources. Some children’s community teams told us they were providing responsive and reactive services to young people to manage their immediate needs. This left them with no time to work with families to plan for the future. CCG staff told us that the number of young people with complex health needs who require transition planning has increased. They said the current capacity of the community children’s nursing team is overstretched. Community children’s nurses said they are aware that so much responsibility falls on the young person and their family to address health care needs after they are 18. One person told us, “It’s a very different world. You are left on your own a lot more to sort things out.”

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



NNPCF measure of experience

We are supported by a key worker/lead professional or case manager and have clear understanding of eligibility for services, and redress opportunities where we do not believe these are fairly applied or acceptable thus reducing the need to ‘fight’ for any service.

Key workers/lead professionals

We asked staff at the 19 CCGs that we visited if they thought there was a key worker or coordinator for all young people with complex health needs to support the transition process. Only eight CCGs were confident that there was a lead professional for each young person.

During our reviews of records and in discussions with young people, their parents and health and social care professionals, we checked whether there was a lead case manager or key worker coordinating the transition process for each young person.

Was there a lead professional to support the transition process pre-transition?

	Yes	No	Total
Case notes	27 (37%)	46 (63%)	73
Health and care staff	32 (30%)	75 (70%)	107
Young people/parents/carers	32 (50%)	32 (50%)	64
Total	91 (37%)	153 (63%)	244



The Department of Health's good practice guide *Transition: moving on well* (2008)⁶ outlines the characteristics of good transition service, including:

- An agreed process for joint strategic planning between children's and adult health services.
- A clear transition pathway.
- Clear identification of the key worker and key worker designate (in adult services).
- A focus on person-centred planning.
- Excellent links across adult and children's services.
- A multi-agency model.
- A service responsive to the needs of young people and their families.
- Effective health contribution to strategic planning for transition service.
- Flexible, timely response: early intervention and prevention through individual health plans, avoiding hospital admission, where possible.
- Integrated multi-agency health transition plans and pathways which enhance a young person's ability to take appropriate responsibility for managing their own health needs, promoting choice and opportunities for independent living.
- The opportunity to develop self-management and self-referral, as appropriate.
- Risk management procedures, including effective follow-up for vulnerable adults.
- Transition teams with core professionals who deliver a comprehensive service.
- A skill mix which ensures that adolescent health expertise, professional/clinical leadership, key working (where required) and supervision of support staff are available.
- A joint planning and funding process within the PCT/primary care/local authority for multiple, ongoing needs.
- Specialist commissioning for needs, such as palliative care or rarer conditions, where evidence demonstrates the benefits of regional partnerships or more centralised tertiary services in conjunction with management health networks.
- Identify quality standards to enable performance management.
- Measurable outcomes to ensure a value-for-money service.

Is there a named lead professional to support care needs post-transition?

	Yes	No	Total
Case notes	42 (57%)	32 (43%)	74
Health and care staff	44 (52%)	40 (48%)	84
Young people/parents/carers	24 (80%)	6 (20%)	30
Total	110 (59%)	78 (41%)	188

Only 50% of young people and their parents said they had received support from a lead professional during the process leading up to transition to adult services. This is higher than the response of teams of professionals looking after the young people. Only 30% of them could say that there was an identified lead professional overseeing the transition for the young people they looked after. This was a similar figure to that recorded in the case records (37%).

One parent told us, “Nobody has particularly talked about transition to us at all. Six months ago I asked our social worker if anyone was going to help us with transition... they didn’t have a clue she was nearly 18.”

Following transition to adult services, a much higher percentage of young people (80%) and the healthcare professionals (52%) providing their care said there was a lead professional coordinating care needs than had been the case during what they often described as the difficult transition phase.

In many cases the lead for the transition process was a social worker, with no separate identified lead for healthcare. Parents and care workers expressed frequent concerns about the number of times the lead social workers changed. One parent told us that her 17 year old son had had three social workers in last 18 months. She had recently been told that his current social worker would also be passing on the case to another person. The manager of a residential home providing care for young people before transition told us they had concerns about the number of social workers assigned as transition leads. They gave an example of one young person in their care who has had five social workers since they started living there. And the social worker was due to change again.

An overwhelming number of parents said they felt as though they were the ones coordinating care. This was confirmed by many of the health and care professionals that we spoke with.

We came across a number of people who had lead transition roles in CCG areas. However, these appeared to be more strategic roles, rather than being more directly involved and understanding individual cases. There was much confusion about these roles and their impact. For example, when asked, a

senior transition nurse could not identify a single case that demonstrated their involvement. The lead transition roles did not demonstrate any increased engagement with health professionals, which was lacking in most areas.

“If we had not already had experience of transition by way of our late son who had the same condition, then we might have missed out on some of the support available. We did all the leg work then so did most of it ourselves again this time.”

However, one 17 year old told us that he has received help to understand how to access health services as an adult: “The case manager has been supportive and helpful in helping to understand options available and how to access health care.” He went on to say that it was “helpful and reassuring” to meet with the adult health teams before transition. He told us how the case manager had arranged “training on how to manage health care to be as independent as possible”.



“There was no nominated individual. The consultant paediatrician was brilliant in trying to co-ordinate services and ensure communication, but the most active and effective person was the community health care assistant who was heroic in persistently chasing people and adult services up. It was mostly down to her efforts, going way beyond the call of duty, and us as parents, battling through and not giving up.” **Parent post transition**



“There are a number of professionals involved, including, the community nurse, paediatrician, speech and language, transition social worker, school, physiotherapist, children’s social worker. I’m not sure who you would describe as the lead.” **Mum of 17 year old**

2 FUNDING / BUDGET

Key findings

- Some young people and their families were left without equipment, services, respite or other requirements during transition, because of a failure to agree who was responsible for funding them.
- Funding arrangements are fragmented and changes to funding are not always clear. Some parents and young people did not know what money they would receive following the move to adult services. There was poor information for young people and their parents about the different funding arrangements during the transition process.
- Continuing health care assessments to allocate funding were sometimes made by professionals with no former knowledge or connection with the young person and their family, resulting in delays to funding when key information was unavailable.

Responsibilities for funding

We saw frequent examples where young people and their families were left without equipment, services, respite or other requirements during transition, because of failure to agree on who was responsible for funding.

Parents told us that the differences between the benefit systems for children and those for adults should be made much clearer. They were left unsure of what money they would receive. This caused anxiety about whether they would be able to make choices based on their young person's needs rather than what they could afford. Parents told us that there had been "no one to guide them through the process and support them with financial information."

Some providers of residential care told us that they sometimes weren't paid until disputes about funding were resolved by local authorities. Some of the case notes that we looked at had jointly-funded care packages. There were clear frustrations in terms of the separate processes to establish funding. For example, a continuing health care package might be approved, but the process still needed to go to the local authority panel. Therefore nothing was agreed or certain. One parent said, "They talked about my daughter as though she was a budget. I found it very depressing."

We asked a 19-year-old girl what could have worked better in the transition process; she told us, "Not having to 'fight for funding' and professionals making decisions and communicating quickly – it's stressful."

Personal budgets

Individual health budgets and, in some cases direct payments, can offer more flexible packages of support that are tailored to an individual. These enable young people to have more choice, control and fun in their lives. Where young people's care was funded in this way, it meant that their care was more flexible and person-centred. We saw that this was highly valued by the young people and their families. One young person told us, "Everyone worked creatively together to find solutions to support me in reaching my goals." However, some parents said that although it's good to have the money, it's not helpful when the services are not available to buy. This was confirmed by health professionals. They told us there were often no 'like for like' adult services available.



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

Some case managers were sensitive to the challenges that families faced in managing these budgets, and identified a lack of support for them in this area. However, there was a sense that once personal budgets were agreed, families were 'left to get on with it'. We found a general lack of oversight as professionals relied on parents to arrange everything. One family told us that the transition from children's direct payment to adult direct payment was "a disaster". It resulted in their daughter receiving both adult and children's payments for months, despite her parents frequently pointing out this error. They told us they had to pay back thousands of pounds because of the overpayment.

Some staff told us that implementing personal health budgets highlighted issues about the safeguarding processes. Some commissioners told us that once young people have received the budget to purchase services themselves, there was no remit for CCGs or other services to conduct disclosure and barring (DBS) checks (previously CRB checks) on the carers they employ. They felt that this left a gap in assuring that suitable people are fulfilling this role.

Although this is a complex area, there is guidance to help organisations, including CCGs, to understand and implement the direct payments. NHS England has produced *Guidance on Direct Payments for Healthcare: Understanding the Regulations*, which relates to adult care but may be useful for all types of personal health budgets.⁷

The guidance states that although individuals can't request DBS checks on an individual when employing or contracting with people, they may wish to ask the CCG or another umbrella organisation if it is possible to arrange for the prospective employee or contractor to apply for an enhanced DBS check with a check of the adult's (or children's if appropriate) barred lists. CCGs should ensure that advice on DBS checks for individual employers is readily available and accessible. The guidance also sets out the importance of the care plans as a way to enable the CCG to be satisfied that the health needs and identified outcomes are likely to be met.

Other common concerns about funding related to time and travel costs. Young people and their families told us that, due to the way adult services are configured, they often have to attend multiple hospital appointments. This often resulted in parents having to take time off work, increasing the financial burden. Added to this is the cost of travelling to appropriate day services that are far away. This is made worse by a lack of funding for the special transport that young people may need.

A 17-year-old who has to travel out of his area for care told us, "While travel costs are subsidised, it is still expensive and a barrier for family and friends to visit or be available for support when having treatment [out of area]."



“We have only been listened to because we made a lot of noise; we were not intimidated by professionals.”

Coordination

We found that continuing health care assessments to allocate funding were sometimes completed by professionals with no previous connection with the young person and their family. This professional often had little understanding of the young person’s specific needs. This meant that key information was sometimes not available. As a result, decisions were delayed and families lost confidence in the professionals.

The family of one young person with very significant neurological and mobility health needs who had been through transition said they wanted “no more battles over funding”. They felt they were not properly represented at the meeting to decide on funding for continuing health care. They said it would have been good if the adult health co-ordinator had been involved at an earlier stage. They have had to negotiate to get vital supplies needed to care for their daughter and have sometimes had to fund this themselves since transition. They told us the constant worry about funding had been difficult to handle, saying it could have been avoided if the adult health co-ordinator had engaged with them “at an earlier stage rather than at the last minute”.

One team of community children’s nurses said they were told that they have to be involved. But they said they don’t have the resources, or even people who know the young person, to make the visit or assessment meaningful.

The manager of a residential home told us that annual reviews for continuing healthcare were “just a form, a tick box exercise”. They went on to say that the case managers don’t always want to involve the parents, although it wasn’t clear why.

We spoke with one parent about her son, Mark, who had received a children and young person continuing healthcare package and direct payments from the local authority from age 15. The transition of his funding arrangements at age 18 was poorly managed. Mark’s severe and enduring physical health care needs were identified as highly likely to need adult continuing health care funding. However, the application process was only started when he was 17 and a half. The approval was delayed until six months after Mark’s 18th birthday but there were then delays in the local authority funding process. This caused further distress and added to delays in recruiting care staff to support Mark. Mark’s parent describes transition as “the most stressful two years of my life”.

3 TRANSITION PLAN

“I didn’t know what age the transition occurred until now”

Key findings

- Planning often started late, which sometimes delayed decisions and caused gaps in care.
- Health passports existed but were not widely used by those involved in planning with the young person and their family, which meant repeating the medical history and wasting time.
- Health assessments were often out of date and there was a lack of a regular review.
- There were often no transition plans at all; where they did exist they were of variable quality.

NNPCF outcome measure

Plans are in place for current and on-going health needs including a written agreed history that includes past medicines, surgery, other interventions etc.

Many of the geographical areas that we visited showed commitment to the concept of integrated care planning, but most of these processes were in the early stages of implementation and it was too early to see what impact they would have on young people and their families as they move to adult services.

The current guidance makes clear that plans to move care to adult services are expected to start at age 14. The plans should be well co-ordinated, documented and designed in partnership with young people and their parents or carers. The plans should involve all teams providing services for young people, including all health services in partnership with other multi-agency providers (for example, education and social care).

Quality of transition plans

We saw numerous examples of young people who had not yet transferred to adult services (age 14 to 18) who had no transition plans for health at all (80% of the pre transition case notes reviewed). Some case notes did record individual health needs, but not as part of a transition plan. We checked this with the commissioning teams that we spoke to. Only two of the 18 areas thought that all young people with complex health needs had a specific health transition plan. Although most thought the health requirements would be clearly documented, even if not part of a transition plan.

The transition plans that we did see were of variable quality. There were wide variations in the extent to which care was planned with young people and their families. This raised concerns that young people's health care was not designed to meet their personal aims and objectives. There was little evidence of any quality monitoring of the standards of record-keeping for the transition period. Many case files were disorganised and incomplete. This made it difficult to assess the content of the transition plan. One review of case notes states:

In one set of records, we saw that there was an assumption that a young person who was nearing the age of transition would be capable of giving themselves their regular injections when they moved to adult services. However, there had been no discussion about transition with the young person or their family. The children's community nurse acknowledged that the young person would be capable of jointly producing a care plan. But they told us, "We have no time for writing things like this with young people." Community nursing teams explained that the lack of consultation with young people about their transition planning was because of a lack of resources and capacity within the team.

One social worker told us:

"It all feels rushed and last minute. Some services transition at 16, some at 18 and if they are at school then it's 19. It's disjointed and confusing for me as a professional, let alone for the family."

The *Together for Short Lives transition care pathway* provides a generic framework that can be adapted locally to plan services specifically for teenagers and young adults with life-threatening, life-limiting or complex medical conditions. The pathway sets out six standards that should be developed as a minimum, with the aim of achieving equality for all young people and families, wherever they live.⁸

NNPCF outcome measure

A communication passport is in place if needed.

Passports

A 'communication' or 'health passport' is a document or booklet that young people can carry with them when attending hospitals or other appointments. It contains information about their care needs, history and requirements. It includes how to communicate with and support them. Professionals were aware of the benefits of health passports or similar documents to support transition arrangements and provide reassurance to young people and their families.

However, we found that they were not widely used and we saw very few health passports. Parents and young people told us that they can waste a lot of time in an appointment repeating past medical history, information about complex needs, medication etc. This was one of the most frequently reported issues that we heard about and causes frustration and stress for young people and their parents. A well-constructed health passport could help to avoid this.

The Cambridgeshire Community Services NHS Trust has developed a new Child Health Action Plan (CHAP) template. This was designed to replace the previous health passport arrangements. The idea was generated by parents and young people who were tired of having to re-tell their story to the many health professionals they need to see. This template was developed with a range of health professionals, young people, parents and the CCG's Caldicott Guardian. It is now being routinely implemented at transition reviews for young people aged 14 and over. Such initiatives were welcomed by staff and young people and their families. However, people did acknowledge that an electronic record providing immediate access to young people's relevant medical history, care needs and wishes was required as a matter of urgency.

NNPCF outcome measure

Everything is reviewed regularly.

Reviews

We reviewed the records of 199 young people who met our criteria. We saw frequent examples of out-of-date health assessments and a lack of regular reviews of care needs. These form the basis of a package of care and how it is provided.

Failure to regularly review and assess needs significantly increases the risk of missing a person's changing clinical health needs. One inspection report noted that there was "...no transition planning in place. Nursing assessments are out of date and it is unclear the extent to which care plans are individualised to the specific needs of the young person. It is also unclear if the care plans are active as they are not dated or signed by the young person, family member or nursing care staff."

We saw that sometimes care was reviewed as a result of changing circumstances or when somebody requested it. When this worked well, young people and their families were involved in the reviews, along with health and other professionals.



Example of good practice

Extract from report:

"Care packages are monitored and reviewed accordingly, and examples have been seen of promoting individualised care based on best outcomes for young people and families.

One case demonstrated a high cost package of support care agreed and funded to allow two siblings with profoundly complex needs and packages to go away without their parents on a cruise."



Example of poor practice

We spoke with a team responsible for a young person with profound disabilities who needed round-the-clock care. Although the young person was 20, their file was still held by the children's community nursing team, who were unclear of any outcome of handover to adult services.

Any work the team had carried out for transition had revolved around arrangements for continuous provision of equipment needed for nutritional support (enteral feeding). Beyond this, there was no transition or health care planning, with no record of consent, capacity or individualised person-centred planning.

The last entry in the file was dated a year previously and suggested the team should be informed once handover had taken place. No subsequent action has been taken and the team were unclear as to the outcomes for this young person.

4 INVOLVEMENT AND CHOICE

“More training for families!”

Key findings

- Only 54% of young people preparing for transition and their families felt they had been involved as much as they wanted to be.
- There was generally poor information for young people and parents on transition arrangements and services available to them.
- Where they were involved, we saw good examples of involvement.
- There were many examples where support plans did not include young people’s wishes.
- There was a lack of options or choices when appropriate services weren’t available locally.
- Records of capacity to make decisions were generally very poor.

NNPCF outcome measure

Family and young people feel involved and have had their future aspirations and 'what is important to me and for me' list identified and met (from year 8).

We saw some excellent examples where young people had been fully involved in the assessment and planning of their care. This had involved a wide variety of methods to ensure that they contributed as much as they could.

Guidance from the Royal College of Speech and Language Therapists *Five good communication standards* (2013)⁹ sets out good standards for reasonable adjustments to communication that people with learning disability and/or autism should expect in specialist hospital and residential settings.

We asked young people and their parents whether they felt they had been involved and kept informed as much as they wanted to be in planning the move to adult services. Of those who had not yet gone through transition, 54% felt they had been involved as much as they wished to be. For many young people there was no transition planning for health with no indication of their wishes for health care or how this would impact on their future wishes, hopes and aspirations. Of those who had already transitioned, 60% felt they had been involved as much as they wanted to be. One parent said:

“There is evidence of some good work by individual health professionals and teams. They have a clear focus on the young person and their family’s wishes and feelings. But generally parents and carers don’t understand how the process will work. They don’t understand who should coordinate it and what they can expect for the future.”



Example of good practice

One 17-year-old had a continuing healthcare assessment using the ‘*All about me*’ format. It was very person-centred. His support needs were clearly outlined and recorded in simple language and using his own words. It had a strong focus on his likes, dislikes and wishes. His father told us:

“The team have worked creatively to expand and enrich his social and practical skills. As a result, his ability to join in and socialise with his siblings and peers has grown significantly. The team are always open to new ideas and often have creative suggestions of their own.”

“At about 14 years of age they were warned that they would need to move to adult services when they reached 18. They were offered the chance to do it there and then but they felt it was too soon and this decision was supported by staff. They then transitioned at 16 years of age when they felt ready. They felt this was the right time as they were starting college, becoming independent and really did not want to continue to receive treatment on a children’s ward.”



There was little evidence that children’s services or transition teams provided any preparation or training for young people and families for the differences they were likely to face at the transfer to adult services in terms of communication, consent and confidentiality, how to navigate the different systems and seek relevant information.

NNPCF outcome measure

Our young people fully understand the services available to them and can exercise genuine choice.

A number of young people we spoke to were going to stay in college until they were 19. But their parents were worried about what would happen then, and the lack of options for them after college. Many of them felt there was very little information or choice available. The lack of facilities in some areas to provide adult healthcare essentially meant that, to keep young people close to home, there was no choice in how or where care was provided. Parents spoke of disappointment and frustration at the lack of information and choice. One community paediatrician told us:

“There is a huge gap in local services and we often have to look outside of our area, but then parents of young people rarely want to even consider this as an option.”

In several cases we were aware that professionals had openly shared their concerns with young people and their parents about the appropriateness of adult health services for their children once they reach 18. We saw a clinic letter in a file that detailed the consultant's intention to keep the case until the young person reached 20. However there was no strategy plan in place for what will happen at that stage. This approach has been mirrored by children's community nursing services and is reflected in the views of parents:

"I'm still asking to be told or shown my options and I have been since [he was] 16... when I am given choices, my choices are disregarded!" "We go around in circles, nobody is really doing anything to give me any clarity" "I've fought for him for the last 18 years, I'm lost and no-one will help me."

Another parent told us:

"We have never been given any choices. Before she was 18 we were told that a lot of thought would go into a tailor made package, but it never happened."

Equality and diversity

The young people's case records that we looked at generally showed what works well for them in relation to communication methods. But their support plans did not sufficiently promote and reflect their wishes and aspirations for the future. There was very limited exploration of young people's faith, ethnicity and culture in terms of their needs and wishes. At Peterborough Hospital, we found there was a post specialising in equality and diversity. This was effective in helping young people and their families to navigate their way through hospital admissions and discharge arrangements. The person in this post facilitates culturally appropriate care, which is valued by people who have experienced repeated hospital admissions.

Consent and capacity

There was often a lack of formal reporting of consent and capacity issues in the case notes that we saw. There was little evidence of best interest decision-making. We are therefore unclear as to the extent that the interests of vulnerable young people are being recorded or that their voices are being heard.

Parents voiced concerns about issues and the changes regarding consent and mental capacity from age 14 and into adulthood, which were not always explained or understood. We found that recording discussions with young people and families about decisions around capacity in case files was generally very poor. Transition leads and professionals acknowledged that there was a continuing reliance on consent from parents – even after young people were 18 and the parent could no longer give consent on their behalf. Some parents were unwilling to discuss the issues around mental capacity to consent. It was an uncomfortable subject. There was little evidence of support or information for parents about these changes.

One mother of a young lady of 17 told us:

“I feel like saying ‘Why don’t you acknowledge that parents are the experts and listen to us? You only know what is in a book and my daughter is not a book and is an individual and we know her better than you do. Don’t make assumptions’.”

The staff in acute hospital trusts told us that basic training in the Mental Capacity Act was included in training on safeguarding. But it was clear that there were gaps in their knowledge. This created a lack of confidence on a practical level in decision-making and best interest processes as the young people moved into adulthood. However, although patchy, where we did see recording of consent between ages 14 and 18, this was generally undertaken by adult health professionals rather than other professionals.

“I have been very involved, however my rights as a mum at this point are not clear as the MCA [Mental Capacity Act] assessment is still underway, so [he] is seen as having capacity; [he does] but not in all areas. Someone met him for an hour to assess capacity; they don’t see what he is like – challenging behaviour, sense of danger – I don’t think the assessment will be accurate. We are in a legal black hole until MCA is finalised.

I feel as though I will be backed into saying I can’t look after him with health care. Waiting for the assessment outcome... We have had no respite since he turned 18 and it has had an impact.

I want some more time; his little brother needs his mum as well.”



5 CARERS

Key findings

- There was limited assessment of the needs of carers or any understanding of what is important to them during this specific time.
- Services often rely too much on parents and families. Parents told us they felt “abandoned” by health and social care services at this most difficult time.

The impact on parents and families who care for young people with complex health needs can be immense. During the transition phase to adult services this can be intensified because of many factors. These include the changes that all young people go through, such as the desire to establish their own identity, and sometimes a period of challenge over health or therapy regimes.

It can also be accompanied by deteriorating health due to physical changes. Added to this is the anxiety and confusion around changes to funding, and changing who provides services, equipment and supplies.

We found there were often no clear processes to record the assessment of the suitability of family members as carers for young people with complex needs. 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. A number of parents told us they felt “abandoned” by health and social care services at this most difficult time. Others talked about the vast number of appointments and meetings that were involved during and after transition.

In some areas, health professionals in acute hospitals and the children’s community nursing service provided training for parents and other relatives. This was to enable them to carry out quite complex health procedures in preparation for transition to adult services. However, in some cases, this has resulted in an over-reliance on parents as carers of young adults. We saw little contingency planning for emergencies or taking into account the appropriateness of young adults receiving personal care from their family.

We did see some cases where support for families was caring and effective. We saw that a single parent had been well-supported to develop confidence in caring for his son's significant needs. In another case, a single parent raised concerns with the children's team about her ability to continue to hold down her job and use her annual leave to care for her child. Additional support was provided as a result.

Even where carers were assessed, the impact of caring on family members does not seem to be sufficiently understood by health professionals. And it is not adequately monitored. One parent told us, "It feels like just a tick box exercise." When we asked another parent what would make the most difference to them in their role as a carer, they answered, "Just someone to pick up the phone and call me once a month, as I am often too tired or exhausted to ring them, and when I do, they are not there." Parents said they received significantly less emotional and practical support from health professionals once the young person they were caring for 'crossed the line' to adult services.

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.

A mum said that, as parents of a young person with profoundly complex needs, staff in adult health services may ask about the needs of the family unit and sympathise with them. But there is little follow-up supportive action, "unless I literally fall in a heap, my own needs are not supported". She told us that professionals have given her leaflets about adult residential homes. But as a former professional in the area she was familiar with all the locations. She was very distressed to realise they were all nursing homes associated with care of the elderly.

"I have no confidence in how it will all pull together or what it will look like. The mental anxieties of all the uncertainties are enough to crack anybody up."



"To be honest I have to chase people. For example, my son requires some specialist equipment and I have had to go to the occupational therapist. For other medical supplies I get these from the GP or the district nurses. I feel everything is on me to co-ordinate care. In children's services the social worker would visit every few months to see how things were going. Now there is no one there to do this."

6 DIFFERENT HEALTH SETTINGS

“I am 16 – I’d rather be on the children’s ward”

Key findings

- There was generally a lack of coordination across children’s and adult health services with regard to planning for the future. Health professionals in adult services were not routinely involved in planning transition to adult services. They only became involved after age 18.
- Support and care provided by children’s services were either not available from the equivalent adult service or had to be provided by several different specialty teams.
- The places where care was provided and how it was provided were often not appropriate for young people.
- Many parents lack confidence in adult services.
- GPs were often not involved in the care of young people with complex needs as children, but then became key to ensuring the right care is provided when the young person became an adult.

NNPCF outcome measure

Young people transition smoothly into adulthood with no gaps in service provision.

In June 2012, Together for Short Lives and Marie Curie Cancer Care published a report called *Don't let me down: Ensuring a good transition for young people with palliative care needs*.¹⁰

Referring to adult health services, the report acknowledged that:

“While it is never going to be possible for them to match the levels of care and support provided by children’s services, adult agencies need to find new ways of using their limited resources to make transition work better, not least by planning further ahead and working in an integrated way with children’s services from young people’s early teenage years. Once a young person with palliative care needs reaches the age of 14, a wide range of children and adult services should jointly agree a five-year rolling plan which tapers services towards transition.”

The report set out a good practice guide for health professionals on planning for transition.

There was little doubt that the majority of individual professionals that we spoke with who work with children and young people were committed to promoting the best possible outcomes. However, their input is often team-specific, task-orientated and responsive and focused on their own clinical expertise.



“I’m left in a place where I don’t know where to go any more. It makes me feel insecure. The GP doesn’t want to see me – they don’t want to take responsibility and want me to go to A&E. They don’t have the experience and paediatric training.

I was discharged from children’s services at 16, but I’m still not acknowledged by adult services.”

NNPCF measure of experience

A lead health professional clinician is coordinating and integrating all the care and the work of other health professionals across different settings.

It was clear from people we spoke to that there was a need for one lead health professional to coordinate health care and determine appropriate funding.

Many of the staff in the registered home care and residential services that we visited were not aware of an identified lead for health and believed that parents were the main co-ordinators of the health needs of their child.

The mother of a 17-year-old told us that she considers herself to be the main coordinator and planner of future care. This includes identifying appropriate services for her son, "I have found everything and providers myself." She also told us, "Staff are uncertain themselves, so it's no surprise I don't know what's happening."

There was clearly an expectation from commissioning staff that health professionals across health services for both children and adults would work together to promote effective, timely and well managed transition. But we saw little evidence of adult health service professionals being involved in transition planning for young people under the age of 18; and the adult health professionals we spoke to confirmed they were not routinely involved before young people reach 18. One children's community team told us that when they try to engage with adult health teams, they are always told "we are not commissioned to do this". In other cases we heard that adult health teams did not engage with children's teams because they had no knowledge of the young people and had not been appropriately alerted to their existence.

Some paediatric staff were unclear about the scope and range of adult services. Therefore they didn't know who to refer young people to. We heard that some health professionals acknowledged that on occasion paediatricians were reluctant to transfer young people to adult services. They preferred to continue providing care from children's services: "Some consultants like to hang on to their cases, particularly when end of life is a possibility and they feel life is time limited." For some young people this may be entirely appropriate. The care needs of some young people are a result of rare and complex conditions that the adult teams may not have come across or treated before. However, flexibility within the services should assess an individual's needs. We saw little evidence that the children's and adult teams were involved in coordinating this flexible approach.

The staff involved in transition often said that some paediatric services will only provide services to young people up to the age of 16. This highlighted potential

NNPCF measure of experience

We are confident that all adult service professionals understand our young person's needs and will meet them.

gaps in acute health services. Practitioners reported that paediatric staff continued to work with young people up to the age of 19 if the young person was still in full-time education. But it was unclear if the support up to the age of 19 was formalised in contracts and policies. If the young people were not in full-time education, they would have no choice but to go to an adult ward if they needed acute inpatient care. Health practitioners expressed concern around the options available to 16 to 17-year-olds in this respect, which did not reflect individual needs or circumstances.

Many young people receive care from a lot different professionals and specialty teams. There were many instances where young people were moved to different health teams or services at different ages. For example, one young person aged 19 who had Duchenne muscular dystrophy transferred from the children's hospital at 16; from the community children's team at 18; and remains with the children's specialist ventilation service because there is no comparable adult service. One community children's nurse commented about a 14-year-old with complex needs: "I've no idea who I will send this case to; I imagine there will be no adult professional willing to take him on."

Many comments about health services during the transition phase suggested that families "feel let down by health". Families told us about some dedicated professionals who supported them when they accessed children's services, describing them as "exceptional individual people who listen to what we want". However, many people echoed the views of one parent who said they had "no confidence in adult services" as there was a "general lack of oversight and co-ordination". One family told us that once their son had moved to adult health services, they had "no one to fall back on for advice, training and support".



"We worry who will take on cases and what we can do about it. There is no-one to refer on to."

Children's community nurse and paediatrician

The father of a 17 year old told us:

“There appears to be a lack of proactive work by acute sector clinical specialists in planning and ensuring that transition arrangements for young people with complex health needs work smoothly. People in health do their own bits very well but it is not properly joined up around the young person and their family. We would like to have more information and advice about potential future problems so that we can do what we can to reduce risk.”

Community services

We repeatedly found that children’s community nurses have difficulties engaging with the adult services. This is particularly where young people present with complex needs such as tracheostomy/gastrostomy requirements. Professionals working in adult community services were seen at times to be reluctant to accept these complex cases. We saw documentation on several occasions showing that district nursing services were unable to accept young people who were not housebound or who did not meet the continuing care criteria for healthcare. In one example, a young person received only the equipment needed for their care, including suction and tube feeding equipment, but not the support to replace the community children’s nurses. The district nurses didn’t visit the young person in their home or provide any direct personal care. Despite the district nurse making extensive enquiries, nobody could establish who should be responsible for the young person’s care and support as they were not the subject of a continuing care package. It was ‘assumed’ that the GP would be responsible for their general health needs.

“I could cry, even now, at the frustration of it all. No one health department seemed to talk to the other and the same is true today. I have to go to one place for hearing problems, another for sight. It’s all over the place, literally. And 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.”

“It’s like they (health) deliberately try to make it difficult to get anything. I was not told we had any choices in what was going to be given to my daughter. Should we have been?” “There is a complete lack of continuity from health care. Why do I have to fight for anything to get done?”

Mum of a 20-year-old with complex health needs



There were gaps in communication between key professionals. One district nurse lead told us that there is no routine communication between the district nurses and the continuing healthcare team. Another comment made by a number of professionals was that transition of young people with complex health needs happens so infrequently for individual teams that there is no formal system for communicating about transition “It happens so infrequently, I can’t say how it happens.”

We were told time and again by children’s service staff and by families that the adult health teams do not routinely engage with the multi-agency planning processes for transition.

One community nurse told us, when asked if there was a transition pathway, “No, not at all... don’t have clear referral criteria either.” The nurses said “we try to wean them [young people] off us” by promoting self-directed care and minimising the need for them to use adult services. Some community district nurses told us that they are overstretched. They said they do not have the capacity to coordinate the complex needs of the young people on top of their already busy workloads. Some have acknowledged that they don’t have the knowledge to meet the high level and complex needs of some of these young people with continuing healthcare packages.

We found that local services were not working sufficiently well together to provide a seamless transition into adult services. This was particularly in relation to respite services. For one young person, the only suitable respite service was to receive overnight care from a nursing home. But the nursing home would not engage with community health services before he turned 18 to prepare a transfer plan.

Specialist services

There were consistently good reports about the transition arrangements for some specialist services, for example, teams specialising in cystic fibrosis, epilepsy, and cardiac services. In one area we saw that there were formal transition guidelines for children and young people who have diabetes. These were developed in April 2013. The guidelines highlight the importance of adopting a flexible approach



“Everything is really fragmented – we go in and do a task and then come out. We don’t have time to communicate and liaise with people – everyone needs to be working together. We need clarity of each other’s roles and accountabilities. Others do not understand our role or how we could play a stronger part in the whole transition process.” **Specialist community nurse**

Example of good practice



At Great Ormond Street Hospital, there is a young people's council. The council recently agreed on the top five issues it would like the trust to address. The top priority was transition and this has now been developed into a project to identify the improvements that are needed.

to transition and supporting the young people to take responsibility for their diabetes and increasing self-advocacy. We saw several examples in these specialist areas where there were clear guidelines and care pathways indicating the processes to be followed and the professionals to be included in the process.

We saw some common characteristics in some of these services:

- The staff were consistent, and knew about the conditions and the young person's history.
- They provided adolescent clinics (adolescence is defined as ages 10 to 19).
- There was good communication with young people, their parents and each other.
- They provided good information about what to expect.

We saw an example of good joint and coordinated working with a young person just after transition, when they were leaving hospital. Although there was no clear, written transition plan, there was evidence of very positive joint working, person-centred planning and good outcomes for them and their family. This was in part down to the effort from the specialist service to engage the adult multi-disciplinary teams and arrange meetings, handovers and training before the young person was discharged to the community.

Example of good practice



We heard from one young woman who receives care from a specialist hospital. There was good involvement and liaison, with both her and her mother regarding her ongoing care and making decisions about options. The young woman is using a patient-controlled medical records system. She communicates with her specialist care team electronically using email and text messages in a secure environment. She told us that this works well and that her nurse always gets back to her quickly.

A consultant neurologist showed us a report that highlighted concerns that adult clinics are only able to provide relatively short appointments. These are not what young people and their families need in paediatric care.

Many health professionals agreed that transition clinics were beneficial, but commented, “they can be a challenge, trying to fit them in with all parties... and there can be issues with the practicalities of trying to match up consultant input to do combined clinics”. In addition, professionals acknowledged that transition clinics still depend on having appropriate, equivalent adult services to discharge young people to.



Example of good practice

Report extract

“Recent action taken by the South Devon Healthcare NHS Foundation Trust (acute hospital trust) in response to a Commissioning for Quality and Innovation (CQUIN) scheme had strengthened these informal arrangements. Joint paediatric and adult clinics had been established in CF [cystic fibrosis], epilepsy, neurology and postural services and these effectively supported information sharing and joint planning. Positively, it also allowed young people to meet professionals in the adult team and prepare for transition and this was valued by young people that we spoke to.”

Hospices

In our programme, we found that children’s hospices were generally highly regarded by young people and their families for their palliative care, support, and respite services. We visited a hospice that provided care for children and adults up to the age of 30. It was able to support young people moving from children’s services to adult services. It made decisions about transition on an individual basis, taking age and development into consideration and liaising with family and other professionals.

Another children’s hospice had not been moving children on to adult services. One of the reasons for this was the lack of suitable hospice arrangements for young adults. This service believed there was a lack of services to meet

“I attended workshops that were organised for parents of children in transition age at a hospice in Oxford. It was the best workshop I have ever attended with a doctor, social worker, supporters from different organisations, and an experienced parent who was in transition. They told us about every aspect of transition to adult services. They told us about difficulties that we could face as the parents and they gave us very good advice [about] what we can do about it. What is more, we have been equipped with the very practical guide for parents in transition. I think it is the best idea ever to help parents and their children and from my point of view every school should organise this kind of workshop.”



Response on web form

the needs of young adults with life-limiting conditions to ensure their needs continued to be met. Families were happy with the service and were anxious about their children moving into adult services. Staff told us that adult hospices generally catered for people in the end stages of their illness and often focused on older patients.

Some children’s hospices provide services for children only, some have young adult units, and some are combined children’s and adults hospices. Often, adult hospices don’t offer the short break services that the children’s hospices offer. There are huge demands on their resources from the growing elderly population. A working paper by Help the Hospices Commission was published in October 2013, *The role of hospices in supporting young people in transition from children to adult services* looks at different approaches such as providing day care for young adults.¹¹

General hospitals

We heard a number of concerns about the changes to care provided in hospital during transition. Families said that admissions to hospital during the transition period can be “a fraught process”. They told us that, as children, they could be admitted directly to a familiar paediatric ward, bypassing accident and emergency (A&E) units. Admission through A&E often causes problems for young people and families. Their treatment can be delayed, as staff are unfamiliar with some of the complex needs and rare conditions as well as the guidelines to treat them.

Some parents told us about poor experiences in A&E with long waiting times because teams were trying to decide where to treat young adults with complex

needs. Sometimes parents witnessed disagreements in A&E between adult and children's wards, and even with intensive care units, about the best place for care to be provided.

Many children's units have facilities to enable parents to stay with their children to best support their needs. But this was not the case once they were admitted to adult wards, where there were no facilities for parents to stay with them. In some cases, this happened when they were admitted at age 16 or 17.

Many parents say that even when they can't stay with their child they want to remain with them on the ward as much as possible. They felt the ward staff lacked the resources or skills, and didn't have sufficient understanding of their child's complex needs to provide appropriate care or to administer medication. We were told that the wards were sometimes poorly equipped to manage some of the complex mobility needs for their children. We heard of concerns about discharge from hospital without appropriate support, equipment and prescriptions. Different hospitals set different age ranges to treat young people in children's services. This resulted in confusion and lack of consistency.

A mother told us that her daughter used to have direct access to the children's ward if needed. She voiced her concerns about admission to the adult ward, so the hospital arranged a meeting for them both to meet the adult team. The mother and daughter met the matron and provided copies of all relevant information and their wishes, which were to be kept on the ward in case she was admitted. This ward keeps files on people who use the service frequently. The young woman had been admitted to the adult ward shortly before we spoke with her and, although she and her mother acknowledged that it wasn't the same as the children's ward, they felt glad they had had the pre-meeting.

General practitioners (GPs)

The role of the GP in the care of young people with complex health needs has been the subject of much comment during this programme. Many parents of young people who were still receiving care from children's services told us that they did not need, or wish to visit their GP. They felt that visits to the surgery were difficult because of access, the environment, waiting times and stress. They felt that as the GP didn't know their young person, it was quicker or easier to go straight to A&E. Here, they could often be admitted directly to the paediatric service that knew and understood their needs. Only five of the young people and parents we spoke to that had yet to transition said their GP was involved in their move to adult services. Twenty-nine said they were not.

However, after transition to adult services, this number increased significantly. Eighteen young people or their parents told us the GP was involved in planning and coordinating their care and 16 said they were not. Following transition, GPs were suddenly the first port of call and expected to manage highly complex and unusual health needs with little or no previous knowledge of the young person or family.

“Only once in 14 years have I known a GP participate in transition planning. Some practices know the young person well and some do not so the level of support and active co-ordination by GP varies hugely.” **Community team member**



Several GPs told us that they would have liked to have been involved in the transition meetings so that they could better understand the young person’s health requirements. However, they either weren’t invited or were unable to attend as meetings were during surgery hours. The children’s healthcare teams that we spoke to often commented that there are difficulties “getting GPs to engage” as they are not always comfortable or confident with supporting young people with specialist needs. One family told us:

“We’ve not had a good experience with the GP service. They keep changing, which is not good when you have a child with complex healthcare needs.”

Other families and GPs valued a good long-term relationship with their GP. This was where the GP was very familiar with the needs of both the family and young person, and was able to support them when needed.



“Everything is such a struggle. For us in transition the worst experience was at Christmas last year when our daughter ended up on the adult ICU but they did not want her because in their eyes she wasn’t an adult, paediatric services would not take her because she was over age 16. They were arguing about who would take her for two weeks while we were in the situation of having a young child who was seriously ill. It was just dreadful”. “It was the worst experience of our lives. Doctors were saying they did not know how to deal with her so they were more interested in getting her over to the children’s hospital and they didn’t want her. No one would take responsibility.”



7 TRAINING FOR PROFESSIONALS

Key findings

- Adult and children's healthcare professionals felt competent to meet the specific clinical needs that they are trained for, and young people and parents agreed.
- But professionals did not feel equipped to manage the transition process as they lacked knowledge about age-specific needs in relation to their complex needs.

NNPCF outcome measure

All relevant professionals are trained to support our young person.

Most professionals in children's and adult services told us they feel competent and equipped to meet the clinical needs of young people based on their professional area or responsibility. This was confirmed by 72% of young people and their parents, who agreed that the professionals have the right knowledge and skills to care for them.

However, when it comes to transition, many professionals told us that they didn't feel equipped to manage the process. This was because although there were written policies, they felt there was no practical guidance or training. There was confusion between the process of transition, which should commence at 14 years or younger, and the transfer or handover of care to adult services, which is the last stage of the transition process. This lack of understanding of the process of transition by healthcare professionals goes some way to explaining the lack of preparation that families reported.

One consultant in adult health services told us that, although he felt confident in dealing with the medical needs of a young adult, he did not feel equipped to deal with the emotional needs of a young person transitioning into his service.

Health professionals acknowledged gaps in their knowledge, understanding and skills in the management of transition to adult health services. We spoke with district nurses and other care staff who had only come across one young person who was transitioning to them for adult services. They said it would have been nice to be involved earlier and have a joint meeting to be introduced.

We were repeatedly told about concerns relating to increasing demand and lack of capacity within the health teams to meet the rising need. Another common concern was the lack of expert knowledge in specific conditions. Many of the children and young people included in this programme have highly complex needs. They are fully dependent on others for all day-to-day activities, requiring one or two people to support them day and night. We heard of difficulties in securing teams of staff with the appropriate level of skills, particularly at night. One parent told us that, following transition to adult services, “we seem to have lost the specialist knowledge”. The mother of a 19-year-old told us the adult community nurses were not trained to meet her son’s complex needs. As a result, she had used the direct payments to train a team of carers.

Areas of good practice



1. Extract from inspection report:

“The new adult advanced practitioner post in the home ventilation team provides a positive and flexible response in enabling continuity of support to young people post transition.”

2. Some areas were providing training in continuing healthcare, which included transition processes. As a result, some children’s community nurses have started to work on joint clinics and handover arrangements for young people with endocrinology, oncology and rheumatology needs.

NNPCF outcome measure

Our young person has appropriate access to advocacy if needed.

One group of district nurses told us, “We are missing a transitional pathway and training around it.” One said, “If we had something to follow, even online training and a pathway, then we could follow it.” District nurses also told us of their concerns around the competency of agencies employed through personal budgets to provide care for those with the most complex of health needs. “People are employing agencies, but we don’t know how good they are.”

One parent told us how they had sourced a family advocate to be involved in the transition planning, as the whole process was not explained to them. They told us, “The information isn’t given to you, you find out about it as you go along.”

8 TRANSFER TO ADULT SERVICES

Key findings

- Most people we spoke to after transfer to adult services told us they had a negative experience of the transition phase.
- There was a shortage of appropriate short break facilities for young people after transition.
- There was no evaluation or quality checking of the outcome of the transition planning for individual young people and their parents.

NNPCF measure of experience

We are confident about the future for ourselves and our young person.

We talked to 83 young people and their parents or carers who had already transitioned to adult services. Although most were happy with services they received once they had transferred, most had negative experiences of the transition phase. Many felt they were “left to get on with it”. One parent told us that now they had transitioned to adult healthcare services, there was a noticeable difference. Most people told us that there was no one person that co-ordinated everything and they did not feel that there was enough preparation for the transition.



Case study: Serena

Serena is 17 and has a degenerative condition. She is cared for at home mainly by her father, who has to lift and carry Serena up and down stairs and in and out of the bathroom.

Although home adaptations have been agreed, they have yet to be carried out. Dad is desperate to get some sort of stair lift installed to help. But they have been waiting for nine months and nothing has happened yet. Serena has to wait downstairs until dad comes home late at night before she can go to bed. She has a power wheelchair, but she can't use this at home because of steps. So it is kept at school. This means that Serena only gets to go out of the house to go to school. Dad told us that the council has refused a request to fund adaptations to bathroom. He had to take out a loan to pay for it himself.

Serena is able to give consent and make decisions, but her views are not recorded in her records. Serena's dad told us that somebody visits them at home regularly, more often when Serena is unwell. If they see anything wrong, they ring the paediatrician and check.

The members of the health and care team that we spoke to told us that Serena's case is "in limbo re transition". They acknowledged that there is currently no clear plan. Dad told us he has been to the Citizens Advice Bureau to find out about equipment for moving and handling. He said that there is now an occupational therapist involved and "she has been helpful". He said, "We haven't been given any information about choices. We have to fight."

Parents often told us that they had had to “fight” to get the same care from adult services as they did from the children’s teams. For example, in many cases that we looked at, there were significant shortfalls in the availability of appropriate local short break services. There are few options for young people with long-term conditions who had used children’s hospices for short break services. There is often no equivalent service when they become young adults.

We visited several services that provide care for young adults with complex physical health needs and saw some examples of very good care. Some young people and families were very happy with the services from adult community teams, residential homes or specialist health teams. However, in most cases there were no arrangements to assess how the transition arrangements had worked or any evidence of working with others on delivering a transition plan before starting services. In one care home that provides 20 places for younger adults with a physical disability, there were no clear processes in place for working with services in advance as part of the transition arrangements. There was no evidence available of strategic planning between children’s and adult services.

Parents found the adult services less responsive to changing needs and said there were fewer opportunities for respite services to give parents and young people a break.

The father of a young woman with significant complex needs told us, “It was so good from children’s, now we have no one.” He told us that since transition his daughter “has lost all of her therapies that she used to really benefit from and we have seen deterioration from this. Her health has deteriorated and it should be so simple. We think our GP should be coordinating her care now but we never see him.” We spoke with a member of the team responsible for providing her care. They were aware that the family “wanted specific therapy provisions to continue, but they haven’t, that’s the way it is”. They told us:

“We function on a ‘here and now’ approach, with the expectation that young people will remain stable and require continually the same level of support.”



“It’s very overwhelming, I thought things would be more flexible, but as he’s got older it’s got harder, I feel like I am more tied, and that’s frightening especially as since they have turned 18, we have not had respite. This has impacted on the whole family.”



“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.”

As well as parents and young people feeling emotional tension caused by the transition processes, the same feelings were described by several of the multi-disciplinary teams that we spoke to. At a meeting with one group of staff they described transition planning for young people with complex needs as “one of the most stressful things to deal with”.

Some commissioners are concerned that the new Children and Families Act 2014 (which will introduce a new Birth-to-25 Education, Health and Care Plan),¹² will mean that difficulties faced at 18 will now move to 25, so will not improve the situation. However, while some feel there is a risk that the ‘transition’ issues are just being delayed to age 25, the intention is to have a joined-up plan that goes up to age 25, which will ensure the transfer to adult services is complete.

Equipment

Parents of young people approaching transition were concerned about what would happen to equipment, such as specialist beds and wheelchairs. They had heard stories from other parents about equipment being taken away after transition to adult services.

We heard that after transition, families became frustrated by the lack of coordination, information and support to access equipment and supplies. We heard many concerns about establishing funding for specialist equipment. In some cases this is not clarified as part of the transition process. This results in delays getting equipment which young people were previously getting as a matter of routine. For example, one young person tried to get a new stock of essential medical supplies. He was told that these were no longer available from his current service because he had been discharged. His mum then had to ring round to find out where the new supplies would come from. In another case, a family had been waiting four months for funding for protective sides for their daughter’s bed.

A community paediatrician told us:

“Children can often outgrow their old wheelchair before they get a new one. The process is so long-winded even physiotherapists carry spanners and screwdrivers to make their own repairs out in the field”.

We asked young people and parents who had transitioned in the last 18 months whether they had been provided with all the equipment they needed following transition. Thirty-five per cent said they had not received all the equipment they required once they had moved to adult services.

9 INTEGRATED / HOLISTIC CARE

“School sent my Health Plan to college so they knew how to support me”

Key findings

- The provision of healthcare and services to meet other needs, including social care, life skills, and educational needs, were often not well coordinated and relied on the parents and carers of young people to take the lead.
- We found little evidence of services being developed with young people and families.
- For young people who weren't in special schools, or who had ongoing health needs below the continuing care package criteria, transition planning was often poor and families told us they felt abandoned.

NNPCF outcome measure

Plans are in place for education, independent living and leisure, including for modifications if needed.

In many instances, both families and health and care teams told us that the processes for working together were fragmented. One team told us, “We all do our own little bit.” We often heard that individual professionals worked hard to provide good care and a seamless transition but the overall services lacked an overarching plan for the move. There was no coordination of transition and no recording of plans contributing to the move to adult services.

Residential colleges provided support for students going through the transition from children’s to adult services, in health, social care and education.

We spoke with two people in a college who were in the process of transferring to adult services. They said, “The college has supported us all the way”. Both students told us they had a learning mentor at the college who was helping them to plan for their future. We spoke with two personalised learning mentors who supported students through the transition period. They explained that by the time the student was ready to leave the college, they would have made decisions about their future and have drawn up a plan. The learning mentors coordinated the transition plan and identified the support each student would need and what services would be involved to meet their adult needs. These services included education and housing, social care, financial support and arrangements, equipment and technology and health requirements. The learning mentors told us they worked very closely with all the various external agencies.

However, outside the educational environment, families feel abandoned. Some of the professionals involved in young people’s care did acknowledge that the provision of healthcare and other needs, including social care, life skills, and educational needs were often not well coordinated and relied on the parents and carers of young people to take the lead. One continuing care worker told us that the integrated needs of one young person just after transition was well coordinated, “but this is because mother is proactive in coordinating professionals and will actively seek help if needed”.

A few cases demonstrated positive risk-taking with young people, to enable them to participate fully in the life of their home and community. A parent told us, “It is great to see how he has moved on from simple activities in the home to enjoying a range of activities in the community.” However, for other young people the focus of planning was heavily weighted toward meeting their medical needs. There was not enough exploration of what the young person might want or need.

Among the group of young people who helped us with this report, the differences and diversity of needs and abilities was immense. Not all of these young people will be able to attend mainstream education or start looking for work. However, as well as providing for healthcare needs, good transition planning involves considering realistic opportunities and providing support where it is needed around further education, housing, future employment opportunities, transport, and a social life.

“It feels that young people are just a list of labels. He is our SWAN – syndrome without a name. Because he doesn’t have a diagnosis, we don’t know what his problems are. I feel like when I go to hospital and explain what is happening, they look at me as if I am over exaggerating, I have to prove it each time and we end up videoing it and have to show it to them before I am believed.

The funding allows 17 days a year respite and sometimes his respite is cancelled because of pressure on beds. At the day centre, it is just a change of scenery without any activities or stimulation and I often find him asleep. He has never been to the baths along with other people in the day centre, even though he used to go at school and he also goes swimming when he has his respite. I don’t know why they won’t take him. He can’t access the sensory room either because his chair is too wide. His list of daily activities is a nonsense.

On a recent admission to intensive care, the doctors kept telling us how much different things cost and asked us if we wanted him resuscitating; we were shocked.”





Case study: Good practice

One young person requiring constant care from two carers transitioned successfully to adult services. Their family stated that there has been no reduction in the level of care and support provided to the young person since transition. The young person lives with friends who they have known from a very young age in supported living accommodation.

The health and care teams that we spoke with also felt that the transition process had been very good. One member of the team told us “Everything that should be in place is in place.” All those professionals at the

meeting felt the provision of services was well coordinated, current health needs are regularly assessed and reviewed and these assessments form part of a continuing care plan. The young person is part of a joint funded, continuing care package and is currently supported to attend college. Their care plans include assessments of associated risks with support plans in place to manage those risks. Their wishes, abilities, likes and dislikes are recorded and form the basis of the support package in place to meet their needs.

Quality assurance and evaluation of transition

Clinical commissioning groups are still relatively new organisations. Systems to measure or evaluate the impact and outcomes of transition arrangements are not yet embedded. Only one of the CCG areas asked said that they had a process to check the effectiveness of transition plans following transition. Commissioners know that they need to obtain feedback about transition. In some areas, families use annual satisfaction surveys to provide feedback and share their experiences of their journey and outcomes following transition. But we have seen little evidence of services developing and setting specifications as a direct result of consulting with young people and families.

CCGs did use a variety of systems to monitor the quality and performance of the services they commission through service level agreements (SLAs) and contracts. There have been some developments in areas such as Commissioning for Quality and Innovation (CQUIN) and quality assurance of the performance of continuing



“What would have made things work much better? To have a ‘magic’ person who knew [my son] well and had a good understanding of children’s health & social care and adult health & social care in order for one person to co-ordinate everything and everybody.”

care packages. Where we did see some activity to capture feedback from young people about the transition process, this was most often in the specialist services such as those for cystic fibrosis, diabetes and cardiac services.

It is difficult for CCGs to monitor the effectiveness of transition work where the young person transfers to adult services that it does not commission. Commissioners need to work in partnership to ensure that there is effective governance and a responsive system to continually evaluate and improve services.

In terms of more general quality monitoring, more needs to be done to ensure that CCGs are aware of all the young people who will need continuing health services from childhood to adulthood. We found a variety of methods to gather information about young people who met the criteria for these inspections. Some commissioning teams held databases of young people receiving the levels of care that we specified. Others had to ask the care providers to provide the lists of young people. It was easier to obtain details of young people who were receiving continuing care packages than those who fell just below the eligibility criteria.

Even so, in some cases, even for those receiving a care package, there was sometimes nothing more than a manual list maintained by the children's community nursing team (CCN). These lists highlighted young people who would need to transition to adult services. We were assured that there were processes to ensure that this list included young people receiving children's continuing health care funding or those who had complex needs but who were not receiving a service from the CCN. This might be, for example, because they were in residential school under the care of the school nurse. However, on one occasion our inspectors identified young people that were not on the list. And there was some anecdotal evidence from professionals to indicate that the list may not be fully comprehensive.

There were often no systems to check the quality of the lists of young people who needed transition planning. This difficulty in obtaining information does bring into question the reliability of the overall numbers of young people who require care.

NNPCF outcome measure

Young people will lead fully fulfilled lives.



Case study: Good practice

One young woman told us that transition was explained to her really well and she knew what was happening and what she needed to do. She didn't want to go to a residential college and

said "All of the agencies worked together to support me in my transition to a local college". Although her first year at college went well, she struggled in the second year:

"Most of the exams I took were typed and due to my physical disabilities I needed extra time to complete them. All through school I was allowed extra time to complete exams, but the college did not seem to understand this and could not allow me to have concessions for this."

To sum up her experience, this young person told us:

"On the whole I have been really happy with all the support I have received from all the agencies working together to support me. Staying in my local area has been a positive experience in regards to my social and life experiences and I am glad that I have had the opportunity to learn alongside able bodied people. However, the support around exams in the local college was not able to accommodate my needs in the same way that a specialist college could have done.

I am enjoying life, my direct payments are in place and I am enjoying my social experiences that I am able to achieve with this support. I am at the stage, now that my college experience has come to an end, that I would like the opportunity to do a voluntary work placement. Due to my needs I would need special accommodation around my toileting needs and disability access. I would also need support with transport.

I have made some initial enquiries about volunteering at the hospital and am waiting to hear back from them. I think it would be helpful to have some supported work placements for people with disabilities. I do not mind if this is paid or unpaid work. I would like to be useful and have something to do in the day, even if only for a couple of days a week."

CONCLUSIONS AND RECOMMENDATIONS

Adolescence and the move to becoming a young adult is increasingly being recognised as a distinct developmental phase, much as children under five or older people are well-established with care needs adapted appropriately. Yet young people do not have the same recognition of any specific requirements when it comes to the provision of healthcare. Perhaps because many young people move through this phase with little need for healthcare facilities they are the 'forgotten' stage in healthcare. There is a general lack of provision for, and knowledge of, the specific needs of the young adulthood developmental phase. This is worse for young people with complex health needs and for the staff who look after them as they transfer to adult services. Staff in these services may only rarely, or never encounter young people with these health issues.

These specific needs may therefore be managed very differently by adult health providers. Many staff we spoke to were aware of the need for developmentally appropriate adult care, but lacked the resources and trained staff capable of caring for the young adult with multiple complex health requirements, both in the community and in hospital. The report Making a difference for young adult patients produced by the charity Together for Short Lives⁸ looked at the experiences of young adults in clinics and in general adult wards, and highlights the importance of developmentally appropriate care.

There is even a lack of consistency about when 'childhood' ends. Some services stop at 16, others at 18; some specialist paediatric services see young people for longer. It is completely unacceptable for parents and young people to become caught up in arguments between health professionals, as to the most appropriate service to provide care during the transition phase. Or to find that a care service just stops when the children's service ends but before the adult service commences.

Children with complex needs are funded in a variety of ways through health and social care. The social care element of their package is provided by the local authority by providing services to children under the Children Act 1989. Some have care packages funded by health services through children's NHS continuing healthcare and for some, care packages are jointly provided by health and children's social care. The eligibility criteria for children's continuing healthcare are different to those for adult continuing healthcare. There are differences in the funding arrangements and the eligibility criteria for adult social care and children's social care. The change in these arrangements can be a difficult process for families to negotiate. As a result, services are sometimes withdrawn while funding responsibilities are established.

Following the final evaluation report of the personal health budget pilot programme November 2012, the Government announced that those already receiving NHS continuing healthcare at home will have the right to ask for a personal health budget from April 2014. However, some young people and their families lack the understanding and support in managing these.

The structure and commissioning arrangements of adult services do not consistently include preparation and planning for managing young adults who require a range of health services throughout their lives. Most of these young people will have been identified at a young age as requiring high levels of healthcare into adulthood. Yet in some areas it proved difficult to identify the actual numbers of young people with complex health needs who were likely to require an on-going healthcare package into adulthood.

Local Health and Wellbeing Boards* are responsible for producing Joint Strategic Needs Assessments (JSNAs) to understand the needs of their local community, agree priorities and encourage organisations involved in health and care to work in a more joined up way. JSNAs look at the current and future health and care needs of local populations to inform and guide the planning and commissioning (buying) of health, wellbeing and social care services within a local authority area. The JSNA informs local Joint Health and Wellbeing Strategies (JHWS)

it is important for the JHWS to analyse and prioritise the health needs of children and describe success.

The Department of Health's policy on improving quality of life for people with long term conditions, together with the proposed changes in the GP contracts, includes extra services to be commissioned from GP practices that will cover:

- a. improving care management for frail older people and other high risk patients at risk of unplanned hospital admissions, and
- b. using technology to help monitor the health of people with long term conditions and improving online access to services.

It is unlikely that a single GP will have more than one or two young people with complex physical health needs in their patient group. Community paediatricians should involve the GPs more throughout childhood to ensure that the GP is prepared and fully able to support the young person and their family as they prepare to transfer to adult services.

We found that there is a failure to prepare, support, inform and educate young people, their families and carers about the changes that will occur as part of adolescence. This includes capacity and consent issues, advocacy and adult service configuration. We also found a lack of support and recognition for carers, many of whom continue to care for a young adult without the familiar long-term relationships they had with school and children's services.

* Statutory members of the HWB include a representative from local Healthwatch, the CCG, the director of children's services, director of adult services, director of public health, and an elected member.

Recommendations

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.

- Local authorities and CCGs, when planning for the new legislation relevant to the transition arrangements for young people from children's health services, must check the implementation of existing best practice guidance and be clear about the responsibilities in each area.
- Local authorities and CCGs must ensure that they agree a clear process to ensure that decisions taken about funding and funding responsibility are taken in a timely and coordinated manner.
- Commissioners and local authorities should ensure that they have accurate and up-to-date local data to ensure that the complex health needs of these young people are known and well planned for.
- Joint Strategic Needs Assessment should specifically include the needs of this group of young people to ensure that there is complete and accurate local data regarding those who will require input from multiple health services throughout their life.

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.
- Children's services provided until adult services take over.
- An effectively completed assessment of their carers' needs
- Adequate access to independent advocates for young people.

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 their inspection and ratings of general practice.

All information about the health care of a child or young person should be shared with their GP to enable them to promptly and best respond to complex and ever-evolving health needs as the young person reaches and moves to adult services.

4. Adolescence/young adulthood should be recognised as an important developmental phase across the health service – 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 the resulting need. What matters most is that 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.

Next steps

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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NHS Barnsley CCG

NHS Bath and North East Somerset CCG

NHS Cambridgeshire and Peterborough CCG

NHS Coastal West Sussex CCG

NHS Harrogate and Rural District CCG

NHS Hounslow CCG

NHS Isle of Wight CCG

NHS Knowsley CCG

NHS Medway CCG

NHS Merton CCG

NHS Newcastle North and East CCG

NHS North Derbyshire CCG

NHS Oldham CCG

NHS Somerset CCG

NHS South Devon and Torbay CCG

NHS Southampton CCG

NHS Stockport CCG

NHS Wolverhampton CCG

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