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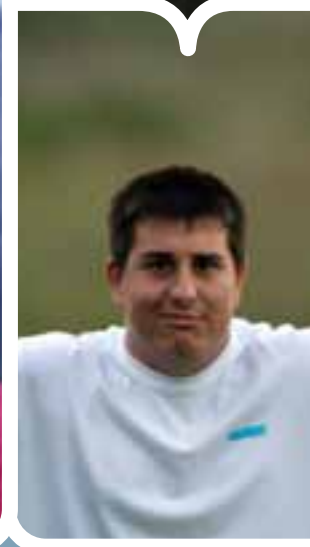

Growing Up Matters

Better transition planning for young people with complex needs

January 2007

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The Commission for Social Care Inspection (CSCI) was set up in April 2004. Its main purpose is to provide a clear, independent assessment of the state of social care services in England. CSCI combines inspection, review, performance and regulatory functions across the range of social care services in the public and independent sectors.

Our Vision and Values

The Commission for Social Care Inspection aims to:

- put the people who use social care first;
- improve services and stamp out bad practice;
- be an expert voice on social care; and
- practise what we preach in our own organisation.

Reader Information

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Contents

Key messages

1. Young people with complex needs (which include combinations of acute and chronic medical conditions, multiple and profound impairments, behaviour problems and learning disabilities) and their families are experiencing considerable difficulties when the young person reaches adulthood and moves from children's services to adult services. Whilst some people have good experiences, there is clearly a problem for many young people and their families. Some say it can be a 'nightmare'.

2. This is an important issue. Young people are losing out on their independence and opportunities to meet their aspirations where adult services have not developed at the same pace as children's services and do not offer the same level of support. From the perspective of resources, it is wasteful if steps taken to support a child to be independent are not carried through into adult life and people end up in expensive and unsatisfactory residential establishments rather than living independently.

3. Services across the country are not comprehensively meeting national standards for transition planning as laid out in Standard 8 of the National Service Framework for Children, Young People and Maternity Services:

   "Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality and family-centred services which are based on assessed needs, which promote social inclusion, and, where possible, which enable them and their families to live ordinary lives."

4. There is now the opportunity to review progress with the separation of adult social care services and children's services and the moves to more coherence between primary care trusts (PCT) and council boundaries. Whilst there are new challenges with different organisational arrangements, it is timely to take stock, to ensure effective services are in place and to improve outcomes for young people with complex needs moving to adulthood.

5. There has been progress in some areas to:

   - Ensure planning with young people focuses on their aspirations and ambitions.
   - Improve co-ordination between social care, education, health, housing and other services so that the move from children's services to adult services is well co-ordinated and timely.

- Plan ahead and commission the range and diversity of services needed for young people with complex needs.

6. Examples of initiatives that have supported good practice include:

   - Transition personal advisers based in learning disability teams who 'broker' care for young people across health, housing, employment and leisure services.
   - Initiatives developed in partnership with families, council, PCT and local universities to bring young people back to their communities from out-of-area placements and to receive personalised one-to-one support.
   - Information technology systems to track the numbers of people receiving a service before transition, their current services and any reasons for changes.
   - Transition planning panels to capture data about young people and monitor quality of transition plans.
   - Proactive planning with housing partners to ensure supported accommodation is available.

7. However, this good practice is not happening everywhere. Inadequate commissioning, poor co-ordination of services and a failure properly to plan with young people and their families are resulting in anxiety, delays, multiple assessments and confusion.

8. Agencies have responsibilities for children and young people at different ages which leads to, and compounds, co-ordination problems.

Taking action

9. Urgent action is needed to ensure young people with complex needs have every opportunity to lead as independent a life as possible and not to be disadvantaged in any way as they move from children's to adult services. This requires action at both national and local levels; action on policy and resource issues at a national level and action on commissioning, organisational arrangements and practice at a local level by councils, NHS, education, housing and other organisations.

Action at a local level

10. Councils and PCTs need to demonstrate a clear commitment to children and young people with complex needs, with evidence of action they have taken. This includes fully involving them in deciding their own care as well as in the planning and development of services locally.

Tackling resource issues

11. As a priority, councils need to work with PCTs and to collaborate with other councils to develop and commission a range of services that can offer choice and independence to people with complex needs from childhood to adulthood.

12. This involves long-term financial planning and steps to maximise and draw in resources from different funding streams. It also includes tackling different eligibility criteria and different levels of funding available for adult and children's services. At least half of the councils in our study reported that the level of young people's services changed at transition and that young people could not maintain activities provided before transition.

Establishing clear ways of working together locally

13. As a prerequisite to good transition planning, the senior local political and managerial leadership in councils and partner agencies need to give a clear commitment. One sign of this leadership would be establishing clear multi-agency protocols and processes together with the pooling of resources and joint development of services between councils and their partner agencies.

Person-centred planning and direct payments

14. The focus must be on supporting independence and providing normal life opportunities. Direct payments offer an important means for achieving these outcomes.

15. Young people should be able to transfer their direct payments from children's to adult services. This not only ensures continuity of support and services but also provides an important incentive for developing more appropriate local services.

16. Directors of adult social services in partnership with directors of children's social services should undertake joint appraisals of local arrangements, commissioning strategies and the outcomes for young disabled people and their families, to assess their progress in successful transition planning. This includes ensuring staff have the necessary time to work with young people, and their parents, to plan services and changes in their lives.

17. Lead members and overview and scrutiny committees should address this issue as a priority.

18. All this can be done now and without reference to central government. However, further improvements would be possible if there was action from central government. However skilled, commissioners from councils and PCTs are facing considerable pressures and problems relating to:

- NHS continuing care criteria which are not yet consistent across children's and adult services.
- The loss of funding for Supporting People.
- The lack of further education and training opportunities for young adults who are severely disabled.

19. Government needs to co-ordinate the priorities of its departments and ensure policies support joint work.

20. But strategic plans, transition panels and partnerships are not enough. Councils and their partners must know what happens to young people with complex needs in their communities, making sure they are genuinely leading the lives they choose. There is an urgent need to improve now the experience of these young people and their families, as they move from children's to adult care services, whatever level of funding is available and whatever processes are in place.

21. How councils support young people with disabilities into adulthood will be a focus of the Commission's action to assess the performance of councils in carrying out their proper statutory responsibilities for this group of people. The Commission will continue to report on progress on this issue.

1

Introduction

1.1 Background

Transition in this study is defined as a process that occurs when children move to adulthood, involving physical and psychological developments coupled with changes to roles and relationships with family and friends, care staff and the wider community. Transition of care services takes place at different ages depending on the service, usually 16 for health services, 18 for social care services and up to 19 for moves from school to college-based education.

Growing up is a time of change and new experience. Transition to adulthood brings particular challenges for young people with complex needs[1] and their families, in part caused by the move from children's services to adult services. Uncertainties about future arrangements can be unsettling and a cause of anxiety for families who told us:

If I don't know where I am going by next year I am going to be very worried."

Young person

"We are just shattering his world."

Parent

"It's like coming to the end of a motorway."

Parent

This special study examines transition for these young people. In particular it looks at the experiences of those young people who have been supported in out-of-area residential placements, and the experiences of their families. The

1 Complex care needs include acute and chronic medical conditions, multiple and profound impairments, behaviour problems and learning difficulties. Two or more of these characteristics were used to define the focus for the study.

numbers of these young people are relatively small. There are approximately 13,300 children with disabilities in long-term residential care.[2]

Young people with complex needs:

- are often placed long distances away from their families and communities which can make transition planning especially difficult; and
- usually require lifelong care which needs to be carefully planned for.

This generates additional complexity for those young people and their families and carers and for the organisation of services. These issues have been examined many times before, especially for young people with disabilities.[3, 4, 5, 6, 7, 8]

Our study shows that things have not improved enough and that there are still organisational and systemic problems in many areas which makes the experience very difficult for too many young people. It also highlights that for those young people with the most complex needs, and who live away from home, transition does not receive the strategic and operational attention from councils it should do.

1.2 Context

It is even more critical that young people with complex needs are properly supported through their move into adult life given the radical changes taking place in councils and health services.

Every child matters[9] and the subsequent Children Act,[10] creating the integration of children's social care with education, offers a real opportunity to improve the ways services for children are commissioned and provided, and to improve outcomes for children and young people. This approach is endorsed by both

2 *Disabled children in residential placements*. (2005). Available: www.everychildmatters.gov.uk

3 Abbott, D., Morris, J. and Ward, L. (2001). *The best place to be? Policy, practice and the experiences of residential school placements for disabled children*. York: Joseph Rowntree Foundation.

4 Dyson, A., Meagher, N. and Robson, E. (2002). Where have they gone? Issues in transition and progression for special school leavers. *Journal of Research in Special Educational Needs*, 2(2).

5 Fletcher-Campbell, F. and Pather, S. (2003). *Outcomes and destinations of pupils on return from out-of-authority special schools*. Slough: National Foundation for Educational Research.

6 *Disabled children in residential placements*. (2003). Available: www.everychildmatters.gov.uk

7 *Disabled children in residential placements*. (2005). Available: www.everychildmatters.gov.uk

8 McGill, P., Tennyson, A. and Cooper, V. (2006). Parents whose children with learning disabilities and challenging behaviour attend 52-week residential schools: perceptions of services received and expectations of the future. *British Journal of Social Work*, 36(4).

9 *Every child matters*. (Cm 5860, 2003). London: Stationery Office.

10 *Children Act 2004*. (c.31). London: Stationery Office.

Youth matters;[11] and by the National Service Framework (NSF) for Children, Young People and Maternity Services.

But this also presents a challenge to social services, health and other agencies. Adult social care services are now separately managed and governed by a complex policy agenda which is still developing. *Independence, well-being and choice*[12] and *Our health, our care, our say*[13] have begun to address outcomes for adults but in a context of significant organisational change and financial constraint. The adult agenda still has not developed the coherent integrated approach that is beginning to be established for children's services.

This separation creates a new set of boundaries to be overcome as well as organisational and cultural differences between services. Since transition was not well managed when children's and adult social care was part of one department, the new organisational frameworks could create even more barriers for young people and their families by reinforcing the differences between services to those under or over age thresholds.

We know that good commissioning is critical to providing good services. Councils need to build a picture of the services that people need over the course of their whole lives, and to be able to commission those services so that they can be delivered seamlessly to individuals. To get that picture, councils need to ensure that they work together internally regardless of legislative or organisational boundaries. We need to ensure that organisational change does not create silo commissioning practices.

1.3 This special study

This study examines in detail the experiences of young people aged 14-19 and their families of transition into adult life. It also examines the perspective of those who provide and organise care and considers the impact of current organisational and policy changes.

It is based on qualitative interviews with:

- young people, their parents and their families in 22 case studies;
- 179 senior managers in children's and adult social services and their partners in education and health – spanning 52 councils in England; and
- 47 care professionals and managers across 20 residential schools.

11 *Youth matters*. (Cm 6629, 2005). London: Stationery Office.

12 *Independence, well-being and choice. Our Vision for the Future of Social Care for Adults in England*. (Cm 6499, 2005). London: Stationery Office.

13 *Our health, our care, our say. A New Direction for Community Services.* (Cm 6737, 2006). London: Stationery Office.

Case studies

We undertook a series of 22 case studies to understand the circumstances in which young people are placed in residential care, how transition planning is managed and the factors that enable young people with complex needs to be less reliant on residential placements. These case studies focused on young people in residential placements, their families or guardians and named social workers in councils. They also included a review of transition plans. In addition, we gathered the views and experiences of young people being cared for in non-residential care, including those in receipt of bespoke community initiatives and those turned down for residential placements.

Some illustrative 'pen portraits'

Jane

Jane is 18 and has profound and multiple learning disabilities. She has lived in residential schools since she was five years old. The school is nearly 200 miles away from her home town. She is regularly admitted to hospital and her mother explains how "she is under lots of hospitals, five in fact, and there have been disputes between PCTs over who is funding her care as her school is on the border of two PCTs". It is unclear where Jane will live when she leaves the residential school.

Kulwant

Kulwant is 14 years old and has cerebal palsy, severe learning disabilities and epilepsy. He requires 24-hour care. Kulwant lives at home three days a week and spends four nights at a residential school. The family moved house to be nearer to Kulwant. In the longer term, the plan is for Kulwant to move into a six-bedded bungalow associated with the residential school to provide "a home for life".

Jason

Jason is 19 years old and has severe learning disabilities, challenging behaviour, severe epilepsy and limited vision. He requires constant one-to-one supervision. He attended a local special needs school until he was 12 years old and now lives in a residential school in a neighbouring county to his family home. The council's decision for Jason's next placement is being reviewed after his mother felt "it was essentially an old people's home and did not meet Jason's needs". Following an assessment that confirmed the situation, the council is reviewing Jason's care.

The study also reviewed transition protocols; information provided to young people and their families on transition; joint assessment documents; placement criteria; and commissioning strategies:

- Chapter 2 covers the legislative background to transition planning, identifies current expectations and guidance for councils.
- Chapter 3 looks at the reality of transition planning from the perspective of young people, and their families, residential school staff and frontline social workers.
- Chapter 4 examines what happens to young people once they have moved on to using adult services and the impact on their lives.
- Chapter 5 examines the effectiveness of the strategic approaches to transition planning and of the structures, systems and operational management of transition by councils and their partners.
- Chapter 6 draws together the conclusions of the study focusing attention on improvements national and local policy makers, managers and practitioners in children's and adult services need to address.

2

The background to transition planning

2.1 The national context

The statutory requirement to plan properly for transition is contained in legislation and statutory guidance.

The Disabled Person's Act 1986 requires local education authorities (now children's services departments) to seek information from social services as to whether a young person with a statement of special educational needs is disabled and so might need services from the council when they leave school.

Under the Children Act 1989 and the NHS and Community Care Act 1990 social services are expected to arrange multi-disciplinary assessments and establish plans which may include further education for children in need including those with significant special needs. Social services should also ensure that a social worker attends the Year 9 (13/14 years) annual review meeting and contributes to the formation of the transition plan.

These requirements remain in force despite successive legislation which affects the way in which disabled children are supported. The policy context has however changed radically in the last 20 years.

In 2001 the *special educational needs code of practice*[14] was published to support the special educational needs provisions of the Special Educational Needs and Disability Act 2001[15]. This includes specific requirements relating to transition planning.

In 1986 the process was seen as primarily an education responsibility and few social services departments were engaged in developing an effective system. The majority of children and young people with a statement of special educational needs had limited social services involvement in their lives. This has developed over time and whilst the legislation has not changed significantly (although it has been extended), the context has.

14 Department for Education and Skills (2001). *Special educational needs code of practice.* London: Department for Education and Skills.

15 *Special Educational Needs and Disability Act 2001*. (c.10). London: Stationery Office.

The most recent statutory requirements and policies that affect transition are found in:

- *Valuing people*;[16]
- *Every child matters*[17] and subsequent Children Act;[18]
- the *National Service Framework (NSF) for children, young people and maternity services 2004* – Standard 8 focuses on children with disabilities and complex needs;[19]
- *Improving the life chances of disabled people*;[20] and
- *Transition: young adults with complex needs*.[21]

There is considerable information available about transition and its importance, with a large volume of general guidance available from statutory sectors and good practice guidelines from other sectors. This includes new guidance as part of the *Every child matters* programme on transition for young people with long-term conditions moving from children's to adult health services.[22] This guidance was published during the fieldwork for this study and has direct relevance for practice with children with complex needs and long-term conditions. Much of the content reflects the issues we identified in this study.

2.2 What should happen

Transition planning for young people with complex needs requires a co-ordinated multi-agency approach which extends far more widely than the school and family. It also needs to link to the various systems in place for all young people, and it needs to consider the way services change to support and empower the young person's move from childhood dependence to adult independence.

16 *Valuing people. A new strategy for learning disability for the 21st century*. (Cm 5086, 2001). London: Stationery Office.

17 *Every child matters*. (Cm 5860, 2003). London: Stationery Office.

18 *Children Act 2004* (c.31). London: Stationery Office.

19 Department of Health (2004). N*ational service framework for children, young people and maternity services. Disabled children and young people and those with complex needs*. London: Department of Health.

20 Prime Minister's Strategy Unit (2005). *Improving the life chances of disabled people. Final report. A joint report with department for work and pensions, Department of Health, Department for Education and Skills, and office of the Deputy Prime Minister*. London: Prime Minister's Strategy Unit.

21 Office of the Deputy Prime Minister. (2005). *Transition: young Adults with complex needs. A social exclusion unit final report*. London: Office of the Deputy Prime Minister.

22 Department of Health (2006). *Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services*. London: Department of Health.

The council's children's services department has overall responsibility for transition with adult services working closely alongside. Councils are required to assess the young person's likely future needs and establish a transition plan. Connexions, PCTs and other partners, including person-centred planning co-ordinators, housing and parent partnership workers attend transition meetings. Head teachers are responsible for convening transition meetings annually.

The NSF for Children, Young People and Maternity Services Standard 4 sets out the standard that should be being applied to transition into adult life:

"All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood."

Standard 8, the standard governing services for disabled children and young people states that:

"Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality and family-centred services which are based on assessed needs, which promote social inclusion, and, where possible, which enable them and their families to live ordinary lives."

A core requirement for governing the process of transition for young people with complex needs is attached to each of the standards.

Standard 4:

- Services support young people to achieve their full potential by providing targeted support through co-ordinated working, through for example Connexions and youth services. This includes addressing their social and emotional needs as well as assisting their educational and career development.
- There is improved access to services and advice for young people – in particular addressing the needs of young people with disabilities.
- Transition to adult services for young people is planned and co-ordinated around the needs of each young person to maximise health outcomes, their life chances and their ability to live independently – this is particularly important for disabled young people or those with long-term or complex conditions.

Standard 8:

- Multi-agency transition planning takes place to improve support for disabled young people entering adulthood, which focuses on meeting the hopes, aspirations and potential of disabled young people, including maximising inclusive provision, education, training and employment opportunities.
- A multi-agency transition group is in place to oversee a multi-agency transition strategy.

- Transition plans take a person-centred planning approach and are consistent with the Special Educational Needs (SEN) Code of Practice.
- Young disabled people aged 16 and above are supported to use direct payments.
- Specific arrangements are made for managing the transition of those with high levels of need, those in residential schools, living away from home, looked after young people leaving care and those with rare conditions.

Our findings are analysed against these key NSF standards and the various components that support them.

3

The reality of growing up: the experience of transition for 14-19 year olds and their families

3.1 The experience for young people and their families

Transition for young people with complex needs continues to be a major hurdle. When those young people are living away from home with a foster family or in a residential service it is even more difficult.

Staff and care residential school staff told us that there is a significant gap for many young people between what should happen and what actually does happen.

We asked young people, their parents or primary carers, social workers and care staff a range of questions about their views and experiences of transition. We found that there were a number of themes emerging from the analysis of the interviews, including:

- the need for greater involvement of young people and their families;
- timeliness;
- person-centred planning for transition;
- dislocated processes, poor planning and multiple assessments;
- co-ordination and responsibility;
- funding; and
- equity.

Whilst we found examples of good practice we also found that there was a serious lack of effective planning for many young people.

3.2 The need for greater involvement of young people and their families

None of the young people we consulted in our case studies was clear about what was going to happen in the future. Most said they felt they had been consulted about their transition plan but did not know what it meant. One young person felt he had not been consulted at all.

Whilst young people were involved in some reviews, they did not feel meetings were clearly centred on their needs and wishes.

> *"I remember there were a lot of people at a meeting but I can't remember what they talked about."*
>
> **Young person**

All the parents consulted found transition planning a very difficult and challenging process and parents commented about the uncertainty they felt. They told us that whilst they were involved and attended annual review meetings, overall the process was often unsatisfactory.

> *"The different service providers appear to be reluctant to work collaboratively."*
>
> **Parent**
>
> *"I knew the school was involved but I don't know who was in charge."*
>
> **Parent**

Parents emphasised the need for better support and recognition of the difficulties they faced in the transition process. They called for:

- help and advice with finance and housing and meeting visiting costs; and
- support for caring during school holidays – parents often struggled to keep their children fully occupied.

No parents reported receiving a carers' assessment.

The national policy agenda expects young people and their families to be effectively involved. Only 14 of the parents in our 22 case studies felt listened to and consulted. In three of these 14 case studies, person-centred planning had resulted in bespoke adult care for the young people involved. One of these parents described how establishing the care package "had been a partnership" where everyone had an opportunity to contribute their views.

We found negative experiences in the remaining case studies where people's views were not fully taken into account when devising the care package. This included the need to consult with a Member of Parliament and solicitor to seek redress.

"It is a terrible thing to feel they won't take on board our views."

Parent

"The transition process is a nightmare and we have our own advocate now as we fear what will happen to our son. It is so frustrating that they will not consult with parents. We are the only constant in his life."

Parent

In contrast, written protocols and commissioning documents recognised the problems parents face during transition, the importance of considering the needs of parents separately from children and acknowledging the changing aspirations of young people and their parents.

There were some good examples of helping young people and their families through the process by holding face-to-face meetings and transition events, as well as providing transition packs that had been developed with young people and their families.

Positive practice

In **Bristol** consultation with young people and their parents led to Transition Information Project (TIPS). TIPS is a signposting service which provides a drop in service, a SEN Transition Planning Pack, and a DVD "Making Plans" – made by young people.

Barnsley has produced a comprehensive multi-agency Transition Good Practice Guide. The guide states that young people and their parents have a central role in planning and what they can expect each agency to do and when. For parents it gives details of organisations that will give them independent support, including the Parent Partnership Organisation. It indicates the importance of young people and their families being:

- aware of all the options available, including opportunities under development;
- asked who they would like to invite to the transition plan meetings; and
- active partners throughout transition planning.

3.3 Timeliness

Parents told us that transition plans were established too late with no clear arrangements between services. Parents were also concerned about the problems of late placement decisions, should initial placement decisions not be suitable and they need to reorganise care.

> *"They should start the plans a bit sooner as a year is a short time for someone with problems to adapt."*
>
> **Parent**
>
> *"You can't say that a placement is going to finish on Friday, and on Saturday this new one is going to open and is going to be all-singing all-dancing."*
>
> **Parent**

Social workers emphasised difficulties of finding suitable placements at the right time. They highlighted their own lack of time to plan appropriately, the challenges raised when adult social care colleagues became involved at too late a stage and the overall lack of resources.

> *"I am chasing my tail, and would be further on and have done a better job if I had more time. There is not enough time to look at places, and parents often have to do this. There needs to be recognition of time pressures on social workers."*
>
> **Social worker: children's services**
>
> *"The challenges are knowing your way around the system, and finding a suitable place with a vacancy, and having enough time to prepare the young person for the change. Transition should not be last minute, which it can be."*
>
> **Social worker: adult social care**

3.4 Person-centred planning for transition

Person-centred planning involves young people, their families and a range of professionals in care assessments. Potentially, it has an important role in transition.

However, case studies revealed a mixed picture of person-centred planning approaches.

"Person-centred planning means young people and their families are involved anyway. This helps drive the service agenda. We have seven young people going through transition and in the past they would have gone to day care, but now none of them are saying this as they have a better understanding of what is available."

Senior manager: learning disabilities services

Half of the 47 professionals and managers of residential placements said that person-centred approaches were well used at transition.

"He is like a five-month-old, the social worker is going to try and get his views – we won't be there. It makes them less credible when they do stupid things."

Parent

"Our advocate reminded the transition worker about doing a person-centred plan."

Parent

Social workers felt assessments were based on the principles of person-centred planning. However, they felt they lacked training in the approach, had limited funds to commission independent organisations to undertake person-centred planning, and social service departments were "old fashioned and not pushing it".

"I have tried to use it [person-centred planning] as much as possible. Personally, this is what I want to focus on. The council still uses an old-style format."

Care manager: adult social care

3.5 Dislocated processes, poor planning and multiple assessments

In the 22 case studies only nine plans were firmly established, and of these six had been finalised once the young person was over 17 years old.

> *"This is one of the biggest problems we have. Young people get lost in the system. We have done our best to make the adult service take them on."*
>
> **Residential school staff**
>
> *"There was no need for us to be involved as he was not going on to education or employment."*
>
> **Adviser: Connexions**
>
> *"It could be that for children who are not likely to return to their parents at 18 that even with a very active and caring social worker their transition plans are very uncertain"*
>
> **Teacher**

Social workers referred to the problems in co-ordinating all the different services and professionals.

> *"The care in the community team may not get very involved as it will be up to the adult learning disabilities team. The children with disabilities team cannot fund the foster carer after the young person is 18 so the learning disability team will have to find the money, but she may not fit the fair access to care criteria and goodness knows what else could happen. Adult respite services have been cut and the carer will need respite."*
>
> **Social worker**

Parents were concerned about the quality and co-ordination of assessments, and sometimes multiple assessments by different services. These could include, for example, eligibility assessments for adult social care and mental health services, a continuing care health assessment, an assessment for a Learning and Skills Council funded college, and a housing needs assessment. In some cases these were self-assessments for parents to complete.

In two case studies young people had been turned down for their next placement very close to the transition deadline causing considerable upset for the families concerned.

"The LSC [Learning and Skills Council] college placement was suddenly felt to be unsuitable in the term before [daughter] was due to leave residential school. The council then wanted me to consider a placement that was essentially an old people's home."

Parent

"The process is inappropriate – it needs to be an interdisciplinary and integrated service with someone co-ordinating all this on his [son] behalf. Someone with authority over the rest."

Parent

However, there were examples of creative thinking and ways to overcome the complex multiple assessment issue.

Positive practice

The **East of England SEN Eastern Regional Partnership** has devised a protocol, 'Supporting transition for young people placed at out of county/borough residential schools and colleges' to help tackle the problem of assessments for residential colleges being turned down late. The protocol is designed to improve clarity in the arrangements for councils and Connexions partnerships to move smoothly across services. See: www.easttogether.org.uk

Poor recording compounded the difficulties of multiple assessments. Given parents' and residential school staff's reports of social workers being replaced frequently, good record keeping is essential.

"There are few resources and the team relies primarily on self-assessments completed by parents."

Manager: adult social care

"It's very difficult dealing with so many different forms. Each local authority has its own set of procedures. We have students from all over the country."

Residential school staff

Again there were examples of positive practice, including establishing joint assessments, but these examples were the exception rather than the rule.

Positive practice

Essex is launching a unified person centred transition plan, 'Looking to the Future', which has been agreed for use across the local council, health services, Connexions and schools. The single plan includes progress records.

3.6 Co-ordination and responsibility

Our case studies revealed a confused picture about which services were leading on transition and the roles of the professionals involved. Parents wanted experienced professionals 'in charge' but rarely did parents know who the professional was, or should be.

"Parents need workers who know what they are doing."

Parent

"The transition process can be quite confusing for parents and young people as a number of new professionals get involved. I have to explain the different workers' roles."

Social worker: children's services

Parents were also concerned that their contribution was not recognised properly although in the end they often ended up taking a major role in co-ordinating a plan.

"I am his care manager, no one else has all his information in one place. We are learning on the job how to sort the madness out."

Parent

"Finding, and getting funding for, the right placement places a huge responsibility on parents."

Advocate

Residential school staff called for improved local council involvement and consistent staff involvement throughout the transition process. Social workers

claimed there were not enough staff nor time for them to undertake the transition work.

> *"Transition- that function is performed by an individual tacked on to their parent teams. There needs to be a dedicated person to lead changes – a transition champion – together with a person-centred planning co-ordinator."*
>
> **Manager: adult social care**

> *"There is a need to improve the planning of services and resources with adult services, and to increase the resources available for transition. For example, to employ another transition worker, so that there is earlier involvement of these workers in developing care plans. It would then be possible to avoid alternatives to building expectations that residential placements will continue, when adult services have different criteria, and will not fund them. The present arrangements lead to discontinuities in the transition plans."*
>
> **Manager: adult learning disabilities services**

Children's social workers saw their role as carrying out needs assessment, monitoring placements and holiday services, and referring to adult services. In one case study the children's social care service had ended contact before handing over to adult services.

Residential school staff reported difficulties in getting social workers and other professionals to attend transition reviews largely due to the long distances of travel involved. Social workers reported attending all, or almost all, of the reviews in contrast with the views of residential school staff.

Thirteen of the 19 social workers we spoke with reported regular visiting – from once a month to every six months. However, these visits were mostly undertaken at the later stages of the transition period.

"It feels like the head teacher is in charge but not a lot has happened as I was told to expect."

Parent

"All professionals are invited to the review and kept informed of any decision. Due to the high level of needs, many professionals are involved, but this is in theory. In practice it doesn't matter how hard we try, their involvement doesn't go beyond a report. There are financial issues. A local authority would not be able to send several professionals to attend the meeting."

Staff: residential school

"Professionals are invited, but there is no guarantee they will come. They all turn up when there is a big question mark around the future of the young person. Sometimes they don't even send reports."

Staff: residential school

Residential school staff valued working in partnership with councils but felt councils did not always understand their perspective.

Despite all the challenges social workers were generally positive about the care ultimately arranged.

"We would like the local authority to understand the nature of our provision, and work harder with us. They don't always understand our dynamics, the way we operate, our ethos. It would make life easier if they understood."

Staff: residential school

"The health service did not engage in the process and securing their engagement was difficult."

Social worker: children's services

"In the end we usually get there, as people respond as time runs out."

Social worker

"Sometimes transition is not a big issue. Go to college, have direct payments. I think it has worked pretty smoothly in the past, if they have a regular package. Then the last year before transition goes smoothly."

Social worker

There were also some examples of good practice and solutions to the co-ordination problems.

Positive practice

In **Somerset** between 30 and 40 young people make the transition to adult services each year. Previous attempts to improve transition planning had been recognised to founder, due to poor inter-agency communication and a lack of systems to help identify future needs. Somerset wanted to provide better information to young people and their families about the process and agree an inter-agency plan before transition.

The adult learning disability service and Connexions invested in Transition Personal Advisors. These advisors are based in learning disability teams and 'broker' post-transition care across health, housing, employment and leisure services.

The Connexions assessment and the community care assessment have been combined based on the person-centred approach. Advisors convene inter-agency meetings with social care, education and health colleagues to agrees how mental health, adult primary care or learning disability services will each play a part in the care management and funding of the young people. Transition Personal Advisors check to see services are put in place as planned. Reflecting on the programme a council representative told us:

"There have been difficulties such as getting the right people to attend at the right time but this is improving as participants get to know one another. The Transition Personal Advisors have found that transition planning for complex cases takes up a great deal of time and they need a very wide range of skills and expertise. Also they concentrate on people living with families and inappropriately placed. A lot of work is being done with housing to get a three-to-five lead in to making more supported accommodation available. They have also had to overcome differences in working practices. The partnership was evaluated in 2004 and the picture was described as very positive."

Residential school staff told us that social workers changed frequently. Parents discussed the difficulties they faced in these situations.

"I am fed up. I invest time getting them up to speed and they are gone. It is not worth it if they leave."

Foster parent

"Social workers change so often."

Parent

In one unusual case a children's social worker had been involved for over ten years. The young person, parents and residential school and all reported excellent communication. The social worker had sensitively led them through the transition process.

3.7 Funding

Funding pressures in adult social care and other services were cited by residential school staff and social workers as inhibiting transition arrangements.

"Sources [of funding] that are available during the children's stage are no longer there when they become adults. This is the biggest source of anxiety for families. They [social care] are so concerned about resources that planning and thinking about transition goes out of the window."

Staff: residential school

"The funding issue is a bit of a lottery. Last year we had two students who did not know until one week before they moved where they were going to."

Staff: residential school

"Realistically we cannot send an education officer to every review because of limited staff and funding."

Manager: education services

3.8 Equity

Residential school staff were concerned that parents from black and minority ethnic communities were overlooked and that one of the biggest challenges for these parents was obtaining a placement in the first place.

"It's a rare thing to have such students [from diverse communities]. It's strange because parents from minority groups do ring up. We give them information so that they can challenge their... [children's service department]. We can't do the fighting for them."

Staff: residential school

Only 42% of the senior managers in children's services and education were able to provide details of young people's ethnicity in out of area placements.

The needs of young people and their families from ethnic communities were less well addressed in protocols, commissioning documents and during the interviews. Councils covering diverse populations told us that their "practice was ingrained" in meeting the needs of all communities and their workforce reflected the different local communities. Overall, however, there was little evidence that councils had given diversity issues sufficient attention.

Positive practice

Hammersmith and Fulham's adult learning disability social care service established an advocacy worker post to work with diverse communities and to pay special attention to supporting carers.

Key points

- Young people and their families should receive information about the full range of choices available, including opportunities to return to their own community. Transition information should be in formats accessible to young people with complex needs and accessible also to diverse communities.
- Services for young people are not engaged at the right time – in part this can be attributed to the different ages each service becomes responsible for young people (see definition at the start of the Introduction).
- To overcome these problems it is essential to establish systems to ensure young people are identified and key professionals allocated to leading transition at Year 9. These systems need to be co-ordinated and properly led by experienced individuals. The roles of key professionals and services in the process need to be better communicated.
- Funding barriers need to be resolved through improved co-ordination and forward planning. Resources should be pooled and services developed jointly between social care and its partners.
- More attention should be given to the needs of parents. Special attention should be paid to parents from diverse communities.
- All services have a duty to ensure young people have continuity of support, even when individual professionals change.
- Person-centred planning approaches should be used, and in particular: 1) with transition plans drawn up with adult services from Year 9 onwards; 2) to co-ordinate assessments and thereby focus holistically on young people; and 3) to ensure timely decisions are agreed to avoid eleventh-hour changes to plans at the transition deadline.

4

Young people's experiences from 19 years onwards

4.1 Changing needs

To understand the effectiveness of transition planning we looked at the choices offered to young people of services providing support and leisure and work opportunities as well as direct payments. We also looked at the challenges facing councils in commissioning and funding services for young people with complex needs.

4.2 Choice at transition

Young people and their families are not being informed about their choices and opportunities in adulthood. Two parents, for example, were worried they would have to give up work.

4.3 Outcomes in adult services

Although the case studies revealed some positive practice and some excellent outcomes for young people with complex needs, the study found that overall councils were not meeting the relevant NSF standards.

Councils reported that most young people with complex needs lived with their parents after transition. Thirty-five per cent of councils however told us that when young people had been in residential schools or foster care they tended to receive out of area residential placements or supported accommodation after their 19th birthday.

Residential school staff told us that the worst outcomes were when young people were forced to return home because alternative arrangements had not been put in place.

Councils told us that there were few young people with complex needs who could benefit from direct payments. However, there were notable exceptions. For example, one council reported 40% of young people with complex needs in their year 2000 transition cohort have direct payments. This may reflect organisational and cultural views of, and attitudes to, the scheme. This raises important questions about how well councils promote the use of such payments.

Half of the councils we spoke with told us young people's care changes at, or after, transition and this represented a significant reduction in services rather than an increase in what was being provided.

Senior managers emphasised the differences in the cost, quantity, availability and flexibility of services for adults compared with children's services.

> *"Children certainly notice the difference [in provision] when they transfer to adult services."*
>
> **Senior manager: adult social care**

Inconsistent use of continuing health care criteria is also causing difficulties and inequities.

> *"We need clarification nationally of the continuing care criteria because current inconsistencies are confusing parents and creating inequalities. A uniform application of the criteria is needed."*
>
> **Commissioner: joint health and adult social care**
>
> *"The health care continuing eligibility criteria lack clarity, making it hard to judge whether challenging behaviour, for example, may be taken into account."*
>
> **Manager: joint transition team**

Two young people in the case studies had very good individualised packages of care once they used adult services. Their parents told us how these services were able to deliver a more meaningful life for their children taking account of friendships, leisure activities and being near their families.

> *"It would reflect what I wanted for my other children, which was that they could still maintain family contact, have a bit of independence and further education."*
>
> **Parent**

Case study

One family worked with the local council, the PCT and their local university to enable one young man to come back from an out-of-area placement and receive one to one support in a specially adapted home. The model was expanded to include others, aged between 16 and 25 years, in similar situations. Support focuses on consolidating and enhancing young people's skills and allows for development at an appropriate pace. The family feels the model could be replicated elsewhere.

Case study

The young person has their own accommodation with carers funded by a direct payment – all services are managed by an independent broker. The young person attends college and participates in a wide range of leisure activities.

The social workers involved in these two case studies felt the packages "work really well". In contrast social workers in the remaining case studies reported having difficulties in finding and arranging suitable services and support for young people 'post transition'.

> *"Suppliers come and go and even when a placement is suitable they may not have a vacancy when needed. In turn this leads to the use of less suitable interim placements."*
>
> **Social worker**

Residential school staff felt the choices offered to young people with complex needs were limited – mainly because of the difficulties of meeting needs and obtaining what can add up to large amounts of funding.

Councils reported that they were taking steps to commission local post-transition services to avoid further out-of-area placements.

"We agree with the white paper that it should not be just about what services are there for people to fit into. Now it will be about how to get the outcomes for the young person. Eighteen months ago people just slotted in."

Senior manager: adult social care

"We have ten approved preferred providers for adult learning disabled. We have given them a pen picture of the 37 young people in 2007 and they are being asked to provide for them. The preferred options are supported living in the community. This could be back with their families with support. Not residential care if we can help it. We want to stop putting young people in out-of-city placements because home or school cannot cope. We are using vocational facilities outside the city and we want to emulate this in the city and get them into jobs."

Senior manager: adult social care

"Part of the challenge will be finding sufficient independent living accommodation. The authority made optimum use of its housing grant under Supporting People and social care faces significant pressures in the future. The situation is complicated by increasing rates of diagnosis of people with Asperger's syndrome. There will also be a growth in the number of young people making the transition to adult life with a mixture of learning disabilities and other significant needs."

Senior manager: adult social care

There were some examples of projects designed to increase local choice for young people.

Positive practice

In **Suffolk** with the help of grants from the Learning and Skills Council, transition brokers have been recruited to help young people and transition workers to implement the transition plans. Brokers were established following consultation with young people who asked for 'buddies' to help them through transition.

Some problems with further education provision were also raised.

"There is a lack of education and training post 19. Further education colleges are not providing much for very disabled children – a national problem."

Manager: special educational needs services

Problems within health services were also reported because of eligibility criteria and thresholds.

"Processes are not smooth, because adult criteria are different and between 16 to 18 they can fall through the net in health – it depends on the disability. Paediatric services finish at 16 and epilepsy and asthma are not well looked after by adult care and families complain. There is a low threshold for children's services and we are looking at transition. They are going to have a multi-agency group and will start planning earlier as they start getting lost at 11. We know 14 is getting a bit late."

Manager: PCT

"We would like the health services to be more involved, and parents are concerned that their children do not seem to fit well with adult health services."

Manager: children's services

4.4 Planning ahead

Councils were not planning ahead or monitoring the changing needs as young people with complex needs grow up. Despite the requirement of the Children Act 1989, for councils to establish a register of children with disabilities in the area to aid planning, data systems to identify who will transfer did not exist or were poorly developed.

We asked councils to provide details of the cohorts of young people who had transferred to adult social care services since 2000. Many could only provide incomplete answers, and three told us they did not have the systems in place to answer these questions. We found 15% able to track the most recent cohort through to post-transition care but only one was able to do this over the full five years.

"The number of people undergoing transition can vary significantly and managing the fluctuations is challenging. Only one person made the transition this year but this is unusually low and last year it was 15. Ten will make the transition next year."

Manager: adult social care

"We have discovered comparatively large numbers of young people will be undertaking transition in the next few years. One of the commissioning objectives will be to achieve best value and cost effectiveness within the available funding."

Manager: adult social care

Identifying the numbers and needs of young people with complex needs is crucial to business planning, not least in terms of budget planning and funding decisions. One council manager, for example, told us that 30 people were expected to transfer to adult social care in 2005-06 at a predicted total cost of £1.5 million. However there was a very serious gap between funding received and expenditure required to meet young people's needs.

As well as not knowing exactly who might need a transition plan, who might transfer to adult services and what their needs were likely to be, information sharing within councils and across partner agencies was also patchy. Whilst this will improve as the Integrated Children's System develops within councils, it will not be in place for some time.

"Sometimes we send information to social care but we are not always sure it is received by anyone who can do anything about it."

Manager: education

Despite the very poor current position, councils recognised the importance of early identification through good quality data systems and were taking steps to improve these.

"We hope to have cohorts tracked for four years. We want to know the financial shocks coming. This is embryonic business planning, at least in advance of transition."

Senior manager: adult social care

It is not a complex or difficult technological problem. We identified some positive practice.

Positive practice

Derby City could review numbers of children receiving services both before transition and after, their current service and reason for changes. This was recorded on a standard community care IT system.

In **Barnet** the adult transition group tracks trends post transition using the Connexions database. These trends are analysed to inform planning and to identify unmet needs.

Key points

- Young people with complex needs have limited choices of services and support to enable them to live full and meaningful lives.
- There is some evidence of direct payments being used but this is very limited. Their widespread use with young people with complex needs has yet to be realised.
- Many councils and their partner agencies are not properly organised to support young people as they move from children's to adult services.
- Some councils are beginning to track young people 'post transition' but progress is patchy and the practice is not valued highly by councils.
- Poor data and monitoring can result in young people with complex needs being hidden within the adult care system so their needs are not addressed properly in the long term.

5

The effectiveness of multi-agency working

5.1 Multi-agency arrangements

This chapter examines the organisational arrangements and commissioning strategies needed to ensure a smooth transition into adult services for young people with complex needs. This includes health services as well as local councils.

5.2 Effective transition

Half of the councils involved in our study and their partners in health and education reported that they had effective transition arrangements. This is in contrast to the experiences of those directly involved in transition. The remaining councils told us they had problems with their transition planning which are likely to be compounded as changes in adult services begin to take effect.

Whilst the worst performing councils were doing very little, the best had given priority to transition planning and were developing integrated approaches.

> *"Until 2004 it wasn't organised. There was no planning before transition and we would learn about a young person in the term before they were due to leave school."*
>
> **Senior manager: adult social care**

> *"There is a lack of co-ordination and there always seem to be an issue about the transfer of children to adult services."*
>
> **Senior manager: children's services**

5.3 Multi-agency leadership

In many councils multi-agency groups had been established to:

- examine the whole process of transition;
- set out a strategy; and
- oversee the changes.

However, these groups did not have an explicit monitoring or quality assurance function in most instances. Nor were governance arrangements and relationships clear between the multi-agency strategic group and the local strategic partnership, children's trust arrangements and each agency. In some

councils the quality assurance was undertaken by the transition sub-group of the adult learning disability partnership board. In others, the group was based elsewhere in recognition of transition affecting a much wider number of young people. The lack of representation of senior managers with decision-making remits was given as the major cause where groups were not working well.

Positive practice

The **Essex** multi-agency strategic implementation group seeks to:

- provide strategic leadership to ensure that the framework and resources are in place for effective transition;
- link with regional and national strategic forums so transition is informed by, and informs other, strategic agendas;
- develop specific transition partnership agreements;
- receive reports from the transition operational management group;
- consider strategic planning information and take action; and
- link with regional SEN partnership groups and feed into the management teams of the organisations represented.

Managers however stressed that multi-agency groups had to focus on effective working relationships as well as on systems and processes. Some managers in smaller councils felt that working relationships were easier due to closer working proximities.

"Processes are fine but it is about working together constructively. We are constantly trying to improve things."

Senior manager: adult social care

"A lot is down to individual relationships on the ground. They are able to share information and respond quickly to local and national demands. It's about willingness and vision."

Senior manager: PCT

Councils emphasised the importance of working together with health and Connexions but work with housing was less widely reported despite it being an important post-transition service.

This is a failure that can seriously affect the range of opportunities and choices available to young people in transition, and affect their independence

and ability to live ordinary lives. Valuing People programmes in councils also lacked the important strategic information they need for future planning as a consequence.

Several councils had recently recognised the need to make rapid improvements to their transition services and responded by setting up multi-agency groups to review and develop transition services.

5.4 Multi agency transition services

The key to effective transition is active management, co-ordination, support and monitoring. Councils told us how they had set up a range of multi-agency and cross-council structures to improve transition planning, including multi-agency strategic groups, operational groups, transition workers and teams.

Multi-agency operational groups had been established to provide a reporting structure for discussing and monitoring individual cases, including worker allocation. In addition the groups:

- examine proposals for post-transition packages and filter information about unmet need to commissioners; and
- progress individual cases which can help to alleviate problems stemming from delayed transition decisions.

> *"The key will be systematic sharing of data on children and young adults and acting on it."*
>
> **Manager: children's services**

Half of the councils told us that operational groups were working reasonably effectively. Again, the lack of full representation was attributed to groups not working effectively.

Positive practice

In **Suffolk** and **Cambridgeshire** there is a transition planning panel in each area of the county, which captures data about the young people and monitors the quality of transition plans.

Thurrock have piloted a 'wrap-around' transition service accessed by young people aged between 14 and 25. They hold a multi-agency transition planning meeting every six to eight weeks to discuss referrals and review care, and to write a plan for young people to include:

- allocated keyworker,
- core people to attend planning meetings,
- met and unmet needs,
- funding issues,
- options available,
- service provision, and
- timetable.

These meetings are organised by a transition co-ordinator who monitors cases from Year 9 reviews.

This model has good potential to tackle the concerns young people and parents have raised with the transition process, including lead professionals, funding and options appraisal.

Jointly funded senior posts improved multi-agency working.

Positive practice

West Berkshire has senior joint appointments in adult and children's services funded by social care and health. They report this leads to strategic planning "owned in one place" to "improve the children's journey to adulthood" with social care, health and education all noted to be working well.

Unusually in West Berkshire, the chair of the children's out-of-county funding panel is a manager of adult social care which provides an effective model towards improving the consistency of decision-making and implementation of funding criteria. Joint funding of this and other senior posts improves the likelihood of health contributing towards young people's transition.

We were given some examples of where joint protocols had been developed which were improving practice and simplifying the process.

Other examples of good multi-agency working include agreements on common assessment forms and definitions of complex needs (despite no nationally recognised definition) and data collection systems being improved.

5.5 Reorganisation and restructuring

We asked participants about the separation of adult and children's social care services. Overall the separation was viewed more positively than it was negatively. Most recognised that the structures were in their infancy and:

- children and adult departments were not working effectively on transition before separation;
- integration allowed education to be 'brought into the fold' when previously education had been furthest away from social care;
- there would be no change as the services already worked closely together and hoped it would lead to improvement; and
- it was already leading to improvements as they had had to get more organised.

On the other hand, some felt the difficulties would get worse because separation would damage established systems.

> *"Families will see the break anyway. We need to put this right not make it worse."*
>
> **Manager: PCT**
>
> *"Separation of services can lead to greater specialisation, and a lack of understanding and knowledge of other services among workers, and there will be gaps in information for service users."*
>
> **Senior manager: learning disabilities services**

The impact of NHS reforms was seen less positively. The ongoing reorganisation of health care was reported to be disrupting joint working relationships, with resources diverted towards implementing change.

Representatives from health services also identified resource and capacity issues, noting that they have lower numbers of staff, when compared with social care, to manage transition.

> *"If I go, there would be a hiatus and funding would be affected."*
>
> **Senior manager: PCT**

Some councils however saw some advantage in the restructuring of health. For example, one council told us of the considerable problems they faced in engaging 11 PCTs and the advantages the change to three PCTs was likely to bring.

5.6 User involvement in strategic planning: lost opportunities

Overall the involvement of young people and their families in strategic groups and wider consultations on transition is very poor. Few senior managers were involving people at every stage of transition planning. Only 21% of councils told us that user involvement permeated all strategic decisions about transition. However, one council linked a young person's group with the transition team.

> *"There are contracts with the voluntary sector to consult with service users and produce quarterly reports on different subjects. There has not been one on transition arrangements."*
>
> **Senior manager: adult social care**

When asked about user involvement more generally, only 55% of councils had carer representation on strategic groups. Similarly, only 48% had young people representation. Councils that did consult on transition and commissioning services reported benefits.

> *"We consulted with young people and their parents on our commissioning strategy and it really sharpened it up."*
>
> **Senior manager: adult social care**

We asked councils what changes they had made as a result of their consultations. Thirty-six per cent of councils had made changes to:

- strategic documents such as protocols;
- information to young people and their families;
- person-centred planning approaches; and

- access for specific services.

"We held a transition conference for young people and their families involved in transition, which was organised by a voluntary agency. This event was organised to be able to listen to their experiences. There are plans to organise an annual event similar to this each year. The improvement of transition processes was started after the first conference. There are parent representatives on the partnership board and a young person who has been through transition."

Senior manager: adult social care

Positive practice

Sutton is a pathfinder children's trust with a management board in place that includes service users who play an active and significant role. There are voluntary organisations that source representatives from families and work on developing opportunities for children and young people to have their voices heard. There is a transition sub-group overseeing the establishment of a transition unit and the sub-group replicates the composition of the management board.

5.7 Improving continuity

Councils with multi-agency or cross-council teams emphasised starting transition planning early and maintaining contact up to 25 years. This allowed for the:

- development of common transition approaches across the council;
- gap between children and adult services to be bridged; and
- improved collection of data to inform adult services planning.

Seventy per cent of councils had specialist transition workers, or were in the process of appointment. Seventeen per cent of councils were in the process of establishing transition teams.

"We hope to have a transition worker for children with a physical disability, which will help improve data collection."

Manager: children's services

"Despite being in post only a short time, the transition worker has already improved information to parents about adult services but more improvements are needed."

Manager: children's services

Where tensions had existed between different agencies, multi-disciplinary teams were seen as an important means of resolving conflict and creating a single unified and positive approach.

"There has been difficult partnership working with the Learning and Skills Council, and between children's and adult health services. This was the reason for setting up the transition team, which works reasonably effectively. If the main responsibility for transition is with children's services there can be a temptation to adopt a short-term vision – it can be tempting to say 'only another year, we'll fund an expensive placement', rather than holistic long-term consideration."

Senior manager: adult learning disability services

"Because there is a shared purpose and we all have to put money into the new team it is working well. There is no shunting of responsibility. We don't fight. There are health-funding protocols and Connexions have been very good."

Manager: adult social care

Positive practice

Bristol created a multi-agency co-located intake team with responsibility for moving young people into adult services. The team withdraw when services are in place.

Senior managers summarised the benefits of the team as having:

- a single point of contact for families for information and support;
- improved communication and co-ordination between services;
- specialist service with a range of skills and knowledge;
- a seamless transition between children's and adult services;
- more efficient use of staffing resources;
- better signposting to mainstream services;
- reduced waiting lists;
- early planning for each young person; and
- greater flexibility and responsiveness to a young person's needs.

Essex is building virtual multi-agency teams around the young person based in 11 localities. Professional membership will include representatives at manager or senior practitioner level from adult mental health, physical disability and sensory impairment services.

Gateshead established a transition team which aims to support young people, manage the different assessment processes and start person-centred planning at Year 9 review.

Social workers and managers have welcomed the development of transition workers and specialist transition teams.

Positive practice

Worcestershire employs transition workers based in adult learning disability service. Staff meet children in Year 9 just before their 14th birthday to begin transition planning and establish links with schools, Connexions service and families. They monitor progress in developing plans, undertake the community care assessment and flag up young people's needs to inform future planning.

Suffolk employs a specialist health worker on the team who helps to ensure continuity in health care as part of the transition plan.

5.8 Transition protocols

Protocols define formal expectations which are critically important when working in a multi-agency environment. The only protocols currently available nationally are contained in the *Special Educational Needs Code of Practice* and in Supporting People guidance. Twenty one per cent of councils told us they did not have transition protocols, or were unable to supply us with them. Some councils recognised the need to further develop their local protocols.

> *"There is a need for more resources to support transition planning, and the development of protocols and guidance, having improved the processes."*
>
> **Manager: joint transition team**

The protocols seen by this study ranged from 3 to 80 pages and also varied in their content. Most councils had a type of protocol outlining key elements of transition or at least when and how agencies should interact during the pre-transition planning years.

Some protocols also contain eligibility criteria for the various services, guidance on legislation, multi-agency definitions of young people with complex needs, and the age at which adult social care should become involved. However the protocols were weak on quality assurance.

The protocols are usually aimed at a professional audience and would be difficult for parents and young people to access, although one protocol was written from the child's perspective. They vary in approach with some more clearly built around the needs and transition experiences of the young people and their families than others. For example some include the need to give families and young people information about transition.

Positive practice

Barnsley's protocol has been developed with the support of the Yorkshire region partnership and states that the protocol should be "clearly understood by young people and their parents/carers and ensure that adult services participate in the assessment process...". It set out what the agencies should be doing in the context of best practice for young people and their parents/carers. It also deals with quality assurance issues stating how the learning disability partnership board will monitor the transition planning process and "emphasise the participation of carers/parents and pupils in the quality assurance process." There is a comprehensive best practice guide, which young people and their parents/carers can use to assess the quality of their service.

There is a joint planning protocol to guide joint working in **Worcestershire**. The protocol also considers the needs of looked after and fostered children. Worcestershire has been involved in a new process, developed through the SEN regional partnerships, that highlights the support needed during transition from children's to adult services. Worcestershire is now starting to embed the process into its transition practice.

The level of investment in and the ability to implement an effective formal transition structure is contingent on several interrelated factors:

- the numbers of young people with complex needs in out-of-area placements, and in the local community, undergoing transition;
- the financial and staff resources available to invest;
- active management at all levels of the organisations involved; and
- strategic backing of senior political leaders and managers.

"There are now systems in place for transition. However, ensuring these are implemented across a large county is now the challenge, and ensuring the skill levels are available to do this effectively. Lack of resources within adult services is causing difficulties with transition plans. There is a need to continue to develop the capacity of local provision to avoid out-of-area placements. There are existing issues of different eligibility criteria between children and adult services which are likely to get worse, particularly with the budget cuts in adults."

Senior manager: adult social care

"I would like to see mental health transition improved and the mental health and learning disability teams need to find a way of agreeing which of them will lead. Getting people in a room together would help as well. Although I have done a great deal of work on transition procedures and development of protocols, local strategic direction is needed. There needs to be commitment to making transition work operationally and it needs project management. There are two transition workers but each operates differently. There is a debate about whether to have transition workers and whether to have transition teams. I am in favour of children's transition teams if they can fit with the wider strategic direction of departments."

Manager: joint transition team

Key points

- There is evidence that councils are beginning to learn from the experiences of young people and their families who have been through transition but this needs to become standard practice.
- The involvement of young people and their families in strategic planning is poor. Councils need to establish partnerships with young people and their families to inform their future transition strategy.
- Multi-agency strategic groups need to focus on what happens to these young people post-transition. Regular consideration of feedback of the views of those who have been through the process should be used to inform future developments.
- Transition will not improve unless there are multi-agency arrangements in place with senior political and managerial commitment to make them work.
- Managers and frontline staff value specialist transition workers and teams. Individual casework approaches risk overwhelming lone transition workers.
- Some councils quality assure their transition performance but there is much more to be done.
- It is important that the current momentum arising from the *Every child matters* agenda is not lost as the health service undergoes major reconfiguration.

6

Conclusions

Despite the efforts of many committed individuals, transition to adult life is clearly not being managed well for many young people with complex needs who live away from home. Young people with complex needs are not universally offered the same levels of care and social activities in adult services as they were when receiving care and social activities in children's services.

Working with young people and families

- Young people and their families should receive information about the full range of choices available at transition and this information should include the option to return to their own community. Information must also be part of a council's communication strategy, and in formats accessible for people with disabilities.
- Person-centred planning approaches are not widely adopted. They should be used:
  - with transition plans being drawn up and managed in conjunction with workers from adult services from Year 9 onwards;
  - as a means to combine assessments and thereby focus in detail on the needs of young people;
  - to ensure decisions are agreed early enough so as to avoid eleventh-hour changes to plans at the transition deadline; and
  - to further embed the ethos of multi-professional working for young people with complex needs.
- There is limited evidence of direct payments being used. More young people with complex needs in both children's and adult services should have the choice and the support to use direct payments.

Improving organisational processes

- Co-ordinated systems to ensure young people are identified and key professionals allocated to leading transition must be established at Year 9.
- The roles of key professionals and services in the transition process need to be better communicated.

- All services have a duty to ensure young people have continuity of support, even when individual professionals change.
- Some councils are beginning to track young people post-transition but progress is patchy. Young people may be hidden within the adult care system making it very difficult to identify needs, establish workable long-term plans and commission the right services.
- Managers and frontline staff see the use of specialist transition workers and teams as important. Individual casework approaches risk overwhelming lone transition workers. Staff appointed to work with young people and parents should have the time and expertise to ensure plans and the services provided centre on people's individual needs and aspirations.

Strategic commissioning

- Transition planning for young people with complex needs especially those living away from home in out-of-area residential schools, is of varying quality. Given the vulnerability, costs and relatively low numbers of these children transition planning should be given priority.
- Transition will not improve unless there are multi-agency arrangements in place with senior political and managerial commitment to make them work. Multi-agency strategic groups need to focus on what happens to young people with complex needs as they get older. Regular consideration of feedback from those who have been through the process should inform all developments.
- Commissioners should ensure that the needs of young people and their families can be met locally with a range of services to enable meaningful choices to be made.
- It is important that the current momentum arising from the *Every child matters* agenda is not lost as the health service undergoes major reconfiguration.
- Funding issues need to be resolved through better co-ordination and forward planning.
- More attention should be given to the needs of parents, and particularly to parents from black and minority ethnic communities.
- The involvement of young people and their families in strategic planning is poor. Councils need to establish partnerships with young people and their families to inform future transition strategy for young people with complex needs.

6.1 There are six key prerequisites for successful transition

1. There is commitment

- Children and young people with complex needs are given explicit priority by senior managers and council members. This means priority for casework (with appropriate time allocated), for service development and for resources to ensure services are provided in time.
- PCTs, housing, education and other services prioritise their involvement in transition planning.

2. Young people and families are fully involved in the process

- Councils involve young people and their families fully in transition planning.
- Young people and their families are also involved in strategic planning for transition.

3. There is effective strategic planning and commissioning

- The planning and commissioning of adult social care services (and associated further education, employment, health and housing services) are informed by an analysis of transition needs of the cohort of young people from 14 onwards receiving support from children's services and who will be requiring services from adult health and social care within five years.
- Strategies are underpinned by good financial planning.
- The range and quality of services commissioned and outcomes for young people are systematically monitored.

4. There is a multi-agency approach with good protocols, systems and processes

- Councils are actively engaged and giving support, from 14 years onwards, to young people and their families that focuses on transition planning.
- Adult social care services take a proactive approach to transition planning from 14 years onwards in partnership with children's services.
- There is a lead professional who is responsible for ensuring all the agencies who need to be involved are properly engaged in the planning process.
- Councils ensure they have proactive and clear systems that help them to manage and monitor transition planning and care across agencies at an individual, operational, managerial and strategic level.

5. There is a co-ordinated person centred planning process

- Person-centred planning methods and processes are used to create integrated transition plans.
- Direct payments are promoted.
- The focus is on achieving outcomes, improving and supporting independence and providing normal life opportunities.

6. Monitoring

- There is regular follow-up to see that the plan remains appropriate and is delivering the outcomes the person sought.

Key recommendations

To ensure the above six points to successful transition are put in place we recommend:

- *Directors of adult social services in partnership with directors of children's social services undertake joint appraisals of local arrangements and commissioning strategies to assess their progress in successful transition planning.*
- *Government to co-ordinate the priorities of its departments and ensure policies support joint work.*

How councils support young people with disabilities into adulthood will be a focus of the Commission's action to assess the performance of councils in carrying out their proper statutory responsibilities for this group of people. The Commission will continue to report on progress on this issue.

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1. Advisory group was convened at the outset of the study to contribute to study questions and design. The members of the group were:

   - Association of Directors of Social Services
   - Mark Peel – Cottage and Rural Enterprises
   - Helen Wheatley – Council for Disabled Children
   - Linda Jordan – Department of Health (Valuing People)
   - Claire Lazarus – Department for Education and Skills
   - Janis Firminger – Hereward College
   - Claire Dorer – National Association of Independent Schools & Non Maintained Special Schools
   - Philippa Russell – National Children's Bureau
   - Katherine Sullivan – SCOPE
   - Janet Read – University of Warwick

2. Representatives from the following organisations:

   - Alderwasley Hall School
   - Barnardo's
   - Bladon House School
   - Breckenbrough School
   - Broomhayes School
   - Chaigeley School
   - Chailey Heritage School
   - Delamere Forest School
   - High Close School
   - Overley Hall School
   - Pegasus School
   - Penhurst School
   - Pield Heath School

- Royal National Institute for the Blind
- RSD UK
- Ryes School
- Sheiling School
- St Dominic's School
- St John's School
- St Mary's Wrestwood Children's Trust

3. Councils

- Bath and North East Somerset Council
- Barnsley Metropolitan Borough Council
- Birmingham City Council
- Blackburn with Darwen Borough Council
- Blackpool Council
- Bournemouth Borough Council
- Bracknell Forest Borough Council
- Bristol City Council
- Buckinghamshire County Council
- Calderdale Council
- Cambridgeshire County Council
- Cheshire County Council
- Darlington Borough Council
- Derby City Council
- Derbyshire County Council
- Devon County Council
- Essex County Council
- Gateshead Council
- Hartlepool Borough Council
- Herefordshire Council
- Kent County Council
- Kingston upon Hull City Council
- Kingston upon Thames Council

- Knowsley Metropolitan Borough Council
- Lancashire County Council
- Leeds City Council
- Leicestershire County Council
- Lincolnshire County Council
- London Borough of Barnet
- London Borough of Enfield
- London Borough of Greenwich
- London Borough of Hammersmith and Fulham
- London Borough of Havering
- London Borough of Islington
- London Borough of Merton
- London Borough of Sutton
- London Borough of Tower Hamlets
- Medway Council
- Norfolk County Council
- North Tyneside Council
- North Yorkshire County Council
- Northamptonshire County Council
- Oldham Metropolitan Borough Council
- Shropshire County Council
- Slough Borough Council
- Somerset County Council
- Southampton City Council
- Southend Borough Council
- Suffolk County Council
- Thurrock Council
- West Berkshire Council
- West Sussex County Council
- Worcestershire County Council

4. Council partners included:

- Barnsley PCT
- Blackburn and Darwen PCT
- Blackpool PCT
- Bristol North PCT
- Bournemouth Educational Needs Department
- Calderdale PCT
- South Cambridge PCT
- Cheshire Special Education Needs Department
- Darlington PCT
- Derbyshire Special Educational Needs Department
- Gateshead PCT
- Kent Education Department
- Kingston upon Hull PCT
- Leeds Education Department
- Lincolnshire PCT
- London Borough of Islington Special Education and Client Services Department
- London Borough of Sutton and Merton PCT
- Norfolk Education Directorate
- North Tees and Hartlepool PCT
- Oldham PCT
- Shropshire and Telford PCT
- Southampton Special Educational Needs Department
- Suffolk West PCT
- Thurrock Special Educational Needs Department
- West Sussex PCT
- Worcestershire Education Directorate

5. Other organisations involved in the study included:

- Challenging Behaviour Foundation
- Foster Care Associates

- Herewood College – students and staff
- Kingwood Trust

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