

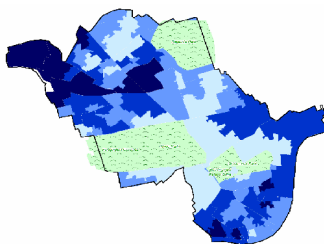
Westminster's
Joint Strategic Needs Assessment

**Transition from Children's to
Adults' Services for Young People
Aged 14 to 25 in Westminster**

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March 2011

Literature Review

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October 2010



Westminster City Partnership

This document contributes to Westminster's JSNA

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Transition case study

J is a young man with autism and challenging behaviour. He is a non-verbal communicator and uses the Picture Exchange Communication System (PECS) as a communication method. He has been known to the Children with Disabilities Team since he was 8 years old when the family moved into the borough as asylum seekers.

J's parents are separated and he only sees his father at weekends. He has two younger siblings and at times has displayed aggressive behaviour towards them.

He attends a specialist out of borough day school for young people with autism and he is due to finish shortly when he turns 19.

J was allocated to the Transition Social Worker when he was 14. She attended his year 9 review which was designed to be as person centred as possible. He was able to attend with support from staff at the school. The school had helped him to devise a brief video in which he was shown doing some of the things he liked and might want to do in the future. People were invited to attend who knew him best and together with professionals they devised an initial Transition Plan. The Connexions worker responsible for out of borough schools was unable to attend but linked in with the school's Transition Worker and the Transition Social Worker to ensure that a service was being provided.

Child and Adolescent Mental Health Services (CAMHS) also became involved when J was 14, which was when he started to display challenging behaviour. Helping J to manage his behaviour better was a key task within the Transition Plan. A behavioural nurse worked closely with J, the Transition Social Worker, the school, the family and the services supporting them in helping to develop strategies to step in before his behaviour became too challenging.

J and his family received a care package of 8 hours with a direct payment carer, which was used at the weekend to enable J's family to have a short break while J was able to engage in activities with his carers which he was interested in e.g. visiting railway stations as he was fascinated by trains.

J was also linked into a specialist youth club which collected him on a Friday evening and he would spend the evening accessing the computer games there, using the tuck shop and engaging with other young people. On a Thursday evening J attended a specialist sports club where he particularly liked basketball. During school holidays he attended a specialist playscheme service three days a week where he was with the older group and was able to engage in a number of activities.

Following the review, the Transition Social Worker started to work with J and his family to build on the plan and think further about what he might need and want in the future. The family had a lot of questions about the types of services available and it was explained that J would be assessed for a personal budget prior to moving into Adults Services. The Transition Social Worker also started to feed this information through to the Adults' Service at the Young Persons Transition Meeting.

Here it was decided that he would not need an eligibility assessment by the Westminster Learning Disability Partnership (WLDP) Psychology Team as he was likely to meet the criteria. Instead they were provided with his statement, school reports and copies of the recent CAMHS assessment. He was also highlighted as a priority for allocation with a WLDP Care Manager once he turned 16.

Once J was 16 the Adults' Care Manager and the Transition Social Worker initially met together to share reports, update information and plan the approach in meeting J and his family.

The initial meeting was to introduce the new Care Manager and allow room for more questions. Following this the Self Assessment Questionnaire was completed with the family. Once a resource allocation amount was indicated the Support Plan was started, building on the previous Transition Plan as reviewed yearly at school.

The WLDP Housing Panel was alerted by the Transition Social Worker and the Care Manager to the fact that the family's preference would be for J to be able to live in a supported living setting in Westminster at a later stage. While this need was not urgent, planning did need to be made around when this might be possible and what support services would need to be in place for J.

CAMHS and the Psychology Team at WLDP met with the two holding practitioners to ensure that there was a handover on the support they had been offering around J's behaviour.

The Connexions Personal Advisor was also able to meet with the family at this stage and met J in one of the youth settings to start to get an idea of the local education and work based learning services that might be most appropriate for him. She was able to link in with the school to ensure that J was not linked into inappropriate out of borough services. She was able to find out that J had become interested in gardening at his school and was able to link him in with a work experience programme at a local park with support in place for him to do this.

On transfer to the Adults' Team at the age of 18 the family were fully aware of who J's Care Manager was, what they would be able to provide and what the differences would be between the two services. A Direct Payment continued to be in place; linking J in with the gardening activity he had started to enjoy, and short break services were organised to assist J with his continuing independence into adulthood.

The Youth Services J attended was able to move him onto the nights when over 18 year olds attended. The holiday playscheme was no longer appropriate however the Personal Budget allowed extra support for those periods.

Executive summary

What do we mean by transition?

The transition period (between 14-25 years) represents a time during adolescence and early adulthood when young people have to make choices about their future, from leaving school to finding employment and moving away from home. For all young people, the transition from childhood to adulthood involves consolidating identity, achieving independence, establishing adult relationships and finding meaningful occupation. For young people who are sick or disabled, this transition is made more difficult by concerns about whether, how and where their health and social care needs will be met.

Why is transition important?

Transition can be an unsettling time for both young people with disabilities and complex health needs and their families for many reasons. It is a time when many avenues of support for a young person may be changing, including education, social services, leisure and health, not all of which may change at the same time. Families and young people may need to get used to unfamiliar services models which are less holistic and centred on the needs of the individual, and more focussed around specific conditions. Or they may find there are fewer services available to meet their needs. The way young people are supported at transition is crucial to their continued wellbeing and their independence, as well as their continued engagement with services and treatments.

Transition is also an important time for services as they prepare to transfer responsibility of care for young people: Children's Services want to know that the young people in their care have somewhere to transition to; Adults Services need to know the numbers and needs of young people likely to transition so that they can plan adequately for their support. Transition for young people with disabilities and complex health needs is complicated by the number of services who may be providing support at any one time. Children's and Adults' Services in many ways work along different service models and have different entitlement criteria but it is important that they work together to ensure a smooth transition for young people.

Transition in Westminster

Young people with disabilities and complex health problems, including mental health problems, are a diverse group with varying needs and levels of need, including educational, health and social needs. As a consequence, individuals are supported by a wide range of services. Not all young people with disabilities and complex health problems who are supported as children will need ongoing support as adults. Also, due to the differences in service provision between Children's and Adults Services, not all children will meet eligibility criteria for Adults Services and 'transition'.

From data currently recorded across Children's Services and the Westminster Learning Disability Partnership (in Adults Services) on the transition-age population in Westminster it is anticipated that between around 49 and 155 young people will

make the transition to Adult Services over the next five financial years. The majority of these are likely to transition to Westminster Learning Disabilities Partnership, although some may transition to the Adults Physical Disabilities Team. As more young people are tested for eligibility for Adults Services post-16, these estimates will become more certain. Data showing new referrals to Adults Services over the past five years indicates that actual referral numbers fluctuate between years. As the numbers of likely transition cases in each financial year varies year by year, and the needs of the different cohorts similarly varies, it is less important to be able to model likely transition numbers over the next five years, as to have clear processes in place to be able to accurately track numbers coming through on an annual basis and have an accurate picture of likely levels of service need.

In the past few years there have been many improvements to transition in Westminster both strategically and at the service level. For instance, Westminster has a multi-agency strategy group and a multi-agency operational group for transition. A transition protocol has been developed to clarify the responsibility of different teams working with young people at transition, and there are written transition pathways for young people with learning disabilities and mental health problems. One of the three teams within Westminster's Learning Disabilities Partnership is dedicated to supporting new service users, including transition cases and there is a dedicated Transition Social Worker within the Children with Disabilities Team. All young people making the transition to Adults Services are now offered self assessments for self-directed support, such as direct payments or personal budgets, and person-centred planning has begun to be embedded within the two local special schools.

Despite these (and other) developments, this needs assessment has identified some areas where transition in Westminster could benefit from further improvements. Twenty-two recommendations have been suggested, around the following areas:

- Data recording and data sharing
- Supporting young people to prepare for adulthood
- Transition pathways
- Transition planning for young people
- Financial and service planning
- Healthcare support
- Improving information for parents and engaging parents
- Documenting and acting on reports from service users on transition
- Vulnerable groups who do not transition
- Developing performance indicators for transition.

These are detailed in full at the end of the document.

Introduction and overview

1.1 What is transition and why is it important?

What do we mean by transition?

The transition period (ages 14-25) represents a time during adolescence and early adulthood when young people have to make choices about their future, from leaving school to finding employment and moving away from home. For all young people, the transition from childhood to adulthood involves consolidating identity, achieving independence, establishing adult relationships and finding meaningful occupation. For young people who are sick or disabled, this transition is made more difficult by concerns about whether, how and where their health and social care needs will be met (DH/ DCSF 2008).

An important element of transition for young people with complex health needs and disabilities is the move between Children's and Adults' Health and Social Services. There is evidence to show that when this is managed poorly, there are worse outcomes for young people. However transition is not merely about a transition between services; it is about supporting young people through adolescence and enabling them to be as independent as possible within adulthood. It is about education and training, employment, living arrangements, social and leisure opportunities, financial independence and health care needs and support. It is about supporting and signposting young people to wider opportunities available for all adults.

This needs assessment will look at transition for young people with learning disabilities, physical disabilities, sensory impairments, complex health problems and mental health problems who receive support from Children's Services and go on to need support as adults. Not all young people who receive social and health support as children will go on to receive the same level of service as adults. This needs assessment will therefore consider the transition pathway of those young people who make the 'transition' to Adults Services as well as those who do not.

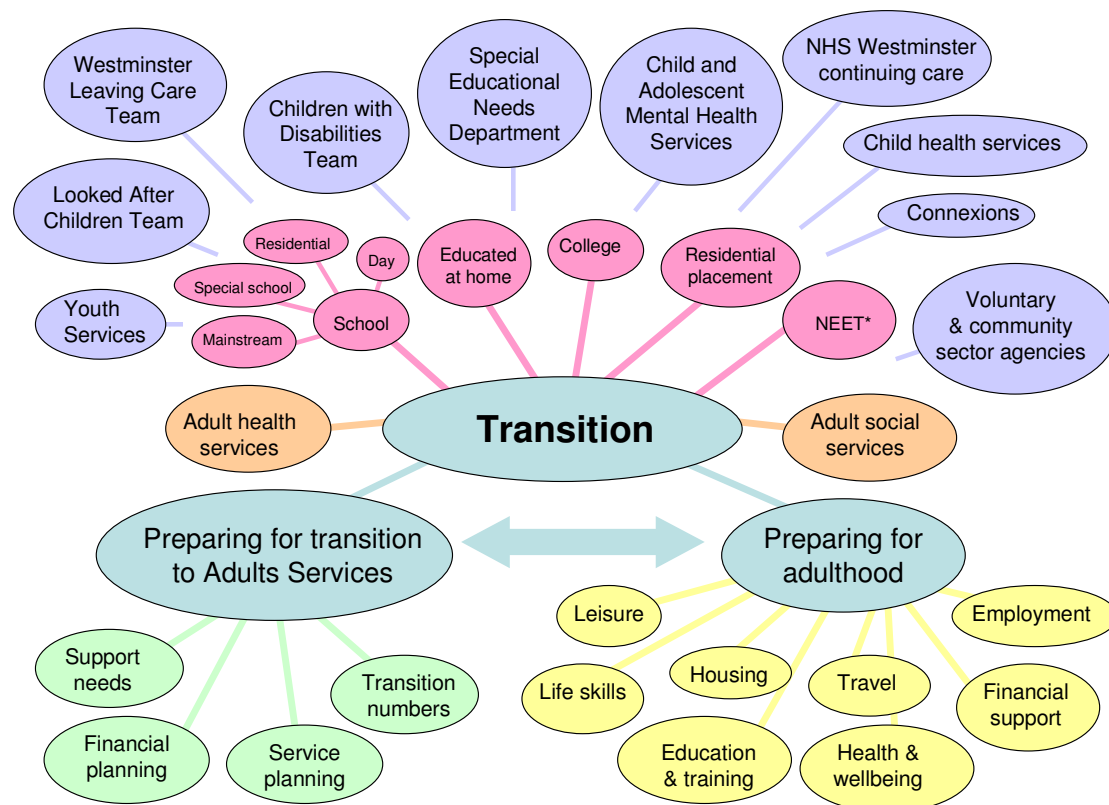
Within the needs assessment the transition process will be considered in three ways:

1. Supporting young people with disabilities, complex health needs or mental health problems who will meet the criteria for specialist support provided by Adult Health and/or Social Services¹, and their carers, to have a smooth transition between Children's and Adult Services;
2. Supporting young people with disabilities, complex health needs or mental health problems who are not eligible for specialist support from Adult Health and Social Services to be signposted to relevant mainstream support services;

¹ Note that some young people may receive health but not social care support.

- Ensuring that Adult Services are adequately prepared, where possible, for the transition of young people to their service, allowing enough time for support and financial planning.

There are many 'transitions' that young people with disabilities will go through in their lives. These include, for example, the move between nursery to primary, and then onto secondary education. Similarly another transition may happen if their care support breaks down in later life and alternative arrangements have to be made, if, for example an elderly parent dies. This needs assessment concentrates on the transitions that young people experience between the ages of 14 and 25 years.



* NEET = not in education, training or employment

Why is transition important?

Transition can be an unsettling time for both young people and their families for many reasons. It is a time when many avenues of support for a young person may be changing, including education, social services, leisure and health, not all of which may change at the same time. Families and young people may need to get used to unfamiliar services models which are less holistic and centred on the needs of the individual, and more focussed around specific conditions. They may find there are fewer services available to meet the needs of the young person or a lack of expertise in Adult Services for a rare condition (DH/DCSF 2008b). The way young people are supported to transition is crucial to their continued wellbeing and their independence, as well as their continued engagement with services and treatments (DH/DCSF 2008a/ DH/DCSF 2008b).

Other factors which highlight the importance of transition for young people, their families and the services that support them include:

- Transition is an important time for services as they prepare to transfer responsibility of care for young people. Children's Services want to know that the young people in their care have somewhere to transition to. Adults Services need to know the numbers and needs of young people likely to transition so that they can plan adequately for their support.
- The profile and number of young people with disabilities is changing. The number of young people with a disability is rising, partly due to the increased survival of babies born pre-term, and also the greater numbers of young people with autistic spectrum conditions being identified. Among this population, the numbers of young people with complex needs is increasing and more of them are surviving into adulthood. There are, for example, more than 6,000 children in Britain who are dependent on assistive technology. Only a few are currently old enough to have entered the transition stage but it is likely that their medical and care support needs as young adults will be considerable (Prime Minister's Strategy Unit 2005; DH/ DCSF 2007).
- There is evidence to show that poorly planned transition for young people with long term health conditions can lead to an increased risk of non-adherence to treatment and loss to follow up. As a consequence young people may be more likely to present later with avoidable and treatable complications of their condition. This can increase morbidity and mortality as well as leading to adverse social and educational outcomes for young people. It can also result in additional health service costs (DH/DfSE 2006; DH/DCSF 2008b).
- Transition is the responsibility of both Children's and Adults Services, which in most cases work along very different service models and entitlement criteria. Furthermore, half of the councils surveyed in a Commission for Social Care Inspection (CSCI) study said that young people's care packages change at, or after, transition and in general this represents a significant reduction in services (DH 2010). It is important that services manage young people and their families' expectations at transition. Many young people with disabilities receive support from several agencies as children and go on to need support from a variety of services as adults. At transition it is important that these services collaborate to ensure continuation of care and to avoid duplication (DH/DCSF 2008a; DH/DCSF 2008b).
- In addition to the different criteria and definitions between Children's and Adults Services, the previous Prime Minister's Strategy Unit's report, *Improving the life chances of disabled people* (2005) points to the following other barriers, which contribute to the persistence of fragmented service delivery:
 - poor communication, tracking, and sharing of individual level data between agencies;
 - a lack of local and regional data to inform planning;
 - cultural and professional barriers between different service providers, and restricted perceptions of areas of responsibility;
 - separate funding streams and targets; and
 - significant regional variation in performance and a lack of dissemination of good practice.

Research has indicated that there are two groups who face particular barriers to well managed transition:

- those with the highest level of need who may experience a delayed transition at 19, on leaving special school and may be offered age-inappropriate and segregated Adult Services due to lack of alternative opportunities.
- those with less significant impairments (such as those with mild or moderate learning difficulties, or communication or mental health problems) who often have little or no contact with services such as social care, but who are at higher risk of coming into contact with the Youth Justice System, experiencing homelessness, teenage pregnancy, drug and alcohol misuse and becoming NEET (not in education, employment or training) (Prime Minister's Strategy Unit, 2005).

This needs assessment considers people at both ends of the spectrum, but focuses more on those with a higher level of need.

1.2 The national picture

There has been a major push in public policy over the last decade to improve the transition process for young people with disabilities. Transition has been identified as a priority in a number of cross department strategies. These include:

- The White Paper *Valuing People* (DH 2001): this was the former government's national strategy for people with learning disabilities. It recommends that every young person with a learning disability and with a statement of Special Educational Need (SEN) has regular person-centred reviews between the ages of 14 and 19. Young people should also have a transition plan with clear actions on health, housing, friends and employment. New Partnership Boards established to oversee the local implementation of the White Paper were supposed to include a transition champion (DH 2001).
- *The National Service Framework for Children, Young People and Maternity Services* (DH 2004): this sets out standards for promoting the health and well-being of children and young people. There are eleven standards: standard 8 covers "Disabled Children and Young People and those with Complex Health Needs." It set out the following marker of good practice:

"Multi-agency transition planning and services focus on meeting the hopes, aspirations and potential of disabled young people, including maximising inclusive provision, education, training and employment opportunities" (DH 2004).

The Standard also requires that 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.

The *National Service Framework* also sets out standards for mental health services, including access to age-appropriate services. It recommends that Child and Adolescent Mental Health Services (CAMHS) should see children up to their 18th birthday. It also recommends the development of protocols for ensuring the

smooth transition of care and the development of Early Intervention in Psychosis services.

- *Aiming High for Disabled Children* (DH/DCSF 2008a): this was the last government's transformation programme for disabled children's services. *Aiming High* also launched a three year Transition Support Programme, a national and local change programme to better co-ordinate the support offered to disabled children and their families around the time of transition. The programmes emphasise the involvement of young people and their families in the transition process through personalised approaches.
- *Valuing People Now* (DH 2009a): this is a three-year cross-governmental strategy aimed at improving the lives of people with learning disabilities and their families, building on *Valuing People*. The former government also published *Valuing Employment Now* (DH 2009b), a strategy for increasing radically the number of young people with learning disabilities in employment by 2025. It highlights the importance of the transition process in supporting young people into work.

The attention on transition in the last few years has led to the publication of a number of guidance documents to improve transition nationally. These include:

- *Transition: moving on well* (DH/DCSF 2008b): a good practice guide on effective transition from Children's to Adult Services for young people with complex health needs or a disability.
- *Transition: getting it right for young people* (DH/ DfES 2006): a guide for the transition of young people with long term conditions.
- *A transition guide for all services* (DH/DCSF 2007): key information for professionals about the transition process, including statutory duties and examples of good practice.
- *Person Centred Planning* (DH 2010a): advice for using person-centred thinking, planning and reviews in schools and transition.

More recently, the new government announced that there would be a green paper on special educational needs and disability published in autumn 2010. There has however, been a delay to its publication. The government has indicated that they are considering reform of the entire SEN system, including how young people with SEN and disabilities can be supported post-16 (DfE news 10/09/2010). The recent review by Ofsted (2010a) of special educational needs and disability concluded that the term 'special educational need' was used too widely and the quality of mainstream education needed to be improved.

Although our knowledge of transition has improved over the last ten years, there is only limited evidence on what works well to ensure a smooth transition and positive outcomes for disabled young people (Beresford 2004). There is however much evidence about experiences and challenges, and a compelling argument that generally, nationally the status quo is not working.

Furthermore the transition of some groups of young people with disabilities has received less attention than others. Those in 'out of area' placements are a neglected area of research along with those from Black and Minority Ethnic (BME) groups

(Beresford 2004). In addition, little is known about the transition of young people with sensory impairments. There has also been relatively little work which focuses on the impact of the family on disabled young people's experience of the transition towards adulthood and independence (Prime Minister's Strategy Unit 2005). Large-scale longitudinal data sources that follow-up a large and representative sample of disabled young people who transfer from child to adult services need to be developed (Prime Minister's Strategy Unit 2005).

The evidence mostly provides support for general principles which seem to support effective transition although these have been rolled out without rigorous evaluation (Beresford 2004). These principles have been highlighted by the good practice guides indicated above. They appear generally to have been accepted by academics and professionals working with young people as important for effective and responsive service provision.

There is a consensus in the literature that services should adopt four key principles in order to support a successful transition for young people with disabilities. These principles are based on the belief that the purpose of transition planning should not be about moving a person from one service to another but should rather support a person while moving from childhood to adulthood. As such transition should be a process not an event, and preparation should start early.

Research conducted by Beresford (2004) indicates that transition can be best supported by service delivery based on the following key principles:

1. **A person-centred approach:** the process for managing transition needs to be individual to the needs and aspirations of the young person; young people, parents and other advocates must play a central role in planning and decision-making.
2. **A multi-agency and multi-disciplinary approach:** the demands of disabled young people are too complex to be responded to by any one individual or organisation.
3. **A long-term view** with sufficient time given for planning, deciding and on-going support, ideally from the age of 14.
4. **The provision of appropriate services,** facilities and opportunities for young people; and continuous service provision where needed.

Good transition is also facilitated by:

- Agencies having **good information systems** to prevent losing young people in transition, in addition to local agreements on sharing assessment information (Ko & McEnery 2004).
- **A strategic multi-agency protocol** on how local services work (UEA 2005). The protocol should include reference to financial agreements between agencies for supporting transition, such as commissioning, transfer of funding and pooled budgets (Singh et al. 2008).
- **Development of a local transition pathway** which sets out the operational detail: how local services - and individuals within them - will support disabled

young people, the legal responsibilities of each service, and performance criteria.

- Each young person with a physical and/or learning disability having a **transition review leading to a transition plan**. This sets out the young person's aspirations as well as the support they will need. It outlines each agency's commitment and how support will be delivered.
- **Evaluation of transition arrangements** - there should be quality indicators of performance. The experience of young people and their carers can be measured through satisfaction surveys and quality of life questionnaires. The impact of joint working should also be evaluated.
- **Involvement of parents and carers** - evidence with regard to good practice on working with families and carers is weak but research indicates the importance of families having support for adjustment to changed relationships with young people, parental involvement in service planning, a family-centred approach, provision of information, and a named key worker who liaises with the young person and family and collaborates with professionals (Forbes et al. 2002).
- Use of **Direct payments** and individual budgets to shift choice and control to service users.

More detail of the research into best practice for transition is provided throughout this needs assessment, and in the literature review provided at the end of this document.

1.2.1 National research on transition in mental health

There has been less research into the transition of young people with mental health needs, compared with other care groups. National policy in the UK emphasises the need for a smooth transition but there has been a lack of published evidence on the process, models and outcomes. In order to fill this gap, the TRACK study was undertaken, to audit the policies and procedures relating to transition within six mental health trusts in London and the West Midlands (Singh et al. 2008, 2010).

The study concluded that the groups who were most likely not to transition to Adult Mental Health Services (AMHS) included those with neuro-developmental disorders (including attention deficit hyperactive disorder (ADHD) and autistic spectrum conditions), those with emotional/neurotic disorders or emerging personality disorders. Those with a severe and enduring mental illness, on medication or with a hospital admission were more likely to make a transition to AMHS. However, many (a fifth of actual referrals) were found to have been discharged by AMHS without being seen.

The study found that according to their criteria of 'optimal' transition, fewer than 4% of cases accepted by AMHS experienced optimal transition. For the majority of service users, transition from Child and Adolescent Mental Health Services (CAMHS) to AMHS was poorly planned, poorly executed and poorly experienced. It is not clear however, whether suboptimal transitions classified in this way equates with poor clinical outcomes, although it may equate with poor patient experience.

Overall recommendations from the study included:

- Protocols should specify the timeframe, lines of responsibility and who should be involved, how the young person should be prepared and what should happen if AMHS are unable to accept the referral.
- Transition should occur at times of stability where possible; young people should not have to relapse in order to access a service.
- Agencies should try to avoid multiple simultaneous transitions.
- Improved information transfer between CAMHS/AMHS with the standardisation of record keeping or, where this is impossible, clear information of what should be made available.
- Carers' needs and wishes should be respected in the transition process and carer involvement in adult services should be sensitively negotiated between clinicians, service users and their carers.
- Services need to develop for young people with emotional/neurotic, emerging personality and neuro-developmental disorders wherever there is gap in such provision.

More detail is provided in the literature review at the end of this document.

1.3 Why are we doing a needs assessment around transition?

This document provides an overarching assessment of the needs of young people with disabilities going through transition. It forms part of a wider rolling programme of needs assessments, the Joint Strategic Needs Assessment (JSNA), undertaken jointly by Westminster City Council and NHS Westminster.

Improving transition in Westminster has been identified as a local priority:

- One of the eight priorities within *The Big Plan 2009-2012*, Westminster's strategy for adults with learning disabilities, was 'making transition a positive experience.' Actions included for every young person to have a person-centred plan, receive services through self directed support and for more young people to go to college and get a job (NHSW, WCC, WLDP 2009).
- The Westminster Physical Disabilities Strategy, *Our Say, Our Way 2009-2012* identified aims to improve the identification and recording of young people who will require support from Adults Services when they reach an appropriate age and ensure links are made with children and young people's strategies to ensure that choice and control is facilitated gradually for young people as they move into adulthood (NHSW, WCC 2009).
- One of the ten principles for Westminster's *Children and Young People's Plan 2009-11* (WCC, NHSW 2009) was 'we will ensure that children and young people are supported through the key transitions that occur during their lives that may cause disruption to their wellbeing including transitions between schools, services, professionals and localities.' More specific objectives included improving the information for parents of young people with disabilities around the transition from childhood to adulthood, and around personalised budgets; and ensuring that young people with disabilities going through transition are offered a health action plan.

As noted above, there has been much activity nationally in terms of identifying best practice around transition. Westminster has made progress in developing transition pathways and multi-agency working to support young people in transition locally. This was recognised within the second annual Transition Support Programme Self-Assessment (2010), which rated transition support in Westminster as 'development stage level 2,' a score which matched that of many other local authorities nationally (a minority were scored as level 3, the top level for that year). The assessment however identified gaps and areas for improvement, something this needs assessment considers in more detail. As part of this JSNA, a literature review has been conducted to identify best practice around transition. This is provided in full at the end of the document.

The intention is that the evidence provided here will inform the development of a Delivery Framework on transition for young people with disabilities and complex health problems aged 14-25 years old. It will also inform future commissioning for this population. Through this needs assessment the intention is to:

- Better understand the transition population and their needs
- Ensure children are not falling between the gaps in services
- Better understand the transition pathway and how decisions are made for this population, and by whom
- Identify ways to improve congruence between Children's and Adults Services at transition
- Identify ways to improve support to parents at transition
- Identify ways to improve the experience of young people through transition and achieve better outcomes for young people with disabilities as they move into adulthood.

It is important to note that this needs assessment is written at a time of considerable structural change and financial strain in the borough. For instance there have recently been changes made to the Fair Access to Care Services (FACS) criteria, which have affected the eligibility for Adult Services for some young people with disabilities. Similarly there are proposals for a merger of parts of Children's Services across different local authorities (Kensington & Chelsea, Westminster and Hammersmith & Fulham). The needs assessment therefore presents the picture within Westminster as at the end of 2010.

1.4 What is the population covered in the needs assessment?

The population covered in this needs assessment can be defined as:

young people with a condition that causes them a disability, who are known to Children's Services and go on to need support from (transition to) Adult Health and/or Social Services.

The population known to Children's Services includes young people supported by Locality Young People's Services who transition to Adults Services. In addition to this narrower group, the needs assessment draws attention to those individuals who are in receipt of Children's Services, including support from Connexions (provided through Locality Young People's Services), and have a condition that causes them a

disability, who do not meet the criteria for Adult Health and/or Social Services.

This uses the definition of disability as given in the Disability Discrimination Act (1995) that *a person has a disability if s/he has a physical or mental impairment which has a substantial and long-term adverse effect on his/her ability to carry out normal day-to day activities* (Section 1(1), Disability Discrimination Act 1995; DfES 2001).

The needs assessment however also acknowledges the social model of disability which defines disability in terms of the way in which society functions, affecting individuals' ability to carry out day-to-day activities (Oliver 1990). At transition it is important that these barriers are minimised to enable young adults to become as independent as possible.

The population covered includes individuals with a wide range of conditions and disabilities, including:

- a learning disability,
- physical disability,
- complex, long term health condition such as a neurological condition,
- sensory impairment, including hearing impairment, visual impairment, dual sensory loss,
- autistic spectrum condition,
- severe and enduring mental health problems.

These may be as a result of conditions lasting since birth (including genetic disorders Down's syndrome or birth defects such as spina bifida; and those resulting from premature birth or birth trauma) or as a result of later injury, illness or other events such as acquired brain injury following a car accident. Some of these may be degenerative such as cystic fibrosis and needs may change over time.

Some individuals may have disabilities which span different care groups, such as long-term health condition and a learning disability, or a mental health condition as well as a physical or learning disability. For instance it is estimated that 25–40% of people with learning disabilities also have additional mental health needs. The combination of learning disabilities and mental health problems can result in very complex needs (Foundation for Learning Disabilities, 2008).

These conditions may affect day to day activities in a wide variety of ways, resulting in a range of needs, including

- mobility
- communication using oral or written language
- continence
- ability to feed oneself
- manual dexterity
- ability to concentrate, perceive, think, remember and learn
- ability to control behaviour and to relate to other people
- perception of risk of physical danger (adapted from Bradford Observatory 2009).

As a result these young people may need a variety of services as children and also as adults to enable them to live independently and achieve economic independence. Their needs will be individual and depend on a wide range of factors including their own impairment and the capacity of their social support networks. These factors may change over time (NHS Islington and Islington City Council 2009a, 2009b).

Without appropriate and adequate intervention, disabled children and those with complex health needs are at risk of:

- Living in poverty
- Social exclusion
- Discrimination
- Poor health
- Becoming NEET (not in education, employment or training)
- Preventable early death (Bradford Observatory 2009)

1.4.1 Population groups not covered within the needs assessment

The following population groups are not considered within this needs assessment:

- Young people with sexual health problems
- Young people with substance misuse problems
- Young people with a health condition which does not cause them a disability
- Young people with attention deficit, hyperactive disorder (ADHD) and other behavioural, social and emotional difficulties which may result in a statement of special educational need, but who do not otherwise meet the definition given above (some of these are educated in 'alternative school provision').
- Children in touch with the youth offending team (YOT), who are not otherwise included in this needs assessment due to another need, such as a learning disability.

1.4.2 The challenges in defining the transition population

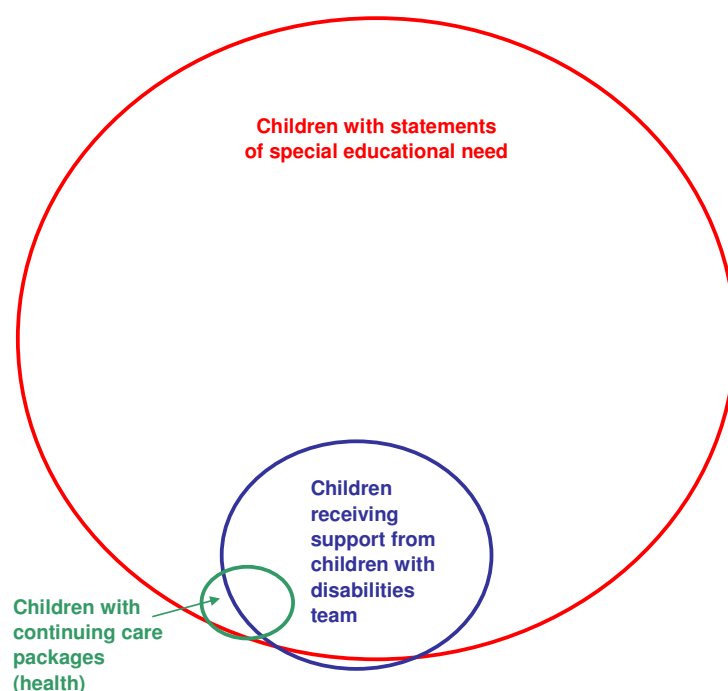
Young people with disabilities and complex health problems, including mental health problems are a diverse group with varying needs and levels of need, including educational, health and social needs. As a consequence, individuals are supported by a wide range of services. Not all children receive support from the same service(s) and the services young people are in touch with may change over time, for instance as health conditions deteriorate or family situations change. Not all young people with disabilities and complex health problems who are supported as children will need ongoing support as adults. Also, due to the differences in service provision between Children's and Adults Services, not all children will meet eligibility criteria for Adults Services.

Capturing the population of young people with disabilities who make the transition to Adult Services is complicated by several factors. Firstly, the different services providing support to this population have different definitions of disability and different thresholds for support. Special educational need (SEN) provides a good example of this. Not all children with a statement of SEN will have a disability; some

children have statements for social, emotional and behavioural reasons or speech, language and communication difficulties. Similarly not all children with a disability, particularly a physical disability or complex health need, will have a SEN statement (the SEN statement recognises an educational need rather than a medical need; if their school provision is able to meet the needs of these children they will not require a statement). Individuals with a physical disability may be eligible for services from the Children with Disabilities Team. However, children with social, emotional and behavioural difficulties or communication difficulties without another disability or sensory impairment may not be eligible for specialist services from the Team (although they may receive support from other services). Connexions services also undertake targeted work with young people with a learning difficulty/disability (LDD); this is a broader group again than those with SEN statements.

Figure 1 captures the relevant sizes and crossover of some of the teams working with these young people. Missing from this diagram are children with mental health needs supported by Children and Adolescent Mental Health Services (CAMHS); this population is relatively large and there is an overlap with individuals supported by the SEN department, Children with Disabilities Team and Continuing Care. Figure 1 also does not indicate that some of the children may be Looked After Children (LAC).

Figure 1: Diagram to show the relative size and overlap between some of the services supporting young people with disabilities in Westminster



Note: not drawn to scale

Another complexity is that just as the definitions of young people with disabilities who receive support from the Children's teams are different, not all the young people supported will be of a severity which will meet the criteria for specialist Adult Services. It is important to note that the number of young people with disabilities actively supported by specialist services as children is larger than the cohort who will transition to specialist Adult Services.

The very individualised conditions and situations of many of the young people with disabilities in the borough, some of whom have conditions and needs which are likely to change or deteriorate over time adds additional complexity. The nature of some conditions means that some individuals may not survive into adulthood. It is not always possible at the age of 14, when transition planning starts, to predict the number of individuals who are likely to need Adult Services or the level of services they will need.

Also, not all children with disabilities who will require Adult Services at 18 (or when they leave education) may be known to, or receiving active support from, Children's Services. In these cases there may not be a 'transition' as such but they may present as new referrals to Adult Services around a similar age as the transition cohort. Where known about before aged 18, these young people should be supported through the transition process as other children are with similar needs. It is very difficult to predict the number of individuals falling into this category and their needs. Examples might be individuals who are privately educated and receiving private medical support, whose parents' financial situation changes; individuals with a physical disability or complex health problem without a cognitive difficulty who do not have a special educational need and whose parents are able to support them during childhood; individuals who have a degenerative long term condition which does not impact them as a child but worsens over time or who have a condition which develops later, for example as a consequence of an accident as a teenager.

A further factor is the transient nature of the population in Westminster and that families with disabled children may move into and out of the borough during the transition period creating fluctuation in the caseloads of services. For example Westminster has a proportionately large number of refugee and asylum seekers some of whom have children with disabilities. Also, almost all of the embassies in London are in Westminster. Figures for 2001-2006 indicated that as a borough, Westminster experienced the highest volumes of international migration in England; with total volumes of migration (both internal and international) estimated to be around 259 per 1,000 population for those years.² Anecdotally, services in Westminster have mentioned that some diplomatic families stationed in the borough have had disabled children who have required local services. Although precise numbers are not available, the numbers are not likely to be large in any of these groups. They should be noted, however, as they provide another layer of complexity in evaluating the numbers of young people with disabilities in the borough and the numbers who are likely to transition. A few families moving into the area with disabled children with complex needs can have a significant impact on services, both provision and cost.

1.4.3 Trends in the transition population

There are a growing number of children with disabilities and chronic illnesses reaching adulthood and needing support from Adult Services. This has implications for planning and commissioning health and Adult Services in Westminster, and managing the transition process and the expectations of Adult Services these young people and their families will experience.

² Source: Westminster City Council and NHS Westminster Public Health Intelligence 2010.

Young people with chronic illnesses

Advances in medical treatment have led to an increase in survival rates of children with complex health conditions. This means that an increasing number of children are reaching adulthood requiring a range of support services to manage their condition (While et al. 2006). For example, in the 1960s, most babies born with cystic fibrosis only survived for a few months or years, now around half of people with cystic fibrosis now have life expectancy of over 38 years. A baby born today with cystic fibrosis can expect to live longer than 38 years because of improvements in medical treatment (<http://www.patient.co.uk/showdoc/27000674/>).

The prevalence of some conditions and disabilities will increase because of growing numbers of babies born preterm (before 37 weeks gestation) surviving. In England and Wales the number of preterm live births is increasing. Nearly 8% of live births are now preterm (ONS 2007).

The EPICure study (Marlow et al. 2005) found that 1 in 10 babies born preterm develop a permanent disability including lung disease, blindness, deafness and cerebral palsy. Children who were born at less than 26 weeks had a greater level of disability: 22% had severe disability, 24% had moderate disability, and 34% had mild disability. Children born before 26 weeks were also found to have a high prevalence of special educational needs and lower educational attainment (Johnson et al. 2009).

Changes in population movement may also increase the prevalence of some long-term conditions. Modell et al (2007) found that sickle cell disease and thalassaemia are increasingly common in Northern and Western Europe because of changes in immigration. However, the prevalence of some genetic conditions – such as cystic fibrosis - may fall because of developments in genetic testing (Massie et al. 2010).

Young people with learning disabilities

The number of young people with learning disabilities in Westminster is likely to increase. The White Paper *Valuing People* (DH 2001) provides estimates for the current prevalence of learning disabilities among young people. It estimates that:

- 25 out of every 1,000 people have a mild/moderate learning disability: i.e. can live independently but with some support.
- 44 out of every 10,000 people have a severe learning disability: i.e. are in need of significant help with daily living.

The White Paper found that prevalence of severe learning disability is uniformly spread across the country and across socio-economic groups but that mild/moderate learning disability is associated with poverty and urban areas. This means that Westminster may have higher rates of people with mild/moderate learning disability.

Valuing People predicts that the number of people with a severe learning disability may increase by 1% per year over the next 15 years due to a number of factors, including

- increased life expectancy – particularly for people with Down's syndrome,

- an increase in the numbers of children diagnosed with autism spectrum disorder,
- an increase in the number of young adults belonging to South Asian minority ethnic groups, in whom there is a higher prevalence of learning disabilities;
- improvements in maternal and neonatal care, increasing the numbers of children with complex health conditions who survive into adulthood.

Emerson & Hatton (2004) have produced estimates for the future number of adults with learning disabilities based on demographic trends. Their estimates are higher than those in *Valuing People*. Their predictions are adjusted for the changing demography of minority ethnic communities and reduced mortality among older adults with learning disabilities.

Their predictions for the two decades between 2001 and 2021 are that in England there will be a:

- 14% increase in the number of adults with learning disabilities known to specialist learning disability services
- 20% overall increase in the number of adults with learning disabilities.

If these predictions are accurate, it suggests that there will be a large increase in the number of adults with learning disabilities living in Westminster who need support.

More information on these trends is given in Westminster's *The Big Plan: Joint Strategic Needs Assessment 2009-2012* (NHSW, WCC 2009). Using Emerson and Hatton's estimates it was estimated that the total number of people with moderate or severe learning disabilities in Westminster was likely to increase by about 50 people between 2008 and 2015 (NHSW, WCC, WLDP 2009).

Young people with special educational needs

A recent report by Ofsted (2010a) shows that the number of children with special educational needs is increasing. Just over one in five pupils have been identified as having special educational needs. Of these, about 250,000 have statements of special educational need. Ofsted found that the proportion of pupils with a statement of special education needs has decreased from 3% in 2003 to 2.7% in 2010. However, the proportion needing less intensive additional support has increased from 14% in 2003 to 18.2% in 2010.

However, these figures may not be a reliable indicator of actual numbers of children with special educational needs. Ofsted found wide variation in the identification of children with special educational needs, between and within local areas. A change in assessment practice or thresholds could influence prevalence of special educational need among school children, and also the number of children reaching the age of 16 who need ongoing support from Adult Services. However, based on current Ofsted estimates, it is likely that Westminster will see an increase in the numbers of young people reaching the age of transition with special educational needs.

Young people with Autism Spectrum Disorders (ASD)

The term ‘autism’ refers to a spectrum of conditions including classic autism, Asperger’s Syndrome and high-functioning autism. As the concept of autism has broadened, estimates of prevalence have increased. Several research studies have produced estimates of prevalence among children in England of around 1 in 100 (Baird et al. 2006; Bruga et al. 2007). An estimated 82% of children with autistic spectrum disorder are boys (Green et al. 2005). Bruga et al. (2007) found that adults with ASD are socially disadvantaged, have fewer educational qualifications, and may not be sufficiently supported by services.

If current trends continue, Westminster is likely to see an increase in the number of children with autism spectrum disorder entering adulthood and in need of ongoing support. This is something which is discussed in more detail in Westminster’s joint strategic needs assessments (JSNA) on autistic spectrum conditions (NHSW and WCC 2010).

1.4.4 Safeguarding

The young people covered within this needs assessment are a particularly vulnerable group in need of safeguarding both as children and adults. Agencies working with young people with disabilities and complex health problems have a duty to work together to protect them from abuse or neglect, prevent impairment of their health and development, and ensure they are growing up in circumstances consistent with the provision of safe and effective care that enables them to have optimum life chances and enter adulthood successfully (Ofsted 2008c). This is something which is embedded within the principles of services which work with young people with disabilities. As such safeguarding is not dealt with as a topic in its own right in this JSNA; instead it is implicit within the wider discussion of transition and preparing young people for adulthood throughout the whole document.

1.4.5 Data

There are two small points to note about data on the population in this JSNA:

- Due to small numbers within the transition population, to protect client confidentiality it is not possible to break down all categories of data to a level which discloses numbers smaller than five. Where these data are displayed within graphs true numbers are replaced with a *.
- Where datasets contained information on the date of birth of service users they were displayed by cohort in the year in which they will turn 18, reflecting the financial and service planning element of transition (discussed in section 5). Where this was not provided, the data is displayed by school year.

2 Young people's and families' views of transition

It has not been possible to obtain the views of young people with disabilities and their families specifically for this needs assessment. There have, however, been a number of consultations in Westminster with young people and their families in the last few years, which have discussed transition. The views expressed are summarised below. As is discussed in more detail in section 3.8, developments have taken place within Westminster to improve engagement with parents around transition and service planning on a more regular basis.

In addition, during the consultation for the delivery framework for 14-25 year old transition, which this needs assessment feeds into, the views of young people with disabilities and their families will be sought.

Consultation on the Westminster Transition Protocol (WCC 2010e)

During the recent review of the Westminster Transition Protocol in March 2010 16 young people aged 16-29 years and 6 parents were consulted directly. The young people were consulted at Queen Elizabeth II Jubilee School, the Stowe Saturday Club and Pursuing Independent Paths.

The overall message from the parents, in the words of one individual, was that “nothing is clear”. Parents valued input from, and information about, Adult Services prior to transition but they felt that their knowledge and views about what was best for their child was ignored once he or she became an adult. They expressed a need for consistency of advice across different agencies working with the family and valued being supported by the same care manager over a long period of time.

Other points that were raised by the young people and their parents can be summarised as follows:

- Preparation will be needed for young people to get the best out of their school reviews. Creative ways to encourage their participation may assist, such as enabling them to take friends into meetings.
- Moving on is an emotional time. Young people leave behind friends, some of whom they have known for over 10 years. Consideration needs to be given to how to support them emotionally as well as practically.
- Non-disabled young people leaving school may take photos of their friends, swap phone numbers, and may also want to stay in touch with teaching staff. Opportunities to do this may need to be created for disabled young people. (*This is something that could be included in a person centred plan, discussed in section 3*).
- Leaving school, leaving college, moving on and getting work should be an ongoing topic for discussion with young people and their parents and carers, not just undertaken by the Connexions worker. (*This is something that could be included in a person centred plan, discussed in section 3*).
- Information and assistance needs to be offered proactively, rather than waiting for a young person or young adult to ask for help.

- Parents, carers and young adults may need time and assistance to get used to the way in which adult services work with them.
- Consideration should be given to providing advocacy for young people in transition. Reasons why this is important are listed in a report from the Office for Disability Issues (Townsend et al. 2009).
- Parents, carers and young people need information about the range of possible colleges that they may attend, including ones outside Westminster.
- Benefits advice is needed from when a young person is 16 years old.
- Photographs of key staff may be useful for young people, so that they can more easily communicate about them, ask to see them, understand what their role is etc.

Issues and Barriers for Young Disabled People in Westminster, report conducted by Westminster Action Network on Disability (WAND 2010)

In early 2010 Westminster Action Network on Disability (WAND) spoke to 5 disabled young people aged between 16 and 19 about their experience of transition.

During this consultation it was felt that good service provision was: person-centred, provides genuine choice and control, gets young people onto the path of independence more quickly rather than relying on parents for support, consists of agencies working in a holistic and multidisciplinary way and provides an element of continuity. The goal of transition planning should therefore be to provide high quality services, offer choice and control to young people and maximise their education, training, employment and social opportunities with a view to creating active citizens.

The specific points that were raised are summarised below:

- Life skills (cooking, cleaning, shopping, making friendships/having a relationship and sex, budgeting, travel) are really important but disabled young people do not get opportunities to meet disabled adults who are living on their own and getting on with life. The disabled young people consulted said that the one thing that would make them want to do something is if they saw another disabled person doing it. Many young disabled people feel unable to express themselves sexually but there is little or no counselling or practical advice in this area.
- Gaining the necessary support workers to enable young disabled people to participate in evening classes or further education is very difficult. For example only specific colleges, for example City Lit centre for adult learning, provide courses in British Sign Language (BSL) (<http://www.citylit.ac.uk/>).
- Greater support is needed for disabled young people to experience work by having access to placements in a work environment. This has been piloted in Westminster but the pilot needs to be expanded to include other industries and proper assessments need to be carried out to ensure adequate support is provided. Another recommendation is that there is a clear employment advice pathway for disabled young people.
- The independence of young people with disabilities is sometimes prevented due to the over-protectiveness of parents and low parental expectations - training is required to give assurance to parents about the balance between positive risk

taking and safeguarding. Support for parents around independence is provided by Parents for Inclusion - <http://www.parentsinclusion.org/>.

- Lack of accessible housing – it is important that the right accommodation is available in the private sector to enable young disabled people to move out of home as soon as they feel able. There is a scheme called My Safe Home which allows disabled people to use their housing benefit to buy a flat, which could be piloted in Westminster for young adults. (*This is on offer for adults with learning disabilities through the Westminster Learning Disabilities Partnership*).
- The provision of social services in Children's Services is very different to Adults Services and sets up a set of unrealistic expectations for both young adults and their families. It is important that young people with disabilities in transition are provided with advocacy support.
- Health and Social Care in Children's Services tends to medicalise disabled people and families. Not much planning is done to look at how barriers can be removed and how young people can be enabled to live independent lives. The emphasis needs to shift towards what the person can do rather than what they cannot do. Personalisation is important in this and should be started as early as possible in transition. (*This is something that could be included as part of a person centred plan, discussed in section 3*).
- It is important that young people with disabilities have access to mainstream services such as leisure, swimming and having the opportunities to go out and have social interactions. Youth provision can be too focussed on the medical model approach (statementing and labelling disabled young people). Disabled young people feel that they are a burden on youth services and they are made to feel that 'special' provisions need to be put in place.
- Information for young disabled adults should not be any different to the information for non-disabled young people. This information should be accessible and it should be clear who and how to get extra support because of an impairment.
- Transition planning should be person-centred and enable individuals to have choice and control in adulthood. Personalisation training and peer-mentoring provisions need to form part of the transition planning. For example, matching young disabled people with peer mentors who live in the community, who can provide travel training, shopping, budgeting and general independent living skills. (*Some peer mentoring currently takes place at Queen Elizabeth II Jubilee School, one of the local special schools; it is also something the Volunteer Centre Westminster is looking to develop*).

Views collected at the consultation events for *The Big Plan*, 2009-2012 (NHSW, WCC, WLDP 2009)

Consultation workshops were conducted in 2008 when drafting *The Big Plan*, Westminster's strategy for people with learning disabilities. Transition was among many topics that were covered.

Family carers stressed the need for good quality information about what opportunities were available and for good quality communication with staff. There was a strong

view that there needed to be better joint working between agencies, particularly between Children's and Adults Services and that transition planning should start from an earlier age – at 14 years of age (year 10).

Family carers also identified a number of things that they felt would help make transition to Adults Services a more positive experience, including:

- being seen by staff and services as unique, with unique concerns and unique aspirations
- being able to discuss all aspects of transition (such as college courses, day time activities, housing and health) at an earlier stage
- being able to discuss and share information with staff and other family carers on a regular basis; this could be facilitated, possibly, by a family link
- having support and advocacy
- being able to go to open evenings run by services
- higher expectations among everyone – especially in schools and at transition that people with learning disabilities can work in paid jobs
- hearing more about people's positive experiences of transition.

'A Seamless Journey. A Seamless Transition': Report on Two Consultation Workshops (Westminster Society for People with Learning Disabilities 2008)

In 2008 two workshops were held to discuss transition in Westminster. The first workshop brought together commissioners and providers of services for children with disabilities and their families from across Westminster. It was attended by 91 people. The second workshop was convened by and for parents. It was attended by 57 parents.

It was recognised across the workshops that poorly managed transition for people with challenging needs can compound the difficulties. The effect of the change on the individual can be underestimated. People returning from residential schools have a particularly challenging experience. This needs proper planning, managing the change of living from residential school to home as well as between services. There are also the effects of changes in friends and relationships which need to be considered and supported accordingly.

During the consultation with parents, the 'red book' issued to new mothers at the time of birth was mentioned more than once as something that could be developed for parents of children with special needs. Another idea was for a loose leaf folder that could be customised for each new child for his/her specific needs. For example, cultural and language differences could be addressed from the start. *In many ways the person centred plan and health action plan, if started from an early age would fulfil the same purposes (see discussion in sections 3 and 3.7.1).*

Overall what was seen as important at transition, and areas for improvement locally across both workshops were:

- Information – to be up to date, transparent, freely available eligibility criteria, user friendly, a single point of contact
- Transition - consideration of appropriate age boundaries, joined up and proactive approach
- Parent participation - at all levels, from operational to planning and strategic

- Multi agency working – developing consistency, shared approach, shared values, flexible working, reflecting the needs of the family not the professionals
- Informed choice – more effective ways of ensuring the views of the whole family views are considered
- Short Breaks – development of more flexible services, more choice and opportunities, equality of access
- Inclusion – more training and support, particularly for mainstream services
- Advocacy – further development.

3 Preparing for adulthood

As highlighted by young people with disabilities and their families, transition is not merely a move between services; it is about supporting young people during adolescence to enable them to be as independent as possible within adulthood. This section will consider in more detail how young people are supported to prepare for adult life.

Becoming an adult is about increased independence and a new orientation in leisure and social activities, housing options, education and training pathways, jobs, finances and health and care support. It is a time when young people have to make choices about their future; leaving compulsory schooling, going to college or further training, finding employment and moving away from home. There are changes in family life, social networks and emerging sexuality to contend with. The concerns and aspirations young adults have during adolescence are the same for all individuals, irrespective of disability.

Young people with disabilities, however, sometimes face disabling social, attitudinal and environmental barriers that can cause disruption, anxiety, and delay or even prevent the achievement of independent living and social inclusion. There are many aspects of people's lives where the existence or absence of disabling barriers will determine whether they can be active citizens. Housing suitable for their needs, transport, assistance and equipment to enable mobility, interpreters and advocacy are just some of the important areas. So too is the provision of health care: a wide range of health services can make all the difference to whether someone can live independently, work, become a parent and participate in their local community (Office for Disability Issues 2008; Prime Ministers Strategy Unit 2005).

The Disability Rights Commission has defined independent living as 'all disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community.' This does not necessarily mean disabled people 'doing everything for themselves' or living on their own, but it means that any practical assistance or equipment people need should be based on their own choices and aspirations and that they should have equal access to housing, transport and mobility, health, employment, education and training opportunities (Prime Minister's Strategy Unit 2005; Office for Disability Issues 2008).

In 2005 the Labour Government commissioned a review into how to improve life chances for disabled people, and how to make progress on the Government's commitment that all disabled people have the same choice, freedom, dignity and control over their lives as non-disabled people (Prime Minister's Strategy Unit 2005). This resulted in their *Independent Living Strategy* in 2008, with plans for how this would be put into practice (Office for Disability Issues 2008).

In the *Independent Living Strategy* the Government recognised the importance of transition for young people with disabilities as a time when the support needed in adulthood is planned, along with their choices and aspirations for the future and reiterated its commitment to improve transition for young people in this area. They emphasised the importance of a seamless transition into adulthood for young disabled people, including those with complex health needs, in all aspects of their life,

including between Children's and Adults' Services, as well as housing, transport, employment, education and training (Office for Disability Issues 2008). *Improving the life chances of disabled people* (Prime Minister's Strategy Unit 2005) explained that opportunities for disabled young people to improve their life chances should be provided through inclusion in further education and employment preparation, and accessible mainstream leisure and cultural activities and youth services.

In 2006 the Government White Paper, *Our health, our care, our say: a new direction for community services* (DH 2006) set a new strategic direction for all the health, care and support services that people use in their communities. One of its key aims was to put people more in control of their own health and care through among other things the use of Direct Payments and Individual Budgets, so that their own actions and choices would become the drivers of service improvements. This was followed in 2007 by *Putting People First: Transforming Adult Social Care* (HM Government 2007) which set out the Government's programme for transforming the model of social care to a more personalised system – one in which people have high quality services that are personal to them, have more control over the decisions that affect them, get the support that is right for them, and where they are treated with dignity and respect (NHSW, WCC, WLDP 2009). These themes of choice and control have also underpinned much of the work that has taken place to improve transition for young people with disabilities, particularly around person-centred-planning.

Following the publication of *Valuing People Now* (DH 2009a) the Government set up the 'Getting a Life Demonstration Project', which has been looking at what needs to happen to improve the experience of young people with learning disabilities as they move from compulsory education into adult life. Much of the work of the project has been around employment and careers but other work streams have begun to look at planning for future health, housing, and making and maintaining friendships and relationships. The project aims to incorporate views of families and young people, as well as services to develop models of best practice in these areas. The findings will be relevant to all care groups, not just learning disabilities.

Five pathways are in the process of being developed, to show what needs to happen at each stage of a young person's progress through transition and into adulthood, using the principles and methods of person-centred transition planning and support planning so that they can have jobs, friends, their own homes and choice and control over their lives.³

Aims for *Getting a Life* include:

- Young people will have choice and control over their lives and equal opportunities;
- Every young person will have a person centred plan that drives their transition to adulthood;
- Young people will leave school or college and go into paid employment;
- Young people will know what is possible and have support to plan for their future housing
- Young people will have friends, relationships, social lives and be part of the local community.

³ For more information refer to - <http://www.gettingalife.org.uk/resources.html>

Person-centred transition planning

Within national guidance around transition, there is increasingly an emphasis that the school transition plan (see section 6.2) for young people with special educational needs (SEN) should address wider aspects of the young person's support needs, aspirations for the future and practicalities for moving to adult services. These include housing, employment, advocacy and peer support, health, including sexual health and social interests, as well as care support provided by family members and carers, and how these might change over time. Transition planning is also encouraged for young people with disabilities who do not have SEN statements (DH/DCSF 2008b).

Within guidance in this area, two aspects which have received particular emphasis are person-centred-planning and health planning. Both of these came out of *Valuing People* (DH 2001), the strategy for learning disabilities first published in 2001 and updated in 2009. As stated in *Valuing People Now* (DH 2009a) all Learning Disability Partnership Boards have a duty to ensure that by 2012 all young people with statements of special educational need, who have learning disabilities, have person centred reviews from age 14 to 19, that actively involve the young person and their family. They also are asked to ensure that all transition plans and year 9 reviews where appropriate contain a section on health needs and start the development of a health action plan. This has been translated into a local target for the Westminster Learning Disabilities Partnership (WLDP). The current strategy for people with learning disabilities, *The Big Plan 2009-2012* has a target for 100% of young people coming through to adults to have a person-centred transition plan at school, which includes information about their health and work aspirations (NHSW, WCC, WLDP 2009). Health planning will be discussed in more detail in section 3.7.1.

A person-centred approach to planning means that planning should start with the individual (not with services), and take account of their wishes and aspirations. It is a mechanism for reflecting the needs and preferences of a person with a disability now and in the future and covers such issues as housing, education, employment and leisure. During transition it ensures that people are treated as individuals and kept at the centre of the planning process (DH 2001; DH/ DCSF 2007). This also fits with the wider personalisation agenda and the drive to give people more choice and control in their lives. Roberson et al. (2005) in their review of the impact of person centred planning found that it had had positive benefits on the life experiences of people with learning disabilities, particularly in terms of community involvement, contact with friends and family and choice, benefits which came without significant additional service costs.

Many tools have been developed and published explaining how a person-centred approach might be integrated into transition planning and what a person-centred plan might contain.⁴ One suggestion is that as part of the person-centred-planning process one page profiles could be developed within the classroom or as part of a person-

4 For example *The Transition Guide for all Services* names Circles of Support, PATH (Planning Alternative Tomorrows with Hope), Essential Lifestyle Planning, Personal Futures Planning, and Personal Portfolios (DH/DCSF 2007).

centred review within the annual review process for young people with SEN statements summarising:

- What do people like and admire about the person
- What is important to the person now and in the future
- What is the best way to support them (DH 2010a).

Themes that might be covered within a larger person-centred plan might be:

- What is important to you and what is important for you?
- What is important in the future
- What is important about work
- What is working/not working
- Who does the person like and admire
- Relationship circle
- Communication charts (DH 2010a).

It is good practice for young people with SEN statements to be invited, where possible, to attend at least part of their school transition reviews. Not all young people, however, may choose to or are able to attend. It was reported in the 2010 Self Assessment for Transition in Westminster that between 80-90% of young people at Queen Elizabeth II Jubilee and College Park schools (our local special schools) attended their year 9 transition reviews. It is important that the views of young people are captured in some way. Efforts are made by Westminster Connexions to ensure that discussions with young people at the two local special schools are held in advance of the review meeting as to what to expect in the meeting, and so that their views can be incorporated in the review in the most appropriate way. A joint piece of work has also taken place in the two schools with the Westminster Learning Disabilities Partnership day service staff, who have provided multi-media support to help ensure transition reviews are more inclusive (WCC 2010b).

Person-centred approaches to transition planning are in the process of being developed at Queen Elizabeth II Jubilee School. During the last academic year work has taken place to embed person-centred planning within the school. Each pupil in the school has a page on their classroom wall where they can add information around what is important to them, what they like doing, what they want to do in the future etc. Teachers also contribute information and the sheets are used for planning for the children. A summary of the person profile is brought to the annual review. A more detailed person-centred planning process was piloted in the last year with the school leavers. This is now being rolled out to all 14-19 year olds. The person-centred plan is currently used for planning within the school context but is designed to be shared more widely at 19 when the young person moves onto other services. As this document is currently more of an internal school document it is not clear whether it fulfils the criteria of a person-centred review plan outlined in *Valuing People Now* for people with learning disabilities.

Person-centred support is also given more widely by the Transition Social Worker and Specialist Connexions Personal Advisors. It is likely that the level of person-centred-planning experienced by young people in transition varies, depending on which school they attend. The level of person-centred-planning which takes place within many of the other schools (mainstream and special schools, in and out of borough)

which are attended by Westminster young people with disabilities is less clear. There remains a need for clarity around the definition of person centred processes across different agencies (WCC 2010b).

3.1 Education and training

Young people with disabilities have the same choices and concerns about their future as other young people when they reach the end of statutory education, for example whether to continue in education, look for employment or alternative pursuits. The schools young people attend and other support services such as Connexions in Locality Young People's Services have an important role at transition to support young people to gain qualifications and skills for the future and to communicate and realise their aspirations.

Young people with learning disabilities consulted as part of the *Independent Living Review* identified a range of outcomes they wanted to achieve through studying, including:

- gain qualifications and be employable;
- gain independence, advocacy and self-assertiveness;
- develop an understanding of computers and IT;
- develop practical work skills;
- learn basic and daily living skills; and
- learn about themselves and relationships (Prime Minister's Strategy Unit 2005).

A key government priority is to reduce the proportion of young people not in education, employment or training (NEET), including those with disabilities. Disabled young people are considerably more likely than non-disabled people to be NEET, particularly from age 19 when many will first transfer out of special school. The *Independent Living Strategy* (Office for Disability Issues 2008) shows that 16 to 17 year old young disabled people are twice as likely, and 18 to 19 year old disabled people three times as likely, as non-disabled people of the same age, to be NEET. By the age of 26, young disabled people are nearly four times as likely to be unemployed or economically inactive as young non-disabled people.

In 2007 the Government released *Progression through Partnership* (DfES 2007), a cross-department strategy for post-16 with learning difficulties/disabilities. This focussed on the need for the Departments for Education and Skills, Health and Work and Pensions to work closely together in helping young people and adults achieve the education they want and need to be able to live fulfilling lives in their local communities and particularly enter the world of work. As part of this they outlined the importance of person centred planning and Individual Learning Pathways for all learners with learning difficulties and/or disabilities to ensure that individual needs and aspirations are central to any and all learning objectives.

The strategy identified several barriers to learning, including:

- low expectations/ aspirations and assumptions about people's (lack of) potential for learning and working; this includes parental views on where and how young people should be educated;

- inadequate and inappropriate provision – particularly for those with more severe or complex needs: often this provision is discrete, segregated and focuses on stereotypical ‘life skills’ or ‘work preparation’ which does not meet the interests or desires of the individual;
- poor transition planning: with schools not considering the whole life needs of the individual young person beyond 16/18; colleges not receiving information given on statements of special education need or other documentation about the existing levels of skills and knowledge, and conversely where this may be received is not implemented adequately;
- lack of real work experience opportunities or real-life situations of learning (proven to be most effective for people with learning difficulties and/or disabilities);
- lack of person-centred approaches at transition to further education and beyond;
- lack of co-ordination or shared responsibility between different agencies involved in decisions around funding placements;
- stigma and discrimination (DfES 2007; Ofsted 2007).

This section will consider education in the context of transition, and how young people with disabilities are supported with opportunities for further education and training in Westminster. Employment is discussed in more detail in section 3.2.

3.1.1 Education opportunities post-16

Statutory school age finishes at the end of the school year in which a pupil turns 16 (year 11), although pupils may stay in mainstream school sixth forms until the age of 18. Young people with a statement of special educational need may choose to stay at school the end of the school year in which they turn 19.

A proportion of young people with disabilities aged 16 and over will remain in special or mainstream education and, if relevant, their statement of special educational need will continue. Others may move to a further education college or specialist, residential placement, for which they may be funded through the Young People’s Learning Agency (YPLA). Some may decide to leave education all together or take up alternative training or employment. Depending on the individual’s level of need and aspiration, some may choose to go on to higher education and look for a university place.

3.1.2 Role of Connexions

Connexions (part of Locality Young People’s Services) offer a universal guidance and support service for all young people aged 13-19 years in education. As will be discussed in section 6.2.4 the service also discharges some of the duties placed on Local Authorities for children with statements of special educational need around transition, including completing a S139a assessment detailing post-16 education in the year they leave school (from year 11 upwards). They also offer a targeted service to identified young people with learning difficulties or disability (LDD) up to the age of 25. This encompasses a broader group than those who, as adults, would meet the criteria of the Westminster Learning Disabilities Partnership and those with a statement of special educational need. For instance it includes people with mental

health difficulties, autistic spectrum disorders, dyslexia, attention deficit, hyperactive disorder (ADHD), physical, sensory and cognitive impairments and other learning difficulties. It should be noted, however, that service provision locally is being reviewed in light of changes in legislation and funding reductions.

The support Westminster Connexions provides to young people with disabilities is determined by their age, level of need and where they are educated. Where a young person has complex LDD needs and attends a special school, they currently receive targeted support from a personal advisor (PA) including transition support at key stages. There are specialist services who offer support to young people, once employment is secured; these include Remploy and Job Centre Plus (WCC 2010b). Where Westminster residents are educated out of borough the expectation is that the “host” Connexions service leads on transition information, advice and guidance. Due to recent changes to national Connexions funding this support is variable.

3.1.3 Local provision for young people with disabilities post-16: special schools

Westminster has two maintained special schools, College Park and Queen Elizabeth II Jubilee School. These schools provide education, therapy and care for children and young people with complex learning difficulties and autistic spectrum disorders. College Park School specialises in helping children with complex learning difficulties and autistic spectrum disorder whilst Queen Elizabeth II Jubilee School specialises in working with children who have very significant or profound learning difficulties. Both schools are day schools. College Park has recently expanded its intake to 16-19 year olds. Both schools now take pupils from the age of 5 to 19.⁵

Speech and language therapists, physiotherapists, occupational therapists and educational psychologists all contribute to the work in the schools. There is a school nurse who works across both schools.

Schools have a key role in young people’s transition and in their preparations for adulthood and for independence. At Queen Elizabeth II, for example, they offer the core curriculum plus ASDAN Towards Independence and Transitional Challenge at Key Stage Four and post-16. They help promote independence for their pupils through travel training, work experience and developing shopping skills (Ofsted 2008; <http://www.qe2cp.westminster.sch.uk/> [accessed November 2010]).

3.1.4 Local provision for young people with disabilities post-16: further education

Westminster has two local colleges, the City of Westminster College, and Westminster Kingsway College, which cater for learners up to 19 and into adulthood. City of Westminster Colleges has range of courses on offer for young people and adults with learning difficulties and/or disabilities, including ‘learning for living’ ‘learning for work’ and ‘skills for working life’.⁶

5 For more information refer to: <http://www.qe2cp.westminster.sch.uk/> [accessed December 2010]

6 For more information refer to http://www.cwc.ac.uk/pages/courses/level_2.asp?AreaID=59 [accessed December 2010]

3.1.5 Other educational provision for young people with disabilities post-16

Ideally all young people with disabilities would be able to be educated locally. This would enable them to participate in the local community and help facilitate the transfer to Adults Services at 18 or when they leave school. However, due to the individual specialist needs of this population, and available local provision, this is not always possible.

Although over half of young people with disabilities and statements of special education need (SEN) in special schools are educated in the two local special schools, the remainder are educated in a range of different schools both inside and outside London, including some in mainstream provision. Similarly some Westminster pupils with disabilities attend further education colleges in other boroughs. The profile of children with SEN is discussed in more detail in section 6.3.

The majority of young people with disabilities and SEN statements attend day schools; a small minority are in residential placements. At the age of 16 the SEN team work to try to bring young people in residential placements situated outside of Westminster into borough provision to facilitate their transition to Adults' Services.

In addition to the young people with SEN statements, a few Westminster young people with disabilities are also in specialist residential placements outside the borough funded by the Young People's Learning Agency (YPLA). Applications are made through the Local Authority and have to demonstrate that there is no suitable local alternative for the young person. These are another group for whom it is important that their transition and return to Westminster is carefully planned.

Connexions also helps support young people into a wider spectrum of training placements, some of them work based.

3.1.6 Numbers of young people with disabilities in education & training post-16

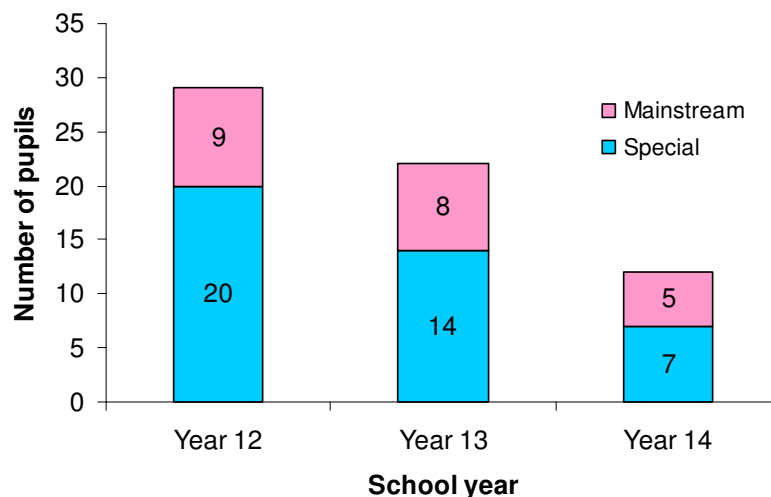
Precise numbers of young people with disabilities continuing in education and training past the age of 16 are difficult to ascertain. One data source is the information on young people with statements of SEN detailed in section 6.3. Another is information on YPLA funded college placements or specialist placements. A third source of information comes from data collected by Connexions. It should be noted however that the definitions of learning disability considered by these different departments/services mean that the data sets are not completely comparable. Furthermore the SEN department covers people whose home residence is Westminster but they may be schooled out of borough. The Connexions data covers young people educated in Westminster (who may be resident elsewhere) and can also include young people educated out of borough who are known to the service, as well as Westminster residents not in education, employment or training (NEET).

3.1.7 Young people with SEN statements post 16

Section 6.3 provides an overview of all young people with statements of SEN and a more detailed breakdown of those with disabilities educated in special schools. Figure 2 shows the numbers of pupils in special and mainstream schools with SEN

statements in years 12-14⁷ (post-16). There is a steady decline in numbers in education in each of these years. The majority of those in special schools in years 12-14 have a disability of the level which may meet adult services criteria or will need testing for eligibility. Of those, around half are educated within borough (at either College Park or Queen Elizabeth II Jubilee) and half out of borough. Fewer than five are in residential placements outside of London.

Figure 2: Westminster pupils with SEN statements in years 12-14



Source: SEN department, Westminster City Council, November 2010

3.1.8 Young people in YPLA funded specialist placements

There are currently six Westminster pupils in specialist (educational) placements of 38 week length aged between 17-22 years, funded through the Young People's Learning Agency (YPLA) (WCC, November 2010). The majority of the placements are outside London. Funding from the YPLA is available for a maximum of 3 years, from the age of 16 upward to 25 (usually from 19+). Almost all of the pupils have been assessed by, and are eligible for support from, the Westminster Learning Disabilities Partnership. A few are already in touch with the service.

3.1.9 Connexions information on destinations of young people aged 16 to 18 - employment, education and training

Connexions conducts an annual activity survey in September/October of year 11 school leavers to find out what they are doing in the new academic year. The idea is to identify young people who are not in education, employment or training (NEET). The survey covers those educated in secondary schools in Westminster irrespective of their borough of residence. Where a young person is identified as having a learning disability and is NEET the expectation would be that they are allocated a Personal Adviser. However, it should be noted that the NEET strategy is being reviewed in light of service reductions.

⁷ There are no pupils in these year groups in alternative provision; an explanation of 'alternative provision' is given in Section 6.3.

The information on current destination is collected for all 16-18 year olds and it is also recorded for the cohort with learning difficulties/disability (LDD), who receive more targeted support from the service. Figure 3 shows a comparison between the current destinations of the 16-18 year old population as a whole and for individuals who have a target group of 'LDD' recorded on the Connexions database from August 2010. As indicated earlier, this group includes a wider group than those with learning disabilities who would qualify for the Westminster Learning Disabilities Partnership (WLDP) as adults.

The data for the overall 16-18 year old population forms part of data returns for the Local Area Agreement indicator on local NEETs. The figures for NEETs and EETs (those in education, employment or training) are weighted slightly to take account of the proportion of unknowns likely to be NEET or EET (based on averages). The data from the LDD population does not form part of this same official data return so there may be some discrepancies in how young people are divided between the different categories. These figures are also unadjusted.

The data from August 2010 shows that there were 184 individuals in Westminster who were recorded as NEET. Of those who were NEET, 37 had an LDD (around 20%). Although the two profiles cannot be directly compared there are indications that a higher proportion of the LDD population are NEET, and slightly fewer are in education, employment or training. Fewer of this group have unknown destinations. 28 of the LDD NEETs were recorded as unemployed; the other 9 were NEET for other reasons.

Figure 3: Comparison of proportion of young people who are EET and NEET within the whole 16-18 population and the LDD population of the same age (August 2010)

Destination	All 16-18 year olds		16-18 year olds classified as LDD*	
	Number	%	Number	%
NEET	184	6%	37	10%
Unknown	245	8%	12	3%
Learning**	2745	86%	309	84%
EET (unadjusted)	2779	87%	314	86%
Cohort (16-18)	3192		366	

Source: Locality Young People's Service, Westminster, September 2010

* the definition of LDD is relatively loose as indicated in section 3.1.2.

** Learning here includes people in education or training; but excluded individuals in employment or in employment and undertaking work-based training.

Note this information for the 16-18 year olds was last updated on 17 August 2010. The proportion of young people in the different categories of EET or NEET or unknown fluctuate slightly throughout the year.

3.2 Employment

The benefits of work are widely recognised including giving people independence, choice, confidence, financial stability and a role in the community as well as improving mental wellbeing and access to wider social networks (DH/DCSF 2007; Mencap 2002). The same is true for people with disabilities.

The number of people with disabilities in employment is, however, consistently lower than the general population. Furthermore, work is often part-time and for low pay. For instance, the Labour Force Survey, between October and December 2007 found that only half of disabled people of working age were in work compared with 80% of non-disabled people. It also found that 24% of disabled people have no qualifications compared to 9% of non-disabled people (NHSW/WCC 2009b).

3.2.1 The national picture

Increasing the number of disabled people in employment has been identified as a priority within national policy documents. For instance, *Valuing employment now* (DH 2009b) set out a vision of radically increasing the number of people with moderate and severe learning disabilities in employment by 2025, closing the gap between the employment rate of people with learning disabilities and that of disabled people generally (around 48%). The aim is for as many people with learning disabilities as possible to be able to work at least 16 hours a week, the point at which most will be financially better off and achieve greater inclusion. In order to achieve this aim there is an acknowledgement of the need to increase the aspiration of people with learning disabilities to undertake paid work.

There have also been commitments to increasing employment for people with physical disabilities, such as government initiatives on Welfare to Work for Disabled People and the appointment of Disability Equality Advisers in local Job Centre Plus offices. A national strategy on Health, Work and Well-being was produced in 2005, followed by a Green Paper and the 2007 Welfare Reform Act, with an objective to move one million people from incapacity-based benefits into work over ten years (NHSW, WCC 2009)b.

Increasing the number of disabled people in work is also a local priority. Westminster's learning disability strategy, *The Big Plan*, had a target for 18% of people with a learning disability (of working age) to have been in paid work during the year by 2010. This target has, however, been revised due to the changes in the economy. In Westminster in 2007/8 this figure was 11% (NHSW, WCC, WLDP 2009).

A number of barriers to employment for people with learning disabilities have been identified. These include:

Structural

- The inflexibility of the benefit system
- The lack of funding to support employment
- Lack of preparation for work
- Inadequate transition planning

- Job Centres and Connexions not having the expertise to work with people with learning disabilities.
- Attitude of employers
- Reluctance of carers
- Availability of information.

Individual factors for people with learning disabilities

- Poor communication
- Lack of concentration
- Lack of social skills
- Lack of independence skills
- Confidence
- Lack of expectation (quoted in NHSW, WCC, WLDP 2009).

Similar barriers were expressed during the local consultation for Westminster's learning disability strategy, *The Big Plan*. There was recognition across the consultation that people with learning disabilities would like to work in paid jobs but that they faced significant barriers, including their own and others' expectations, the concerns and attitudes of employers, and the impact of work on eligibility for benefits. To overcome these barriers, there needed to be higher expectations among everyone, especially in schools and at transition and work aspirations needed to be included in the person centred plans (NHSW, WCC, WLDP 2009).

There are some similarities in the barriers to employment across the care groups including experience of discrimination and lack of specialist employment support provision. In many ways, however the needs for people with physical and learning disabilities and those with mental health problems are different and there are differences in the support services required to help them. The barriers faced by people with disabilities and the challenges for services in increasing the number of people in regular paid jobs across all care groups are particularly acute within the current economic climate.

3.2.2 Planning for employment at transition

There has been recognition nationally over the past few years that more needs to be done at an earlier age to help support young people with disabilities into work. This includes recognising that employment is a realistic option, as well as ensuring that young people have the skills they need in order to find employment (Prime Minister's Strategy Unit 2005). Although these values continue, the current position of the labour market means that it is challenging for school leavers of any ability to find employment.

Evidence of best practice and what works in terms of enabling the transition to work has highlighted the following key themes:

- Raising aspirations and expectations of young people and families that young people with disabilities can and do work; and identifying employment goals early on;

- Schools and families encouraging young people to develop skills in areas such as good time management, team working, completing/finishing work and/or problem solving, and recording what they can do in these areas;
- Discussing young people's aspirations for the future, what they enjoy doing, what their strengths and skills are, what would be a good work experience and who will support them doing that work experience at transition review meetings from Year 9;
- Developing training packages to support the individual;
- Providing flexible and supported work experience placements, with on-going support for the individual and employer;
- Professionals working with young people understanding the employment options open to young people and can signpost them to the information, guidance and support they require;
- Working with employers to increase disability confidence of staff has a significant impact on retention (Prime Minister's Strategy Unit 2005; DH 2009b; DH/ DCSF 2007; DH 2010a).

Research has indicated that the combination of well-structured work awareness training provided through schools and/or colleges, and supported work experience provided through external employment agencies in the last year of school, has an impact on the likelihood of a young person's gaining employment. They advise that the most important aspect of this for a young person with a learning disability is to plan for them to take part in work experience in year 10 (DH 2010a).

3.2.3 Work experience at school

Enabling young people with disabilities to take part in work experience placements whilst at school, in the same way as is routine for young people without disabilities, has been emphasised nationally and locally as a key area for development. It is also something which is valued by parents and young people with disabilities: one third of parents responding to a published survey in 2003 about the transition process for their children said that work experience or link placements was the most positive aspect and young people themselves reported on the positive aspect of this experience (Heslop et al. 2003).

Work has taken place in Westminster's local special schools to improve the work experience offer for pupils in years 11 and 14. For instance at the age of 14, pupils at Queen Elizabeth II Jubilee School are offered internal work experience within the school and at 18, in the last year of school, they are offered community placements.

Connexions Personal Advisors (PAs) working in special schools have implemented work experience projects with pupils with complex needs and those working in mainstream local schools have also supported young people with learning needs to access their school's work experience programme in year 10. The Connexions PAs work closely with organisations such as Remploy and Westminster Employment Service to support young people into employment. The experience of PAs has been, however, that local work experience programmes are in general less accessible to those with learning needs (WCC 2010b).

Connexions ran a 'Work Based Learning Project' funded by the Learning and Skills Council until April 2010. It was accessed by 40 young people in Westminster with learning difficulties and disabilities aged 14 to 25. This offered tailor-made courses to provide young people with a taster experience into their chosen area of learning, to facilitate entry into employment. Areas of learning included catering, horticulture, multi-media and business administration.

Despite the progress that has been made in recent years, this remains an area for development. One gap identified, for instance, in last year's Westminster Transition Support Programme Self-Assessment is for the small number of young people who may receive tuition or who are educated at home (WCC 2010a).

Westminster has recently received some funding from the Transition Support Programme to increase work experience provision locally. It is currently being decided how this money will be spent. This work is intended to use the expertise of Westminster Employment, the local supported employment agency and other agencies such as Connexions to build on and expand the work experience currently arranged through the local special schools (College Park and Queen Elizabeth II Jubilee). It aims to raise expectations of young people with learning disabilities and their families that they can and will work; help prepare young people with learning disabilities for work and providing them with experience of what it is like to work, increase young people's independence, confidence and work awareness and help their transition from school. By helping to increase young people's expectations and understanding of work at a younger age it is also hoped that interaction with employment support services as adults might be much more effective as these services will be able to focus on job searching and interview practice rather than education of what work involves and the clients ability to engage in it.

It should be noted, however, that although there is some provision locally for those pupils in special schools and through Connexions to experience work whilst at school, it is not clear what opportunities are available to young people with disabilities educated outside the borough.

3.2.4 Nationally provided employment services

There are a number of national mainstream programmes and initiatives aimed at helping workless people into employment. However, reports such as *Improving the life chances for disabled people* (Prime Minister's Support Unit 2005) have shown that existing programmes do not provide adequate provision for supporting young people with disabilities into work. For example, programmes aimed at helping young people enter the labour market, including new Apprenticeships and the New Deal for Young People, make little provision for disabled young people's additional needs. Other employment initiatives, like Pathways to Work, Access to Work, and the New Deal for Disabled People, focus more on return to work and retention than on entering the labour market for the first time (WCC 2010d).

The new coalition government has plans to simplify the array of employment programmes currently on offer under proposals for a "Work Programme". This will replace all existing employment related support with a single welfare to work service for all workless people and deliver "coherent, integrated support more capable of

dealing with complex and overlapping barriers to work”⁸. It is not clear how the proposals will help those with complex needs who are unable to work at least 30 hours per week. An additional programme called ‘Work Choice’ is also being developed for people with complex needs. Although this is a positive development it is not clear that the capacity within the proposed services will meet the need for the number of disabled people of working age in the borough (WCC 2010d).

3.2.5 Local employment services

There are a number of employment support services provided in Westminster for those with the greatest barriers to employment, including long term unemployment and disability. One of the overarching initiatives is ‘Westminster Works for employment’, an integrated employment support service which provides support for the long term unemployed through a network of 11 neighbourhood based advisers (across 7 different organisations) each working with a case load of between 70-80 job-seekers. The partnership is managed by Paddington Development Trust (PDT). Advisers provide a single point of contact for job-seekers helping them to access a range of services such as childcare, training, benefits advice, volunteering opportunities and work experience. PDT report that 205 of 2010 referrals (approximately 10%) indicate that they have a physical disability; while 22% say that they have health barriers to employment (WCC 2010d).

Adult Services’ teams also separately commission 3 distinct specialist employment support services for people with disabilities: Training for Life (for people with physical disabilities); Routes to Employment (for people with mental health problems); and Westminster Employment which is principally for people with learning disabilities. It is likely this provision will be reviewed in 2011/12.

3.2.5.1 Training for Life

Training for Life, hosted by the Centre for Independent Living, is a registered charity providing employment support for people with physical disabilities and those who are deaf or hard of hearing, or who are registered as disabled by Westminster City Council. It offers a supported employment service, including job coaching, support with job applications, CV development, help with finding jobs, links with employers, post employment support, access to education and training and help finding volunteering placements. It runs 4 "Prospect Centres" where previously long-term unemployed apprentices are trained to move from unemployment to full-time education or employment. It also runs two restaurant-based social enterprises. 100% of their profits are re-invested into training apprentices.

Data for 2009/10 shows that 50 people attended the service, with 7 people being supported into fulltime or part time jobs and a number of others into voluntary work or higher and further education. It is not known what proportion of clients were aged 18-25 (WCC 2010d).

⁸ <http://www.dwp.gov.uk/docs/framework-eoi.pdf>

3.2.5.2 Routes to Employment Project

The Routes to Employment Project is provided from within Community Mental Health Trusts (CMHT) for people who are accessing secondary mental health services. The service follows the IPS model of supported employment, which is evidence based and recommended for example by the Commissioning Guidelines for Vocational Services (DH, DWP 2006) and Realising Ambitions (DWP 2009), as the most effective model for assisting mental health service users to return to paid work. It is open to mental health clients who are under the care of a CMHT or equivalent who have an identified Care Programme Approach (CPA) coordinator⁹.

Data for 2009/10 shows that 70 people had an initial assessment. 15 were supported into full time or part time jobs and 19 into unpaid work placements. 31 individuals were supported to retain a job. It is not known what proportion of clients were aged 18-25 (WCC 2010d).

In addition to this service, for service users in touch with the Early Intervention in Psychosis Service (discussed in section 9.1) there is a dedicated Employment Specialist to provide employment support.

3.2.5.3 Westminster Employment

Westminster Employment is a specialist employment support service within the Learning Disability Partnership (WLDP) in Westminster City Council's Adults Services Department. The service's main client group are adults with learning disabilities and autistic spectrum conditions known to the WLDP. Since 2008-9 the service has had an additional contract from Westminster Works to support other groups of people including people with learning disabilities not known to the WLDP, people with mental health problems, people with physical disabilities, people with substance misuse problems, young offenders (aged 18-24) and individuals on the New Deal.

Westminster Employment principally provides dedicated person-centred one-to-one advice, guidance and support in the following areas as required:

- 1 **Preparing for work** – Using the skills people already have and considering what other skills they may want or need to develop (for example through work experience or by finding a college course), as well as helping clients with their Curriculum Vitae (CV).
- 2 **Looking for work**- Searching for vacancies on a regular basis, offering support to complete and send off job application forms.
- 3 **Interviews** - Preparing clients for interviews as well as supporting them during interviews.
- 4 **Learning the job** - Job coaching, helping them to feel confident and become independent at work.
- 5 **Ongoing post-employment support** - Meeting with clients and employers to problem solve. Giving clients help and advice when they need it¹⁰.

⁹ CPA is explained in more detail in section 9.3.

¹⁰ More information is available at

Depending on the needs of individual clients, the service may work with individuals for a couple of years, including up to one year post-employment.

The service had 54 learning disability clients (of working age) on their active caseload in September 2010. Of those, 20 are currently in work and receiving post-employment support and 34 are seeking work; fewer than 20% are aged 18-24 years. Over the past 12 months around 130 new clients have been referred to the service, of whom 90 have attended. The majority of new referrals were aged over 25, with fewer than 20% being under 25 (provided by Westminster Employment, September 2010).

There is a national indicator which monitors the percentage of adults with learning disabilities of working age known to Councils with Social Services Responsibilities in paid employment at the time of their last assessment or review.¹¹ This supports the Government's aim to increase the number of learning disabled adults in paid jobs, especially jobs of 16 or more hours per week.

Data collected at the outturn for 2009 showed that in Westminster a total of 40 clients, out of 489 clients aged 18 to 64 known to the Council and reviewed (or due a review) during the year (8.2%) had had some form of paid employment including:

- 8 clients had work of more than 16+ hours per week
- 13 clients had work of between 0-16 hours per week
- 19 clients had had some form employment, less than weekly.

There were also ≤ 5 clients who had both paid and voluntary work during the year and 9 clients who had voluntary work only (data provided by WCC, October 2010).

Although these figures give an overall impression they do not show the numbers of people in continuous or regular employment; individuals employed only for one week or on a one-off job for a few hours are also included. Furthermore, the figures are not likely to capture all people with a learning disability locally in work because the figures are only taken from those who have been and still are in touch with Westminster Employment.

3.2.5.4 Pursuing Independent Paths (PIP) for young adults

Pursuing Independent Paths (PIP) is an education project for young adults with learning difficulties which aims to teach skills and raise awareness. It focuses on the provision of a structured programme to support service users through transition to adult life / service, including to employment. It is a voluntary organisation initially set up by parents, and funded by Westminster City Council. Support offered includes:

- Vocational and life skills training

<http://www.westminster.gov.uk/wldportal/jobsandlearning/jobs/we.cfm> [accessed December 2010]

¹¹ Paid work includes those working in paid or self-employed work for 30 or more hours per week / 16-30 hours per week / 4 and 16 hours per week / 0 and 4 hours per week/ or working regularly as a paid employee or self employed but less than weekly (e.g. fortnightly, monthly or on some other regular basis). The indicator also collects data on those in voluntary unpaid work, both working as a paid employee or self-employed and in unpaid voluntary work and those in unpaid voluntary work only. <http://www.esd.org.uk/Solutions4Inclusion/ProjectsByIndicators.aspx?NI=146&weekImpactOn>

- IT and Internet guidance
- Support and access to education and training at colleges of further education
- Support in travelling independently
- Support on work skills development and obtaining paid work
- Support on social & recreational development
- Work experience with a range of employers
- Individual life planning sessions with key workers
- Transition planning to assist service-users' progression from school to work/college
- One-to-one individual work.

Generally referral to the service is made through Westminster Social Services, although self-referral is possible¹².

3.3 Housing and accommodation

The opportunity to move away from home and live independently for most people forms a key part of growing up and becoming an adult. The *Independent Living Strategy* found, however, that young disabled people often have very limited opportunities for moving away from the parental home and these are more often determined by service availability and eligibility criteria, than by young people's choices about where to live and who to live with (Office for Disability Issues 2008).

Housing options form an important element within the government directive for increasing choice and control and independence for people with disabilities and complex health problems. As noted earlier, independent living does not necessarily mean living on ones own or doing everything for yourself. It is about having greater choice and control over the support needed for people to go about their daily lives, including access to appropriate housing (DH 2009a). National policy recognises that residential care for people with disabilities should continue to be available for those who choose it, but that more emphasis is needed on alternative ways of providing the housing that people want and the support they need to live in it (DH 2009a).

3.3.1 The local picture for adults with learning disabilities

People with a learning disability are less likely to live on their own or with friends or partners, and own their home than the general population. The Westminster JSNA on learning disabilities showed that nationally only about 15% of people with learning disabilities own their own home or live in accommodation with a secure long-term tenancy, compared to 70% of the general population. Over half of adults continue to live with their families into middle and older age, with the remainder living in residential care, or other kinds of placements or shared housing that they may not have chosen themselves. Issues may present themselves as people age, where families may not be able to continue to care for them (NHSW and WCC 2009a).

The vision for housing within *The Big Plan 2009-12*, Westminster's strategy for

¹² For more information refer to <http://www3.westminster.gov.uk/weldis/organisationdetails.cfm?contactid=10932> [accessed December 2010].

adults with learning disabilities, is that by 2012 'more people with learning disabilities in Westminster will live in rented accommodation with a secure tenancy. Fewer people will live outside Westminster and nobody will live in NHS accommodation. There is an accompanying target for the proportion of people living in settled accommodation to increase from 57% to 75% by 2012 and for the proportion of people living outside Westminster (due to lack of suitable housing within the borough itself) to have reduced from 26% to 15% (NHSW, WCC WLDP 2009). This follows the national drive to increase choice and control and ensure that people with learning disabilities have the opportunity to access the kind of housing in Westminster they want and need.

The learning disabilities JSNA showed that people with learning disabilities do not have the same opportunity as non-disabled people to develop independence in housing choices due to a number of factors – a shortage of affordable, accessible housing, the cost of some care packages and in some case the families' own expectations. Staff and carers consulted as part of the JSNA highlighted the need to ensure that any increase in independence was matched by appropriate levels of support so that people are supported to manage the running of their homes and be involved in their communities. It was recognised that as housing options and preferences change over time there is a need to evaluate and monitor the quality of life and satisfaction to ensure that changes are to the benefit of the service users (NHSW, WCC 2009a).

Consultation with people with learning disabilities and their carers carried out for Westminster's housing strategy for people with learning disabilities (2007) and *The Big Plan* (2009) showed that supported housing and residential care options are a high priority for people with a learning disability and their families and carers. People with learning disabilities and their carers expressed their anxieties around their future and how their needs will be met. In particular, older parents were concerned about the future support options for their children. It was felt that there is a need to promote a culture of independent living among families and organisations, ensure that housing was included in people's person-centred plans, consider private tenancies as an option (and not think solely in terms of social housing) and ensure that people were supported properly to live independently (WCC, WPCT, WLDP 2007; NHSW, WCC, WLDP 2009).

One of the three teams within the new Westminster Learning Disabilities Partnership (WLDP) structure has responsibility for supporting housing options for people with learning disabilities in the borough. Within the restructuring of the teams there has been a drive to increase the assessment and discussion of possible housing needs of young adults coming through transition. A register of the housing needs of people with a learning disability has been in operation since 2006 together with a housing panel to match these needs to available housing resources (WCC, WPCT, WLDP 2007).

3.3.2 The local picture for adults with physical disabilities

One of the overarching objectives within the local Physical Disabilities Strategy, *Our Say, Our Way, 2009-2012*, is to increase the number of disabled adults supported to live at home. Between 2003-04 and 2007-08 the number of disabled adults helped to

live at home increased from 386 to 609, an increase of 58%. During the same period the number of disabled adults admitted to residential and nursing home care declined steadily and has remained below the Inner London and national averages (NHSW, WCC 2009b).

Applicants for social housing who have mobility problems are prioritised for accommodation that is suitable for them (in that they can bid for accommodation which matches their mobility category). There is however a severe shortage of accommodation which is suitable for people who use wheelchairs or who are unable to manage stairs due to the difficulty in converting properties to allow wheelchair access and the fact that most flats are in blocks which have stairs (NHSW, WCC 2009b).

Community equipment such as a mobility aid or bath seat, or a minor adaptation such as a grab rail, can help people to function as independently as possible within their own homes. Over the last five years there has been an overall increase in the total number of equipment items delivered per year by the Westminster Community Equipment Service and a marked increase in the proportion of items delivered within seven days of assessment, over 95% in 2008-09, above the local target (NHSW, WCC 2009b).

A major adaptation such as a stair-lift or level access shower can also make a significant difference to a disabled person in terms of accessing facilities within their own home. In 2007-08 the occupational therapy contractor for Adults' Services, Dependability Ltd, completed 955 assessments and recommended 467 major adaptations. During this period the average time from assessment to start of works/grant approval was 14 weeks. This is well inside the 25 week target but still a long time from the service user's point of view (NHSW, WCC 2009b).

3.3.3 The local picture for adults with mental health problems

Two of the priorities within Westminster's Mental Health Strategy 2010-13 relate to housing, both to 'make sure that people have access to a full range of support and are helped to live independently' and to 'ensure that where possible we prevent homelessness and reduce rough sleeping for people who have a mental health problem and make sure that they receive services that meet their individual need' (WMHP 2010). There is a range of local services to support people as they move from hospital into the community and to support individuals to live and remain living independently.

Westminster has a strong focus on homelessness prevention for people with mental health problems, where officers act as mediators or negotiators to prevent people from being evicted from the family homes or from their tenancies. Through the local Joint Assessment Service there is a housing specialist based at each of the Community Mental Health Teams. Westminster has 372 units of supporting housing for adults with mental health problems, ranging from high support 24-hour schemes to semi-independent units with visiting support. Services are jointly commissioned by Housing, Adults Services and NHS Westminster through the Supporting People Commissioning Body. In addition Westminster has a floating support service provided for people living in their own independent accommodation who require

support to prevent the loss of tenancy, the majority as a result of mental ill health. Mental health services also receive an annual quota of independent housing units from the City Council for people with mental health problems living in supported housing who are able to live independently (WMHP 2010).

3.3.4 Planning for housing at transition

During transition young people are faced with many decisions about their future, which require careful planning. One of these is where they will live. At the time of transition some young people will be living at home and attending day school provision, either in Westminster or other local boroughs. A few attend residential schools on placements of either 38 or 52 week duration.

A number of housing options are available for young people in transition including support in the young person's own accommodation or with their family, shared ownership, council housing, private rental options and residential placements. These options will depend on many considerations including, the choice of the young person, the young person's support needs, the family's preference, the family's ability to support the young person on a full time basis at home on leaving school, whether the young person is looked after or not, as well as the availability of suitable properties to meet the young person's needs.

Housing has been identified as an area which is often neglected in transition planning (Heslop et al 2003). It is important that housing options and choices are discussed at transition to help families and services plan for the future. It should be acknowledged, however, that the needs and wishes of the young person and their family may change over time so it is important therefore that these choices are regularly reviewed.

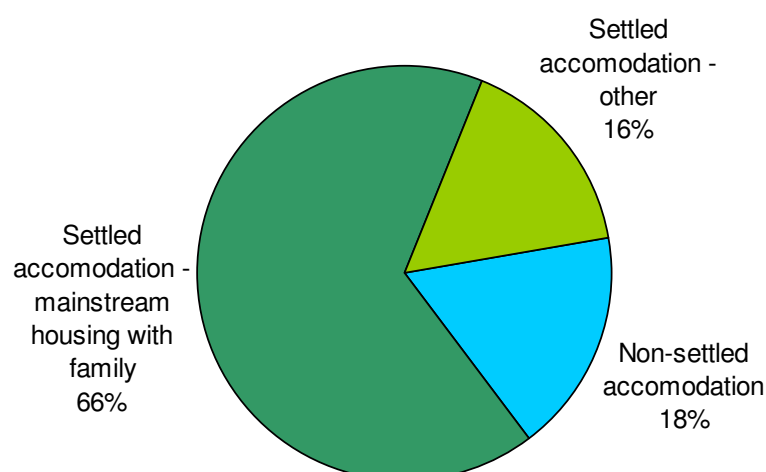
In Westminster, there has been a drive to ensure that housing needs of young people are discussed as part of routine transition planning. The Transitions Senior Practitioner from the Children With Disabilities Team attends the Westminster Learning Disabilities Partnership Housing Panel on a quarterly basis, when the housing needs of young people aged 16-19 are specifically reviewed. The Westminster Learning Disability Partnership has a specialist housing officer who is able to provide advice across the range of options. The service works with an underlying strategy of exploring and focusing on in-borough options in line with good practice and the service's Housing Plan. Two DVD's have recently been developed involving service users, to help explain housing options for new clients. Another DVD on how to bid for council housing is being developed. Information gathered from the quarterly Housing Panels is used to support the financial forecasting and service planning arrangements required for the Council and key partners (WCC 2010b).

At the time of publication of Westminster's housing strategy there were 41 young people with a learning disability who were predicted to transfer to adult services in 2007 – 2010. Of this number, 18 were identified as likely to require a 24 hours supported living model, 15 were likely to require very high level supported living models and eight were identified as having very complex needs. It was noted that there had been, on average, four young people per year who have required specialist residential provision. The service noted that there are increasing numbers of young

people who have both a learning disability and physical disabilities (WCC, WPCT WLDP 2007).

Data on future housing choices for the transition population was not specifically collected for the needs assessment. Data collected on new referrals to the WLDP over the last 5 years, aged between 18 and 25 years on referral, shows that of the 80 individuals currently open to the services and with a housing tenure recorded, 82% are in settled accommodation and 18% in non-settled accommodation (WCC October 2010). Here 'settled accommodation' refers to arrangements where the occupier has security of tenure/residence in their usual accommodation in the medium to long term, or is part of a household who holds such security of tenure/residence. Non-settled accommodation refers to arrangements which are precarious or where the person has no or low security of tenure/residence in their usual accommodation and may be required to leave at very short notice (Audit Commission 2010).¹³ This data shows the individuals' current tenancy rather than their tenancy at the time of their referral. The majority of those in settled accommodation were living with their family. Others were living in a range of tenure types including public and private tenancy and supported living accommodation. The majority of those in non-settled accommodation were in residential care provision.

Figure 4: Tenure type of new referrals to the Westminster Learning Disabilities Partnership, between 2005/6 and 2009/10, aged 18-25 at referral



Source: SWIFT, Westminster City Council, October 2010.

Note there were two cases open to the WLDP which had no recorded tenure.

¹³ Types of accommodation classed as 'settled' include: Owner occupier/shared ownership scheme; Local Authority/arms length management organisation/Registered Social Landlord/Housing Association tenancies; private landlord tenancies; settled mainstream housing with family/friends (including flat-sharing); supported accommodation/supported lodgings/supported group homes; adult placement schemes; approved premises for offenders released from prison or under probation supervision; sheltered housing. Non-settled accommodation types include: rough sleeper/squatting; night shelter/emergency hostel/direct access hostel; refuge; placed in temporary accommodation by local authority (including homelessness resettlement) – e.g. bed and breakfast; staying with family/friends as a short term guest; acute/long stay healthcare residential facility or hospital (e.g., NHS or Independent general hospitals/clinics, long stay hospitals, specialist rehabilitation/recovery hospitals); registered care or nursing home; prison/young offenders institution/detention centre; other temporary accommodation.

Although the data sets have different dates, the information on the recent 18-25 year old referrals can be loosely compared to data on the total learning disability population given in the learning disabilities JSNA to give an indication on patterns in types of accommodation. The learning disabilities JSNA indicated that in 2009 29% service users were living with their families, 38% in residential care and 24% in public sector tenancy (NHS, WCC 2009a). This indicates that a lower proportion of the 18-25 population appear to be living in residential care, and a greater number living with their family compared with the total population with learning disabilities, which matches what would be expected for this age group.

3.4 Leisure and social support

As young people grow up their leisure time is increasingly used in exploring their own interests and making new relationships, relying less on their families (DH/DCSF 2007). Young people consulted as part of the *Independent Living Review* (Prime Minister's Strategy Unit 2005) emphasised that maintaining friendships and having a leisure life were issues of primary importance to them. They acknowledged, however, that these were not always regarded as important by others involved in their transition planning.

Evidence shows that people with learning disabilities have often have very few relationships and have limited opportunities to form and sustain them. One of the reasons for this can be their exclusion from the places where other people form and maintain relationships, such as at work, college, leisure centres and clubs. Another can be because decisions regarding service delivery do not take account of existing relationships and break up friendship patterns. *Valuing People Now* acknowledges that it is important that services getting the balance right between protecting vulnerable people and helping them to have a life; risk taking should be a part of everyone's life, including those with more complex needs (DH 2009a).

For disabled young adolescents, access to youth clubs and other organised activities are often one of the few opportunities they have to meet up with their peers and make friends. This is particularly the case for disabled young people who attend special schools or out of authority placements away from their local community. It is important where possible that these opportunities and relationships are maintained as the young person moves into adulthood (DH/DCSF 2007).

In many areas youth services offer a range of activities for all young people. Research has shown, however that access and inclusion for disabled young people to activities is often dependent on a range of factors, which include:

- Transport to the service
- Accessible buildings
- Skills and knowledge of staff
- Letting staff know in advance of particular needs
- An environment in which young people feel safe (DH/DCSF 2007).

National evidence of best practices has shown that in some areas families and disabled young people have chosen to use Direct Payments to participate in activities with the help of a personal assistant. In other areas, time allocated for short breaks has

been used to access a range of formal and informal leisure activities. A number of local authorities now offer leisure passes to disabled young people and carers so that they can claim a range of discounts at local leisure centres (DH/DCSF 2007).

One of the five pathways produced as part of *The Getting a Life* project for transition is around friends, relationships and being involved in the community. Elements seen as good practice at transition include:

- Young people setting up a ‘circle of friends,’ including best friend and other people from neighbourhood or school and connecting this with their wider ‘circle of support’;
- Recording in the transition and support plan what is important for the young person about friends and having a social life;
- Discussing how to ensure that friendships are maintained after school ends and how best to stay in touch;
- For young people to take part in extended school/out of school activities;
- Using direct payments/individual budgets to support meeting friends;
- Being able to take part in the same things as other young people such as going out with friends;
- Considering whether the young person could learn to drive or travel on their own;
- Questioning whether the young person is going out often enough and whether they are part of the community;
- Considering how year 10 options at school help towards supporting the young person to achieve their future goals;
- Considering whether there are possibilities for peer mentoring.¹⁴

3.4.1 Local provision for children

A range of sports, leisure and social activities are available to young people with disabilities in Westminster through for example, mainstream and specialist youth provision, mainstream leisure services, extended schools, short breaks, holiday excursions, play schemes and provision provided by local voluntary organisations. There is also a new service ‘Asperger Support, Signposting and Information Services Team’ for young people aged 16 and over and adults with Asperger’s, which offers one to one and group social, leisure and other support.

A specialist youth service is run for 13-19 year olds with disabilities provided through the Rainbow centre (funded jointly by *Aiming High for Disabled Children*, the Children with Disabilities Team and Locality Young People’s Service). The service is principally a social service but there are some topic-based activities such as a youth council and education based learning.

Consultation conducted as part of the Aiming High for Disabled Children Short Breaks Transformation (Simon 2009) highlighted that a wider range and greater quantity of positive activities are required for young people. In response, work is ongoing to expand provision and gather feedback from young people about how they can best be supported in the future in respect of their leisure time.

¹⁴ The pathway can be downloaded at: http://www.gettingalife.org.uk/resources/friends_map.htm
[accessed December 2010]

3.4.2 Local provision for adults

Westminster City Council commissions day service provision for adults who have been assessed as eligible to receive services by the Westminster Learning Disabilities partnership (WLDP). Some young people receive bespoke packages of care based on their individual level of need. The focus of local day services has changed over the last few years from a buildings based service to one that facilitates activities in the community and one that helps people develop and learn new skills (NHSW, WCC, WLDP 2009).

Commissioned services for people with learning disabilities are currently located in both the north and south of the City. They provide a range of support to facilitate access to local colleges, sport, leisure and arts facilities in London and travel training. There are also specific activity groups organised, such as healthy living, computer and multi media work, men's and women's groups and creative arts. The work of the Flexible Response Service within the WLDP is aimed at supporting people with challenging needs to safely access community facilities.

Community integration and leisure support is also provided through *Pursuing Independent Paths*¹⁵ for people with learning disabilities. This can cover a very wide range of events and recreational and social activities from maintaining membership of the local football club and attending weekend games, to evening activities such as attending concerts and going to nightclubs. A leisure programme is run in holiday periods throughout the year. This involves supporting members to choose and take part in a wide range of social and recreational activities. Typical examples are outings to theme parks, London aquarium, canal boat trips, bike riding etc.

WAND (Westminster Action Network Disability) have developed a directory of all accessible sport and leisure facilities for disabled people, where clients can access services.

3.4.3 Local sports and fitness provision, children and adults

Individuals with a disability and their carers are entitled to a concession card for sports and leisure activities. This carries an entitlement for free swimming and up to 70% off other leisure activities at Council facilities. Many of the fitness facilities managed by Westminster City Council including Paddington Recreation Ground, Queen Mother Sports Centre, Moberly Sports & Education Centre and Little Venice Sports Centre are 'Inclusive Fitness Initiative' accredited facilities, meaning that they are accessible to, and inclusive of, disabled people. Specialist activities are provided for both children and adults with a wide range of disabilities across the borough, including pan-disability football for all ages, swimming lessons for people with physical and learning disabilities, swimming sessions for the visually impaired, exercise classes for Westminster day service users and body management classes for people with profound disabilities (WCC 2009b).

¹⁵ <http://www.piponline.org.uk/home.aspx> [accessed December 2010]

3.5 Travel

Being supported to travel independently is an important part of gaining independence in adulthood. Young people with learning and physical disabilities can face significant difficulties in accessing public transport and being able to travel independently. This may be due to limited wheelchair accessibility, lack of accessible signage and information for transport, not having someone to travel with, attitudes of staff and the fact that people may feel vulnerable to abuse (NHSW, WCC, WLDP 2009). Not all young people with disabilities will want to or be able to travel independently. Also not all parents may support this for their children. However, it is important that these needs and wishes are considered as part of transition planning and discussion of young people's choices for the future.

Individual support to promote independent travel is part of the transition process locally. There are several avenues by which young people may receive tailored travel-training to support them to travel independently on public transport. Westminster City Council has a 'home to school' travel arrangement policy for pupils with special educational and additional needs (SEN) up to the age of 18/19, detailing responsibilities and criteria for additional support provided, depending on individual circumstances. Travel training and escorts on public transport may be provided, depending on an assessment of individual travel needs.

Travel training is undertaken in various forms with pupils at Queen Elizabeth II Jubilee School, one of the boroughs two special schools. All students from years 12 to 14 have travel training on their timetables, accredited using the ASDAN Towards Independence Units, 'Getting Ready To Go Out' and 'Getting Out and About'. For the most recent cohort this has focussed on keeping safe whilst out, and time and money management. In addition there is local travel training available which is specially commissioned to support young people for their travel to youth clubs and to support college attendance (WCC 2010a). The Westminster Learning Disabilities Partnership also funds some travel training for service users through *Pursuing Independent Paths*.¹⁶

The local physical disabilities strategy *Our Say, Our Way, 2009-2012* (NHSW, WCC 2009) noted that accessible transport remains a major concern for disabled adults and people with sensory needs. In Westminster physically disabled adults may be eligible for a number of travel concessions including a freedom pass, taxicard, Dial-a-Ride, and Disabled White Parking Badge. There is a London-wide programme to improve access to public transport for disabled people. Since December 2005 all London buses have been wheelchair accessible and there are currently 62 Tube stations with step free access (<http://www.tfl.gov.uk/corporate/projectsandschemes/5792.aspx>).

Some transport is provided for adults with learning disabilities who require support to attend local day services. Adults with learning disabilities are also eligible for a freedom pass and taxicard from Westminster City Council which allows for a limited number of journeys in black cabs at subsidised fares.

¹⁶ <http://www.piponline.org.uk/SS.aspx>

3.6 Financial support and personalisation

The Government's 'personalisation' agenda introduced in *Our Health, Our Care, Our Say* (DH 2006) centres on giving people more choice and control in the health and social care services they receive. The agenda supports values to promote the independence of people with disabilities and give them more of a say in how their care is financed and delivered, and what it is composed of. It also links with the drive, particularly within learning disability services, to promote person-centred approaches to planning and service delivery, both for young people going through transition to Adult Services and wider groups (DH 2009a).

The aim is that personalisation offers flexibility and choice to people with disabilities allowing them to choose services that best meet their needs. This may mean:

- greater choice and control
- the option to pick and choose services that best suit personal needs and appropriate times
- better working links between service users and providers and subsequently the development of services that better meet the needs of a population
- increased user involvement in the development and delivery of services may again lead to the development of services better tailored for the needs of the population
- increased accountability of organisations to individuals and communities.

A key component of this agenda has been the introduction of direct payments and personal budgets, which are discussed in this section.

3.6.1 Direct payments

Direct payments are cash in lieu of social services provision. They provide service users and carers with the flexibility to purchase services that are tailored around the need of both the service user and their carer if appropriate. They can also help maintain the consistency of service provision. As with commissioned care services, direct payments are means-tested, assuming that where possible people will contribute to the cost of their care (Samuel 2009).

Direct payments can be made to people with parental responsibility for disabled children, disabled people themselves aged 16 or over, and to carers aged 16 or over in respect of carer services (DH/DCSF 2008a).

Direct payments are available for eligible social service users across Learning Disabilities, Physical Disabilities and Mental Health Services.

3.6.2 Personal budgets

Like direct payments, personal budgets are a method of delivering self-directed support. A personal budget refers to the amount of social care money that an eligible person has to fund their care and support, calculated on the basis of an assessment of their needs. The eligible recipient can have control over the budget in a number of ways:

- as a direct payment, a cash payment held directly by the person or where they lack capacity, by a “suitable person”;
- as an ‘account’ held and managed by the council in accordance with the person’s wishes (that is to pay for community care services commissioned by the Council, or as an account placed with a third party (provider) and ‘called-off’ by the user in direct negotiation with the provider);
- as a combination of the above.

Examples of ways that a personal budget might be used include:

- Employing a personal assistant instead of a having a carer provided by the Council
- Using a care agency of the individual’s choice
- Helping the individual become involved with leisure or community activities
- Pay for training or job support (WCC 2010g).

Personal budgets for service users are now being fully rolled out in Westminster. It is a priority locally (as well as nationally) to increase the number of social care clients receiving self directed support such as direct payments and personal budgets.

Currently personal budgets are not offered to the families of young disabled people. This was recommended for future consideration in *Improving Life Chances for Disabled People* and pilots are currently exploring their use in a few local authority areas (Prime Minister’s Strategy Unit 2005; DH/DCSF 2007).

Consultation with parents conducted nationally as part of *Aiming High for Disabled Children* indicates that there has been a mixed response to direct payments. Some parents described direct payments as having positively “transformed their lives”. One survey found that parents appreciated the flexibility, freedom, choice and control that direct payments offered; that they could make sure that their child was happy with their carers if they chose them themselves. However other service users felt that the additional responsibility of managing a budget for services was too much of a burden, particularly given their existing care responsibilities and found that there could be difficulties in finding suitable people to employ. The review commented that some young people have benefited from receiving direct payments, choosing who provides them with assistance and what activities they engage in (DH/DCSF 2008a).

3.6.3 Financial support planning during transition

Developments around personalisation through personal budgets and direct payments have filtered into proposals to improve planning for young people and their families at transition. Young people with disabilities may choose to receive direct payments that previously went to their families in their own right from the age of 16 or 17. Once they are 18 they may be eligible for a personal budget. Guidance around transition planning encourages the discussion of future funding and personalised funding being brought into the statutory transition review process and throughout the transition planning. This links in with person-centred approaches to wider care support (DH 2010a). The principle is that in the future young people on personal budgets should remain on personal budgets as they move from Children’s to Adults Services.

3.6.4 Local picture: Children's Services

Families with children with disabilities are not currently able to receive personal budgets in Westminster, although direct payments are routinely offered. There is, however, a government pilot around introducing person-centred individual budgets due to end in March 2011. Information from these pilots will be used to inform future systems in the borough (WCC 2010b).

Eligibility for direct payments is identified through an assessment from Children's Services. If an assessment identifies needs for the young person or carers in families, which could be met by direct service provision, the family and young person must be offered the choice of direct payments as an alternative. The exception is where the Children with Disabilities Team have a genuine concern regarding safeguarding. Families can choose to have all of their identified needs met through direct payments, some, or none of them.

As at December 2010 there were 29 children on direct payments aged between 11 and 17, including 17 between the age of 14 and 17 (WCC 2010b).

The money that families receive varies according to their individual needs. The majority of direct payments are spent on carer support. Many are for regular service provision, in and/or out of term-time, depending on education provision, although sometimes direct payments are used for one-off payments. Other examples of how direct payments are spent include for example paying a support worker from a similar cultural background and who speaks a similar language or creating a bespoke community based support package to facilitate engagement in mainstream cultural activities for individuals who find it difficult to participate in more universally-provided day services (WCC 2010b).

During transition, case workers from the Children with Disabilities Team and receiving Adults Care Teams support eligible individuals and their families (identified by the Westminster Young Person's Transition (YPT) Operational Group (refer to section 5.2.3 for more detail) to fill in a self assessment questionnaire identifying their needs. This information is used to inform the Resource Allocation System score (RAS) which determines how much social care money will be allocated for the young person's care package through a personal budget. A support plan is then developed with the young person and their family to be in place for when the young person reaches adulthood and leaves school (WCC 2010b; WCC 2010h).

All young people moving into to Adults Services are offered a Supported Self Assessment (16/17 and 18 year olds) with view to receiving a personal budget if appropriate when they enter Adults Services. The exception is those individuals on Continuing Healthcare funding (WCC 2010b), although this may change with the personal health budgets pilots.

3.6.5 Adults: direct payments & personal budgets

Figure 5 below indicates the total number of people receiving self-directed support in Westminster, across Physical Disabilities, Mental Health and Learning Disabilities Services at snap shot dates over three monthly intervals in 2010. The same data is also

broken down into those aged less than 25. The figures include those service users who were receiving ongoing direct payments or who had a personal budget.¹⁷ It does not include those who received a ‘one-off’ direct payment.

The information indicates that over the 6 month period shown there was an increase in the number of people receiving self-directed support. Different care groups are currently at different places with regard to numbers of people on direct payments or personal budgets. Young people aged under 25 make up a considerable proportion of people receiving services from the WLDP receiving self directed support. This may be as a result of increasing work in this area with the transition population. It is not known what proportion of services users in each service are receiving self-directed support.

Figure 5: Snapshot figures indicating service users in receipt of self directed support in 2010

Age group	Care Group	Snapshot date		
		31/03/2010	30/06/2010	30/09/2010
All ages	Physical Disabilities	201	206	214
	Learning Disabilities	90	100	120
	Mental Health	74	82	91
18-25 years	Physical Disabilities	7	7	7
	Learning Disabilities	36	37	37
	Mental Health	*	5	6

Source: Westminster City Council September 2010

* indicates a number too small to disclose

Note this does not include Older adults (65+) (of whom there were 245 as at 30/09/2010) or ‘other vulnerable adults’ (such as those with HIV, substance misuse, cognitive impairment or brain injury not included in the other groups) (of whom there were 11 as at 30/09/2010). It also does not include carers.

Due to complexities in recording direct payments and personal budgets (because of the different teams and recording systems involved, and the nature of the payments) it is not always easy to find what people spend their direct payments and personal budgets on. As the number receiving support packages in this way increases, this information will be increasingly valuable to inform commissioning of services.

3.7 Health and wellbeing support

It is essential that the health and wellbeing of young people is maximised to gain and maintain independence. At transition it is therefore important that young people with disabilities receive the specialist medical support they need to monitor existing and ongoing medical conditions but also that they have access to mainstream primary care services such as general practice, eye services, podiatry and dental services to ensure other risk factors are detected early. Within this it is important that they are supported to access prevention services where provided, such as regular health checks and

¹⁷ For example an approved Support Plan for ongoing support, which would either be a direct payment or council commissioned services or a combination of both, as a result of a Supported Self Assessment.

screening, and have healthy diets, regular exercise and good sexual health in order to prevent other health risks. It is also important that those who require it have access to the appropriate equipment and aids to help them in their daily lives.

As the health needs of the population covered in this needs assessment are very diverse this section will present only high level need and service provision, and the key issues around transition.

As indicated throughout this needs assessment, many of the young people with disabilities coming through transition have additional and sometimes complex health needs which require ongoing support and management. Both nationally and locally services attest to the increasing number of children with complex health needs surviving into adulthood and requiring support. Studies of the health of people with learning disabilities have shown that compared with the general population they are more likely to have a range of conditions such as high blood pressure, respiratory disease, mental health problems, epilepsy, heart problems, including coronary heart disease, visual and hearing impairments, and they are more likely to have poor oral health and be overweight or obese, which is itself a risk factor for diabetes, cardiovascular disease and respiratory problems. In addition studies have indicated that people with learning disabilities are less likely than the general population to eat a balanced diet and achieve the Department of Health's recommended level of physical activity¹⁸ (NHSW, WCC 2009a).

Studies have also shown that people with severe mental illness have poorer health than the general population. People with severe mental illness die on average of 10 years earlier than the rest of the general population, and have higher rates of diabetes, cardiovascular disease and respiratory disease. There are a number of reasons for this; the first is that people with severe mental illness tend to have less healthy lifestyles than their peers, such as poor diets, less physical activity and higher rates of smoking; secondly, they are likely to have long term effects of antipsychotic medication use and higher rates of substance misuse. The presence of mental illness may also prevent people seeking help, or persons with mental illness may lack the skills to adequately communicate their symptoms to healthcare professionals. When people with mental health disorders do access care, particularly primary care, physical symptoms may be overlooked in favour of the mental illness (which is seen as a priority) (Phelan et al., 2001).

Depending on need and other factors such as location and type of school, much of the medical and other health support for children with disabilities is often provided through their school, for example by a school nurse, school-based speech and language therapy (SALT), occupational therapy and physiotherapy and visiting paediatricians. They may also receive some support from community nurses, health visitors, the child development centre, child and adolescent mental health services, their GP, other specialist hospital-based physicians or externally provided allied health services funded for example through the Children with Disabilities Team. It is important that the school-based provision is monitored to ensure that it continues to

18 The current Department of Health recommendations for physical activity levels are:
Children and young people - 60 minutes of moderate intensity physical activity each day;
Adults - 30 minutes of at least moderate intensity physical activity on at least five days a week
<http://www.healthknowledge.org.uk/>

meet the needs of the school population, especially as more people with complex needs are likely to need support in the future.

The model of care in Children's Services is often very different to that in Adult Services. For instance Adult Health Services are less holistic and arranged around care pathways for different conditions. Whereas a young person may have seen only one paediatrician for many of their needs as children, as adults they may have to attend several different specialist clinics, which may be located in several different hospitals (DH, DfES 2006). Similarly whereas SALT, physiotherapy and occupational therapy is often provided on an ongoing basis for children, such as through their school, these services are often only provided for short time periods as adults, for example for 6-12 week programmes with specific goals for the clients to meet. Furthermore, where young people with rarer conditions are surviving into adulthood, it may be that there are no specific services specialising in their condition, something noted in published literature, particularly for individuals with some neurological disorders (DH, DfES 2006). It is important that children and families are prepared for the changes in service provision when they turn 18.

Published research has indicated that the health of young people with disabilities often declines at transition. This can stem for instance from the loss of health services previously accessed through school and the challenges presented by there being no single contact point to which a paediatrician can hand over. Research has also shown that adolescence is a time when young people with complex health care needs may be more likely to disengage with health services and less likely to comply with treatments, with consequently poorer health outcomes (Prime Minister's Strategy Unit 2005; Office for Disability Issues 2008). It is important that there is no break in treatment regimes and young people are referred into the appropriate adult services. In some areas some of these difficulties have been overcome through the development of specialist adolescent clinics, such as the transitional clinics in diabetes and epilepsy at Imperial College Healthcare NHS Trust.¹⁹

Young people with disabilities may have had minimal contact with their general practitioner (GP), especially if their school and/or paediatrician provided much of their health care and if they were educated out of borough. It is vitally important that their GP is involved in the transition planning process since, on the young person leaving school, the GP becomes the first point of contact for on-going referrals for any therapies which may have been provided via the school (Viner 1999; DH, DfES 2006). Where there are continuing needs and an adult service exists, health professionals, including therapists, involved with the young person may be able to refer on directly, but it is important that the GP is kept informed as the ongoing medical link (DH/DCSF 2008b). Depending on the school a young person attends, they may not be registered with a Westminster GP. It is important that they are registered with a local GP on their return from school.

It is not known specifically how the handover from children's to adult health providers happens currently in Westminster, how far in advance of a young person's 18th birthday their health transfer is planned and to what extent GPs are involved in

¹⁹ For more information refer to:

<http://www.imperial.nhs.uk/stmarys/ourservices/paediatrics/adolescentmedicine/index.htm> [accessed December 2010]

the process. Furthermore it is not clear whether children with less complex needs or no current health involvement apart from the school nurse are less likely to have their health needs assessed early on in transition. A pathway for referral for some services, such as physiotherapy, occupational therapy and speech and language therapy for young people transitioning to the Westminster Learning Disabilities Partnership are included within their wider transition pathway. It is important that these processes are clearly documented to ensure continuity of service provision where relevant.

A project has recently started (December 2010) to improve the health transition for people with learning disabilities in the borough. Discussion with Children's and Adult's Services as part of this work has revealed that the transition to mainstream health services for children with learning disabilities is often poorly planned and Adults' Services are ill equipped to manage the complex needs of young people with learning disabilities. The project aims to develop a health transition pathway for young people with learning disabilities, clarifying the roles and responsibilities of different services. Other aims include:

- To reduce duplication among services in provision.
- To improve service user experience.
- To identify any workforce development issues early on so that adult health staff are able to appropriately meet the needs of individuals following transition.
- To flag gaps and risks, such as equipment / specialist support.
- To ensure that parent and the young person are clear about their role and responsibility around transition
- To encourage greater engagement with the GP prior to transition
- To increase number of Health Action Plans and Person-Centred Plans.
- To raise awareness of personal health budgets.

A draft pathway has been developed and is shown in Figure 6. Before they can begin putting this pathway into action, services have identified the necessity of improving the quality of current data systems around health information for this population.

The 'Health Action Plan' and 'Annual Health Check' referred to in this pathway are explained in more detail in the next two sections.

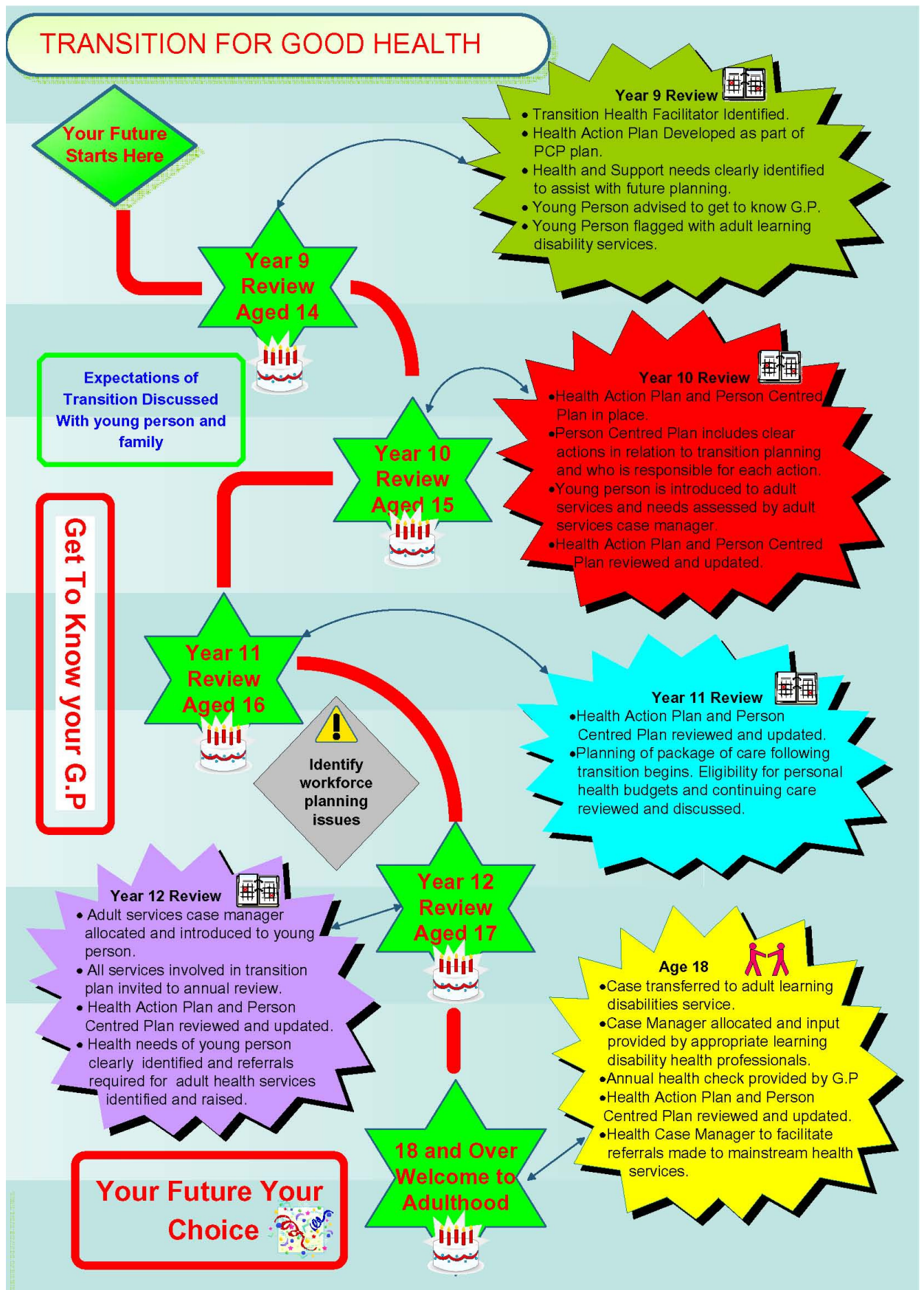


Figure 6: Health transition pathway for young people with learning disabilities

3.7.1 Health Action Plans

Health Action Plans are increasingly recognised as a model of good practice, to help ensure that health support for young people with disabilities is coordinated and that young people receive ongoing support and referrals to appropriate services through the transition period. These were first developed for adults with learning disabilities as part of recommendations in *Valuing People* (DH 2001) but have since been recommended for young people in transition, as part of wider person-centred transition plans, detailed at the start of section 3. There has not to-date been the same national drive for Health Action Plans for people with physical disabilities and long term conditions. One of the main difficulties for people with physical disabilities is access to services to meet their needs. It may be that Health Action Plans, in addition to individual care plans, could help clarify some of these issues and support needs during transition.

Guidance in *Valuing People* (DH 2001) suggests that an individual's Health Action Plan should contain information on:

- Specialist health interventions
- Oral health and dental care
- Fitness and mobility
- Continence
- Vision
- Hearing
- Nutrition
- Emotional and mental health needs
- Details of medication taken and side effects
- Records of Screening Tests.

These factors are all relevant for young people going through transition. Although not mentioned in *Valuing People* it may be useful for the Health Action Plans to also include information on immunisation status, particularly if Health Action Plans are developed for children, and started at a younger age.

Work undertaken to evaluate models of best practice as part of the *Getting a Life Programme* has resulted in the development of a pathway for transition planning for good health for young people with disabilities. This centres around the health plan component of the person-centred transition plan, which they advise should be developed in year 9 and reviewed annually until transition. It is suggested that the following should be discussed during transition so that the young person and their family are clear about the process:

- How will health needs be met
- What equipment and aids will the young person require, who will arrange it and who will fund it
- Which health professionals will continue to support the young person and which will change
- How and when will discharge and transfer from services happen
- Who will work with the young person on discharge from children's services
- Who will coordinate the health plan
- Who will make sure health support is in place in good time

- Who will ensure the young person begins to engage with mainstream health services.

It is also important that young people have accessible information about prescriptions and dental services, occupational and other therapies, opticians, health diets and exercise, relationships and sexual health at transition.²⁰

The health plan should serve as almost a checklist for transition, referencing current and ongoing health needs and service provision; where ongoing referral is needed, to which services, where, when and who will make the referral; whether they are registered with a local GP etc. It should contain information from all the relevant health professionals engaged with the child and a copy should be sent to their GP. It should also contain information about what the young person can do to be healthy to reduce the impact of their health needs and maximize opportunities for independence, such as helping develop skills for monitoring/managing their conditions (DH, DCSF 2008b). It is important that they are reviewed and updated regularly, as appointments are made or new needs are identified. For some young people with life-limiting conditions it may be important for palliative care needs and wishes to be a consideration within the plan. For those with long term conditions it may be important to consider how and when the young person may be supported to begin to manage their own medical condition or whether there are any relevant expert patient groups they could engage with (Prime Minister's Strategy Unit 2005).

Whilst focussing on the person's health needs the plan should link closely with the education and social care elements of the young person's transition plan and be initiated at the start of the transition planning process when the young person is aged 13-14 (for SEN Children – for more information refer to section 6.2). It can be used to inform the care plan in adults (DH/DCSF 2008b). Once established, the idea presented in *Valuing People* (DH 2001) is that the Health Action Plan should be integrated within the person-centred-plan, rather than being a separate document.

Health Action Plans and discussion of health issues for young people with disabilities going through transition have been identified as a priority area locally: ensuring that all young people with disabilities going through transition are offered a Health Action Plan is noted as a priority outcome for keeping young people healthy within the *Westminster Children and Young People's Plan 2009-11* (WCC 2009) and in *The Big Plan* for people with Learning Disabilities (NHSW, WCC, WLDP 2009).

In 2009/10 Queen Elizabeth II Jubilee School completed health plans for their school leavers. Work is taking place with school nurses in the local special schools to try to embed Health Action Plans within wider transition planning on an ongoing basis. However, in order for this process to be implemented fully in local schools clarity is needed as to whose responsibility it is to coordinate the Health Action Plan. For those young people moving into the Westminster Learning Disabilities Partnership their transition Health Action Plans can then become their adult Health Action Plans following transition. Around 35% of adults aged 18-25 in touch with the WLDP currently have a health action plan recorded on SWIFT (the adult social care database). This low number is, however, likely to reflect poor recording on the adult services database.

²⁰ For more information refer to: www.gettingalife.org.uk [accessed December 2010]

3.7.2 Annual health checks for people with learning disabilities

Westminster has had a Local Enhanced Service (LES) with local GPs for people with learning disabilities since 2005/6. The LES established a contractual payment for GPs to manage the physical health needs of, and provide health promotion advice to, people with learning disabilities. Payment structure is based on the number of patients with learning disabilities registered at the practice. Eligibility for the register is defined by being in contact with the Westminster Learning Disabilities Partnership (WLDP). The key tasks in the LES are completing an annual health check. This includes recording blood pressure and body mass index (BMI), dental / eye screening, identifying a health facilitator for the individual, and the development of health action plans.

There are currently 32 GP practices out of 52 signed up to the LES (December 2010). Since 2005/6 there has been an annual increase in the number of people registered in practices, suggesting more people are being identified, accurately coded and provided with services. The WLDP provide services to patients registered to practices not signed up to the LES to ensure full coverage (NHSW, WCC 2009a). As at 31 January 2010 there were 564 adults with a learning disability known to the WLDP and 466 adults with a learning disability registered with a GP practice within NHS Westminster's control. 85% of all practices within Westminster currently have systems for identifying and recording patients with a learning disability (NHSW 2010).

The annual health check is available for adults aged 18 and over in touch with the WLDP. It is important as part of transition planning that the process is set in place for young people transitioning to the WLDP to have their health check as soon as possible after referral into the service at 18 or when they leave school. For this to happen it is important that they are registered with a local GP. The scheduling of this appointment could be added as another item on the young person's health action plan.

3.7.3 Sexual health

Research has shown that people with learning disabilities can experience a number of barriers to good sexual health and that they are less likely to undergo screening for cervical and breast screening. It has been identified that the sexuality of people with learning disabilities is not routinely acknowledged and so their needs may subsequently be ignored. People with learning disabilities may be over protected by professionals and family carers which can result in them being unable to express their sexuality.

Adolescence is a time that young people go through puberty and grow in sexual awareness. Young people with learning disabilities have the same rights as all young people to have safe and fulfilling sex lives. At the same time it is important that they are given the skills and confidence to recognise potentially abusive or harmful situations (NHSW, WCC 2009a). It is important that sexual health and relationship advice are part of health discussions at transition and that, as necessary, young people are signposted to appropriate support services as adults.

A local project was launched in Westminster in 2007 to embed good sexual health for adults with learning disabilities including:

- Providing sexual health and relationship education
- Providing sexual health training for staff working with people learning disabilities
- Undertaking support work with parents and carers
- Developing a Sexuality Policy
- Developing guidance on consent and setting appropriate values
- Increasing access to screening and genitor-urinary medicine (GUM) clinics
- Increasing access to cervical smears and breast screening (NHSW, WCC 2009a).

Sexual health education has been identified as an area for development in the local special schools and work has taken place to develop a tuition programme as part of the Personal Social Health Education (PSHE) curriculum around sex and relationships. This project has taken place with support from the Family Planning Agency and school staff have received some training around sex and relationship education. Much of the work involves teaching the difference between public and private behaviour and between good and bad touching. The plan is for classes to start in year 5 and for the knowledge to be built up through repetition in subsequent school years. If there are particular topic areas which some pupils need support on then sessions may be arranged with those pupils. There are hopes to develop a similar programme at Westminster College, which will build on the school programme. Queen Elizabeth II Jubilee School and College Park School have been arranging coffee morning with parents to discuss sex and relationship education and the local projects around this. The first coffee mornings that have been arranged have been well attended.

It is not known what level of sex and relationship education takes place in other special schools, attended by Westminster pupils.

3.7.4 Oral health

Oral health is an important part of well-being as it impacts on a person's ability to eat, speak and socialise. Children (and adults) with a disability are more likely to have worse oral health than the rest of the population (Gallagher & Fiske, 2007), with those at the severe end of the disability spectrum likely to face greater oral health challenges than children with milder disabilities. Reasons for poorer oral health include, difficulties in establishing and maintaining good oral hygiene; increased rates of gastric reflux, vomiting and rumination disorder, tooth grinding and increased traumatic injuries (Shaw et al, 1990); medications containing sugars, or high sugar diets to maximise caloric intake; and reduced access to dental services and limited restorative care (Cummella et al, 2000).

Providing dental services to children with more severe or complex disabilities and medical conditions can be challenging and requires specialist skills and time to overcome physical problems, such as uncontrolled movements, limited mouth opening, or learning difficulties resulting in non-co-operation. Complex medical conditions can make treatment more difficult. As many as one-third of the 129

institutionalised special needs children in one British study required general anaesthesia in order for dental treatment to be completed (Nunn et al, 1993).

Transition is a time of growing independence, where previous tooth-brushing habits and preventative measures may no longer be overseen by adults. A recent Westminster dental needs assessment for people with learning disabilities highlighted the poor transition of children with special needs to adult dental services. Young people aged 17-19 were identified as a particularly vulnerable group in terms of dental neglect and unnecessary hospital admissions for toothache. Following the findings from this piece of work there are plans to ensure that young people do not lose contact with services at transition. The adult community dental services team at Central London Community Healthcare (CLCH) (CLCH provide full dental services for people whose needs or disabilities mean they have difficulty accessing appropriate treatment in a mainstream dental practice or who require more tailored services) is in the process of making contact with all young people who are currently in transition to adult learning disability services, who are not known to CLCH (thought to be around 27 young people) to establish their dental needs and ensure they have continuing dental care. Where these individuals are currently receiving dental care from paediatric specialists (such as at Chelsea & Westminster or Guy's and St Thomas' Hospitals) then staff at CLCH will contact their service providers to ensure that when the patients are discharged they are referred directly to CLCH.

3.7.5 Equipment and aids

There are a wide variety of services providing equipment and other aids to young people with disabilities and sensory impairments. These are invaluable in helping to support young people in their every day lives and in promoting and maintaining independence. Some specialist equipment is bought and provided by hospitals. Several of the service providers are the same across Children's and Adult's Services, which is positive for transition since young people do not have to return equipment provided by one service and engage with an entirely new service at age 18.

Further information on the different service providers in Westminster can be found in Appendix B.

3.7.6 Adults: personal health budgets

The Department of Health has set up a pilot programme to test the concept of individual budgets, including direct payments, in health. The national pilot consists of around 70 pilot sites in England. Westminster is part of the Central West London pilot, 'Your Health, Your Choice'. This is a joint initiative between the Councils and Primary Care Trusts (PCTs) of Hammersmith and Fulham, Kensington and Chelsea and Westminster and their joint provider organisation, Central London Community Healthcare. The intention is to offer personal health budgets to up to 120 individuals across the three PCTs during the pilot period. The pilot runs from May 2010 to March 2012 (NHS Hammersmith and Fulham et al. 2010).

The client group chosen for the pilot includes individuals with 'long term conditions' who:

- Are in receipt of NHS Continuing Care funding living in the community (this is explained in more detail in section 4.2);
- Have a long-term health condition at risk of hospital or care/home/ nursing home admission.

Clients considered for the scheme will have an assessment of their needs which will inform a support plan. This will include health outcomes and state how they will be met through the personal health budget. The value of the budget will be calculated on a case by case basis, depending on individual needs. This may involve getting a direct payment for the total budget or a part of it. In cases where individuals have both assessed health and social care needs an integrated health and social care budget will be sought (NHS Hammersmith and Fulham et al. 2010).

None of the clients in the pilot from Westminster are aged 18-25. Depending on the results of these pilot initiatives, this may be rolled out as a way forward for providing health and social care support for this client group in the future. This may be particularly suited to people with rarer conditions with high support needs, and for whom there may not be specialist support services routinely provided, to enable them to have flexibility about how their support is provided (NHS Hammersmith and Fulham et al. 2010).

3.8 Supporting parents at transition

Not only is transition a difficult time for the young person moving between services and planning their future but it is also a difficult time for parents and carers. Like the young people themselves parents and carers have to adjust to the differences in service provision between Children's and Adults services, that their child may no longer be in full time education, that their child is becoming an adult and may want independence and the fact that services are more geared to the individual rather than the family; the young person may have a choice in whether their parents attend appointments with specialists. Parents also may have anxiety about post-school options and be worried that their child's expectations are being raised unreasonably about potential support and career choices after school. Some of these anxieties may not surface until their child turns 18 (DfES 2001).

Consultation during the development of Westminster's *Moving on Protocol* for transition raised the importance of professionals listening to and understanding the needs of parents/carers, and being more open about what is possible. There was a common perception that services need to improve the way they find out what parents want and that the planning processes need to be more transparent and clearly related to these needs. Parent forums and support groups were seen as a valuable way of enabling more participation but they need to be more parent-led and inclusive (WCC 2010i).

It is important that services prepare parents as well as young people for transition and the different services they can expect in adulthood. Within this, however, there needs to be a balance between promoting the independence of the young person and ensuring that they have the necessary support services, and involvement of parents within decision making (WCC 2010e; Prime Minister's Strategy Unit 2005).

National research has identified that there may be particular gaps for parents of young people in mainstream schools and those in residential schools. Although acknowledging the positives of the focus on expanding disabled young people's participation in mainstream education, leisure, and social activities, *Improving the Life Chances for Disabled People* noted that mainstream schools can lack the contacts and information that special schools have access to and a mainstream context can lead to individuals experiencing isolation from other disabled people (Prime Ministers Strategy Unit 2005). On the other side, the families of young people who attend specialist residential provision out of borough can be vulnerable to losing contact with services in their home authority.

Increasing parents' knowledge of, and confidence about, transition is a shared local priority (WCC 2010b; WCC 2009).

3.8.1 Information and engagement within the transition process

Access to high-quality, timely information is one of the issues families consulted for national strategies, as well as locally in Westminster, say is essential during the transition process. To try and better meet the needs of disabled young people, many local authorities have produced a transition pack for families which gives information on the local transition protocol, potential specialist support services and wider general support services (WCC 2010e; DH/DCSF 2007).

It is acknowledged locally that more work is required in order to meet the information needs of all young people with disabilities and their families in the borough (WCC 2010b). A transition leaflet for young people is in development and an 'Information Group' has been formed to look at both the sources of information available to parents and young people and to develop more creative and accessible methods of delivery. It is recognised that not all families want information at the same time in the same way and services need to be flexible in the way they provide information. Consultation with parents and carers in Westminster in 2008 noted that cultural, and especially language barriers, are a big factor in preventing families seeking and accepting support (WSPLD 2008). It is important that this is reflected in the information provided.

An important development in support for families in Westminster has been the employment of a Family Support Worker to provide support to parents of children at the two local special schools. The Family Support Worker is funded by the special schools; Westminster Society for People with Learning Disabilities (WSPLD) is commissioned to deliver the service as part of their Family Support Services. The Family Support Worker plays an important role in liaising with parents, information gathering, and supporting with advocacy where necessary. Coffee mornings are also held at Queen Elizabeth II and College Park for parents where discussions can begin around transition, colleges, post school options and introduce adult services. These are hosted by the specialist Connexions Personal Advisor and the Children with Disabilities Team's Transition Social Worker. Staff from Westminster's Learning Disability Partnership also take part. As the local Special Educational Needs Outreach Centre develops, attached to the special schools, parents with children educated out of borough will also be able to access specialist advice through these channels (WCC 2010b).

3.8.2 Parent forums

Past parent consultations have pointed very clearly to the need to increase parental confidence in the transition process through improved information and services delivered in a more responsive manner. There have been developments in this area locally. There are parent forums at the two Westminster special schools and The Family Services Team provides parents and carers with information about transition and support through the transition process. Transition features regularly as a topic for their monthly Parent Information Groups (WCC 2010b). The Family Support Services (WLDSD) provides parents and carers with 1:1 emotional support, mediation and advocacy where required. In addition to this the Westminster Parent Participation Group (PPG) has been running for the last eighteen months.

The Westminster PPG was originally established as part of a national drive to increase parent participation around children with disabilities services as part of the wider *Aiming High for Disabled Children* programme (DH/DCSF 2008a). This group is supported by a key local voluntary sector provider and as Aiming High funding comes to an end it is anticipated that Westminster City Council Children's Services and WSPLD will allocate future funding. A key aim for the PPG is to make use of funding opportunities arising through applying for external funding so as to enable the group to keep growing and ultimately, become self-sustaining. Parent representatives from the PPG are members of City Council/partner meetings such as the Short Breaks Steering Group and the DCATCH (Disabled Children Access to Childcare) Steering Group. It is planned for two parents to join the Transition Strategy Group. It is anticipated that representation on Council-led meetings will continue and increase as the PPG become more established and parents become more confident after accessing appropriate training and support.

The Westminster Children with Disabilities Team funds a Parent Involvement Service delivered by a key local provider, WSPLD, through their Family Services Team. This service is currently being refreshed and will offer a range of support to parents across the City including a quarterly newsletter for parents who register to join the Parent Involvement Group, and organising training and specific consultation events, which will cover transition. The PPG will also benefit from some further additional support through this service.

An evaluation project on Westminster's short break provision for children with disabilities included two events for parents in early 2011, and again highlighted the requirement to continue prioritising parental involvement in service planning and transitions.

3.8.3 Support for parents and carers in their own right

Parents of children with disabilities often continue to be a primary carer long after their 'child' has turned 19. For example, an estimated 60% of adults with a learning disability continue to live in the family home, with a further 20% heavily dependent of families for support in supported accommodation (DH 2001). Parents and carers often, however, provide care at a significant cost to themselves. As a result of caring carers can suffer social, financial and health inequalities.

The needs of carers in Westminster and the services providing support were analysed in detail within a joint strategic needs assessments in 2009, which informed the Westminster Carers Strategy (NHSW 2009; NHSW, WCC 2010b).

It is important to note, however, that as part of transition planning, the needs of carers should also be considered to explore the impact of changing circumstances. Carers who provide (or intend to provide) substantial levels of care on a regular basis should be offered a carers assessment (DH 2010b).

4 Criteria for transition to Adult Services in Westminster

Young people with disabilities and complex health problems, including mental health problems, are a diverse group with varying needs and levels of need, including educational, health and social needs. As a consequence, individuals are supported by a wide range of services. Not all young people with disabilities and complex health problems who are supported as children will need ongoing support as adults. Also, due to the differences in service provision between Children's and Adult's Services, not all children will meet eligibility criteria for Adults Services. The number of young people with disabilities actively supported by specialist services as children is larger than the cohort who will transition to specialist Adult Services.

Children's and Adults Services work along different service models, and have different definitions for service entitlement. Children's Services tend to work in a holistic way to support the health, social and other needs of young people with all types of disabilities; services are not generally provided separately according to type of disability, but provided by an overarching service which tailors provision according to individual need. By contrast Adults Services are divided according to different care groups, with individuals being supported principally by teams that provide for their dominant need, whether it is for instance a physical or substantial health need, a mental health need or a learning disability.

Eligibility for specialist Adults Services is assessed in two ways, which will be explained in detail in this section. Each team has their definition of the population they work with, based around the severity of an individual's health need or disability. The level of support provided and how it is funded is then assessed through either the Fair Access to Care Services (FACS) criteria or the NHS Continuing Care criteria.

4.1 Fair Access to Care Services (FACS) criteria

Eligibility criteria for Adult Social Services were introduced by the government for all councils under guidance known as Fair Access to Care Services (or FACS). Under FACS there are four levels of eligibility based on people's needs – critical, substantial, moderate and low. Councils are required to use this criteria to identify eligible needs, based on the risks to an individual's independence, both in the immediate and longer term. Councils are allowed to decide where they set the eligibility threshold in relation to the four levels according to their financial resources. Once the threshold has been set the council has a duty to make arrangements to meet the needs that fall above it (from FACS consultation document, WCC 2010; DH 2010).

The guidance on FACS assessments (DH 2010) stipulates the following regarding eligibility:

The evaluation of a person's needs as part of the assessment process for FACS should take full account of how needs and risks might change over time and the likely outcome if help were not to be provided. This should include consideration of the impact upon the person of changes in the circumstances of any carer(s). Where eligible needs have been identified, an appropriate support plan can then be put together in collaboration with the

individual, describing the support they will draw upon to overcome barriers to independence and well-being, both immediately and over the longer term. Councils should take steps to meet the person's needs in a way that supports the individual's aspirations and the outcomes that they want to achieve.

Where councils do not offer direct help following assessment or where people refuse or opt out of assessment, councils should still be prepared to provide individuals with useful information and advice about other sources of support (DH 2010).

Between September and December 2010 Westminster City Council ran a consultation on possible changes to adult social care eligibility. Following the consultation the threshold for FACS has been set at a higher level: only people whose needs and risks are assessed as being 'substantial' or 'critical' within the national FACS scheme will receive services (WCC, 2010; WCC, 2011). This has been brought about due to a combination of recent financial pressures and increasing demands for social care. As a result of these changes, people who are assessed as having moderate needs will no longer be eligible to receive support; a change that applies to people who are currently receiving services as well as to people seeking support for the first time. As such it is likely to affect those who have recently undergone transition and those scheduled to make transition to Adults Services in the next few years. Those no longer entitled to this care will be offered an improved range of preventative services and information on other support available. Westminster City Council is not alone in this action; many other councils have already raised their thresholds. Latest research shows that last year around three quarters of councils in the country set their eligibility threshold at 'substantial', including all except two other London councils (WCC 2010).

The FACS consultation document explained that the Council intends to offer everyone, whether they meet the eligibility criteria or not, the following, as appropriate:

- information and advice on other organisations and services that might be able to provide help and support
- help to access an increased range of preventive services which help to avoid or delay the need for care; these could include items of community equipment like mobility aids and community (or link) alarms
- a programme of reablement from occupational therapists and physiotherapists to enable them to reach their full potential for independence, as required (WCC 2010; WCC 2011).

4.2 NHS Continuing Care

Continuing care is defined in the National Framework for NHS Continuing Healthcare as 'care provided over an extended period of time, to a person aged 18 or over, to meet physical or mental health needs that have arisen as a result of disability, accident or illness'. *NHS continuing healthcare* means 'a package of continuing care that is arranged and funded solely by the NHS' (DH 2009c).

The legislation and the respective responsibilities of the NHS, social care and other services are different in Child and Adult Services. The term *continuing care* also has different meanings in Child and Adult Services. The National Framework for NHS

Continuing Healthcare are notes that is important that young people and their families are helped to understand this and its implications right from the start of transition planning. The National Framework and the supporting guidance and tools should be used to determine what continuing care services people aged 18 years or over should receive from the NHS. There is a separate policy on continuing care services for those under 18 years (DH 2009c).

The National Framework advises the following regarding NHS Continuing Care eligibility:

Where a person's primary need is a health need, they are eligible for adults' NHS continuing healthcare. Deciding whether this is the case involves looking at the totality of the person's assessed health needs. The diagnosis of a particular disease or condition is not in itself a determinant of eligibility for NHS continuing healthcare. Where an individual has a primary health need and is therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual's assessed needs, including accommodation, if that is part of the overall need.

If a person does not qualify for NHS continuing healthcare, the NHS may still have a responsibility to contribute to that person's health needs, either by directly providing services or by part-funding the package of support. Where a package of support is provided or funded by both a local authority and an NHS body, this is known as a 'joint package' of continuing care. A joint package of care could include NHS-funded nursing care and other NHS services that are beyond the powers of a local authority to meet. The joint package could also involve both the PCT and the local authority contributing to the cost of the care package, or the PCT commissioning and/or providing part of the package.

Apart from NHS-funded nursing care, additional health services may also be funded by the NHS, if these are identified and agreed as part of an assessment and care plan. The range of services that the NHS is expected to arrange and fund includes, but is not limited to:

- primary healthcare;
- assessment involving doctors and registered nurses;
- rehabilitation and recovery (where this forms part of an overall package of NHS care, as distinct from intermediate care);
- respite healthcare;
- community health services;
- specialist support for healthcare needs; and
- palliative care and end of life healthcare.

The NHS's responsibility to commission, procure or provide care, including NHS continuing healthcare, is not indefinite, as needs could change. This should be made clear to the individual and their family. Regular reviews are built into the process to ensure that the care package continues to meet the person's needs (DH 2009c).

The National Framework for NHS Continuing Care notes that regarding transition:

- It is desirable and best practice that future entitlement to adult NHS continuing healthcare should be clarified as early as possible in the transition planning process, especially if the young person's needs are likely to remain at a similar level until adulthood.
- Children's continuing care teams should identify those young people for whom it is likely that adult NHS continuing healthcare will be necessary, and should notify whichever primary care trust (PCT) will have responsibility for them as adults. This should occur when a young person reaches the age of 14.
- This should be followed up by a formal referral for screening at age 16 to the adult NHS continuing healthcare team at the relevant PCT.
- At the age of 17, eligibility for adult NHS continuing healthcare should be determined in principle by the relevant PCT, so that, wherever applicable, effective packages of care can be commissioned in time for the individual's 18th birthday (or later, if it is agreed that it is more appropriate for responsibility to be transferred then).
- If needs could change, it may be appropriate to make a provisional decision, and then to recheck it by repeating the process as adulthood approaches.

If a young person who receives children's Continuing Care has been determined by the relevant PCT not to be eligible for a package of adult NHS continuing healthcare in respect of when they reach the age of 18, they should be advised of their non-eligibility and of their right to request an independent review, on the same basis as NHS continuing healthcare eligibility decisions regarding adults. The PCT should continue to participate in the transition process, in order to ensure an appropriate transfer of responsibilities, including consideration of whether the PCT should be commissioning, funding or providing services towards a joint package of care (DH 2009c).

Adult Continuing Care funding can only start from the date of the person's 18th birthday but, as the guidance suggests, the process can be started before that date. According to the guidance, locally a full assessment has to be completed one month prior to the NHS Westminster Continuing Care panel receiving a recommendation from the multi-disciplinary team carrying out the assessment to determine whether a client meets the Continuing Care criteria. However, that is not to say that a checklist could not be undertaken in the months beforehand. As the guidance suggests, it would be also good practice for young people to be identified for screening for Continuing Care at 14 years and then screened at 16, although the full assessment would have to wait until just before the person's 18th birthday. This would help forecasting activity and expenditure and planning options for packages of care. In transition cases for individuals with physical disabilities it would be good practice for the Physical Disabilities Continuing Care Assessor for Adults to undertake a joint assessment with the Children with Disabilities health and social care team.

4.3 Criteria for specific care groups

4.3.1 Learning disabilities

Learning disability is described in *Valuing People* (DH 2001) as including the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.

In order to meet the criteria for Westminster Learning Disabilities Partnership (WLDP), the service user must show all of the following:

- A significant impairment of intellectual functioning; IQ score below 70
- A significant impairment of adaptive living skills in two or more of the following areas:
 - self-care
 - communication
 - home-living
 - social/ interpersonal skills
 - use of community resources
 - self-direction
 - functional academic skills
 - work, leisure, health and safety
- The age of onset of these impairments must be present before the age of 18 years.
- There must be no differential diagnosis (such as head injury, stroke, emotional trauma; Alzheimer's, mental illness etc.) (WLDP, AMHS 2010).

There is an acknowledged gap locally and nationally around provision for some autistic spectrum conditions such as asperger's syndrome, where individuals may have poor social functioning but are likely to have an IQ of above 70 (for more information refer to the Westminster Autistic Spectrum Conditions JSNA and Strategy, NHSW, WCC 2010a; WCC, NHSW 2010).

Where possible psychometric and other standardised assessments are carried out with the service user to ascertain their level of intellectual and adaptive functioning. In addition the clinician will search for evidence of developmental delay, special educational needs support, significant difficulties at school relating to academic performance, significant behavioural problems not associated with mental health problems and difficulties despite adequate material and social opportunities. Where there is evidence of additional problems the clinician may carry out further assessments, which can include:

- A screening of pervasive developmental disorders (PDD) (and autistic spectrum conditions).
- An examination of the relationship between long term mental health and learning disability.
- An assessment of the impact of physical impairments, including motor and/or communication difficulties that may impede performance of tests of intellectual

and adaptive functioning e.g. hearing or sight impairments and mobility problems (WLDP, AMHS 2010).

Following assessment, if someone is not eligible they will be signposted to alternative services; if eligible a support plan will be developed.

4.3.2 Physical disabilities

In order to qualify for local authority services individuals with physical disabilities must meet the FACS criteria and have a permanent and substantial disability such as:

- People with a congenital condition
- Hearing or visual impairment
- Chronic diseases
- Neurological conditions e.g. Epilepsy, Muscular Dystrophy
- Traumatic Disability arising from an accident
- Brain injury (Acquired or Cognitive)
- Those who have suffered strokes.

People who have a physical disability, long term condition or sensory impairment can access health care services through primary, secondary or specialist services, depending on their individual assessed needs. These are universal services, however some individual services may have their own eligibility criteria.

People with high levels of needs are eligible to be assessed for NHS Continuing Healthcare. This is care that is provided over an extended period to a person over the age of 18 years. Care can be provided in any setting, although this is often a care home [with nursing] or the individual's home. Where NHS Continuing Healthcare is provided in a care home, it will cover the care home fees, including the cost of accommodation, personal care and healthcare costs. If NHS Continuing Care is provided in the home it will cover personal care and healthcare costs.

Eligibility for NHS Continuing Healthcare is considered by a Multi-Disciplinary Team who will carry out an assessment and make a recommendation. This is then submitted to a panel at NHS Westminster for ratification. Where a service user does not meet the criteria for NHS Continuing Healthcare but continues to have ongoing nursing needs they may be eligible for NHS-funded nursing care. This consists of a weekly contribution from the NHS towards the cost of nursing care within a care home setting.

4.3.3 Mental health

The level of NHS mental health services an individual requires are determined by diagnosis and level of need. Diagnosis is assessed according to the categories given in the International Classification of Disease Version 10 (WHO, 2007). Mental health problems are commonly divided between 'common mental health problems' and 'severe and enduring mental illness'.

The most common mental health problems include depression, eating disorders and anxiety disorders. Many of these can be treated effectively in primary care, but some

individuals will need referral to secondary care services for assessment and advice or treatment. Some people with severe and enduring mental illness will continue to require care from specialist services working in partnership with the independent sector and agencies which provide housing, training and employment. Examples of severe and enduring mental illness include schizophrenia, bipolar affective disorder or organic mental disorder (dementia), severe anxiety disorders or severe eating disorders (DH 1999).

The structure of primary and secondary mental health services are discussed in section 9.1.

Eligibility for social services support is examined according to FACS criteria, as with other care groups.

4.4 What happens to those who do not meet the criteria for Adults Services?

The JSNA focuses on young people with disabilities, mental health problems and complex health needs who make the transition between Children's and Adult Health and/or Social Services. It is acknowledged throughout, however, that there are a large number of potentially vulnerable young people on the edges who do not meet the eligibility criteria for specialist support as adults. For instance only a small proportion of young people identified at school as having special educational needs transition to Adults Learning Disability, Physical Disability or Mental Health Services (discussed in section 6.3). Similarly the population receiving a service from Child and Adolescent Mental Health Services (CAMHS) prior to the age of 18 is much larger than the number of young people who meet the criteria for secondary mental health services for adults (discussed in section 9.2).

This is a population for whom longer term outcomes, service needs and health and social cost implications are less well understood within current research (Singh et al. 2010). Some research, however, has indicated that individuals with less significant impairments (such as those with mild or moderate learning difficulties, or communication or mental health problems), who have had little or no contact with services such as social care, are at higher risk of coming into contact with the Youth Justice System, experiencing homelessness, teenage pregnancy, drug and alcohol misuse and becoming NEET (not in education, employment or training) (Prime Minister's Strategy Unit, 2005).

Looked After Children with a disability or mental health problem that do not meet the criteria for Adults Services are a particularly vulnerable group, since the family networks that support other young adults with similar disabilities do not exist for them (discussed in section 5.1.3). Another vulnerable group which have been flagged both locally and nationally are young people with autism, who have tended to fall between the gap in mental health and learning disability services, although developments are taking place in this area. This is a growing population with complex needs. (These are discussed in more detail in the *Westminster JSNA on Autistic Spectrum Conditions* and *Joint Commissioning Strategy on Adults with Asperger Syndrome* (NHSW, WCC 2010a; WCC, NHSW 2010).

With the recent changes to the FACS criteria within Westminster fewer young people with disabilities as a whole will be eligible for Adult Social Services (refer to section 4.1 for more detail).

Although this population may not be eligible for specialist support from Adult Services, depending on need, individuals may be eligible for some targeted support provided by services such as Connexions (for young people with learning difficulties and disabilities, discussed in sections 3.1.2 and 6.2.4) and also mainstream services. It is important that young people and their families are signposted and supported to access appropriate services, where available. For instance, where a young person has a statement of special educational need but is not eligible for Adults Services there are a number of possible interventions and support strategies that can be offered. These include:

- signposting to universal services such as youth clubs and hubs, and voluntary sector provision.
- referral for ongoing targeted services via the Locality Young Peoples Services Multi Agency Allocation Meeting – such as mentoring and PAYP (Positive Activities for Young People)
- receiving ongoing targeted support from a Connexions adviser.

Similarly, young people receiving support from CAMHS, who do not meet the criteria for Adult Services, depending on need, should be referred to services in primary care, provided through their GP, such as counselling services or the new Improving Access to Psychological Therapies (IAPT) services,²¹ or mainstream support services, such as youth counselling service or Connexions.

Given the potential vulnerability of this population and the lack of a clear estimate of the number of young people affected, their needs and what services are available for support, it is recommended here that an additional piece of work is carried out to understand these factors in more detail.

21 IAPT offers Cognitive Behavioural Therapy (CBT), psychological assessment or signposting to other services, where appropriate.

5 The transition process in Westminster: financial and service planning

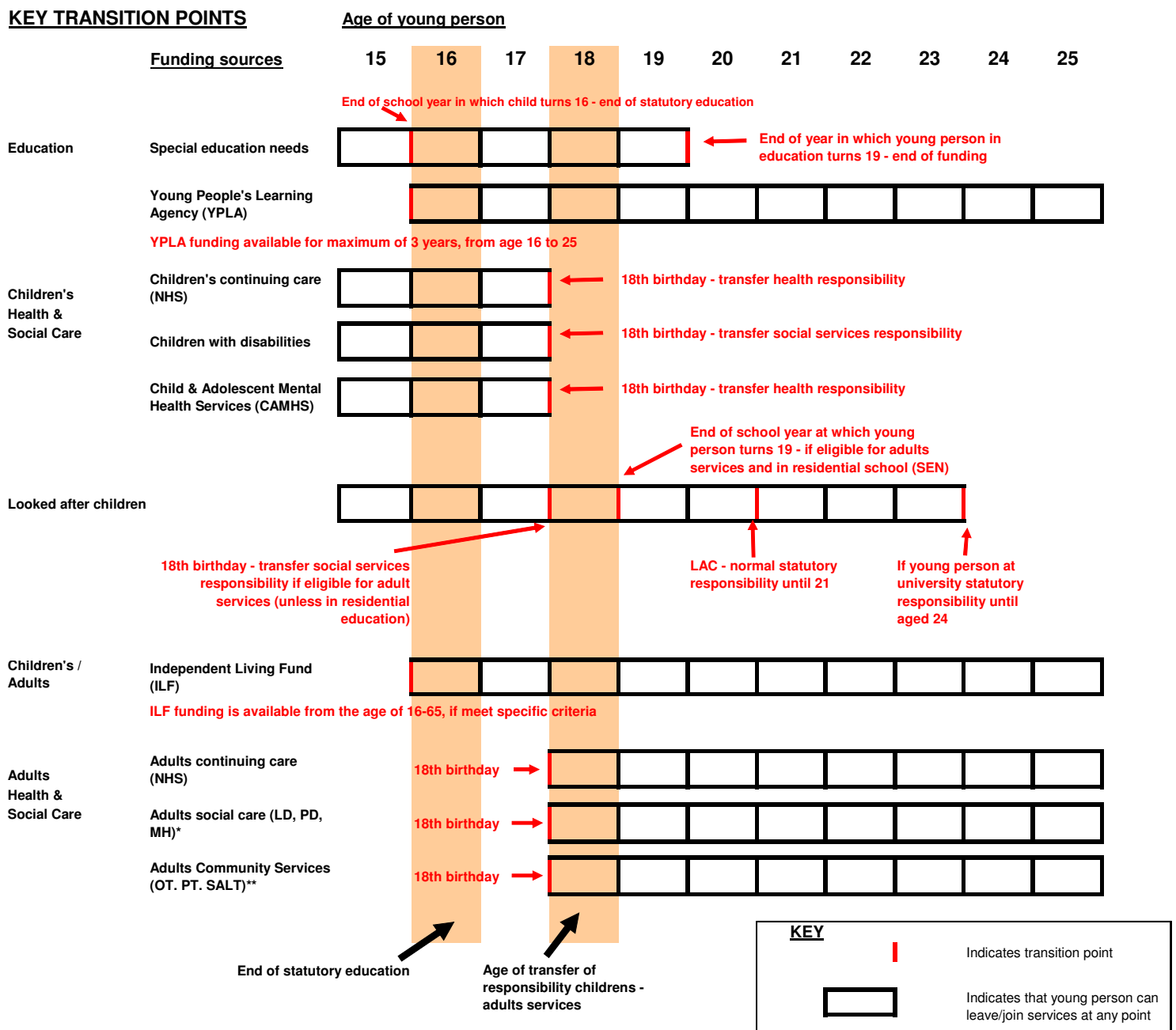
Transition works at different levels; at the personal level of the young person and their families; and at also at a service level. Transition is about young people reaching adulthood and using the same, mainstream, services as everybody else as far as possible, although recognising that some specialist support may be required. In addition to the planning which takes place with young people around their future aspirations and needs, and their transition between services, there is also work that goes on within the services themselves to ensure that they are able to provide the services needed by the young people and that they are adequately prepared financially for their transition. It should be noted, however, that some service users have very complex and unique disabilities for which there may not be an obvious service to meet their needs in adulthood. It is important that agencies and individuals involved in both levels of planning communicate and work closely together.

Depending upon the level of need in each individual case, the agencies and professionals involved in supporting young people with disabilities during adolescence and early adulthood will vary. In all cases the mix of professionals will include those that work directly with the young person and their families and more remote personnel such as service commissioners. These different professionals and agencies will have different service and funding responsibilities and will be involved at different times. It is important that services are aware of these complexities and when their own and others' responsibilities transfer in order to adequately plan and financially forecast for transition. It is also vital that services share data around the numbers and needs of the transition population. This section provides some clarification of the ages at which responsibility changes for different services and the local multi-agency involvement within transition planning.

5.1 Ages of transition and transfer of responsibility

The age at which different services stop providing support and funding for young people, and the ages at which responsibility is transferred to Adults Services, varies across different agencies. This adds to the complexity of financial planning for young people coming through to Adults Services. This is illustrated in Figure 7. The funding and responsibility for these young people may cease at different stages depending on the level of assessed need of the young person and their choices. Funding for placements and care packages for children may come from a variety of teams, including Education, Children with Disabilities, Continuing Care, and from the Looked After Children Team for children looked after by the Local Authority.

Figure 7: Funding Chart



NOTE:

* LD = learning disabilities
PD = physical disabilities
MH = mental health

** OT = occupational therapy
PT = physiotherapy
SALT = speech and language therapy

5.1.1 Education funding

Pupils with statements of special educational need (SEN) can leave school at the end of Year 11 (statutory school leaving age is 16) and any other time up until the end of the academic year when the young person turns 19. SEN funding ceases when a pupil leaves school (from Year 11 up to and including the end of the academic Year 14, the year in which the pupil turns 19). Most pupils with severe needs remain at school until the end of Year 14, but on occasion may leave earlier. Pupils with special educational needs are discussed in more detail in section 6.

Funding for education is also determined by the type of educational institution a pupil attends. If a pupil transfers to a college placement (as distinct from a school placement) at age 16 upwards then funding through a statement will cease. Funding for their college placement is available from the Young Persons Learning Agency (YPLA), a national funding agency.²² Depending on the placement agreed and funding allocation by the YPLA, Adult Services may be asked to contribute towards the funding. If the specialist college placement is outside Westminster, justification has to be given as to why provision cannot be found locally for the young person. This placement may continue beyond the young person's 19th birthday.

The process for arranging funding for specialist placements through the YPLA is complicated. Funding is received for up to three years, subject to review (relating to factors including the young person's progression and the provision remaining suitable to the person's needs).

If the young person and their family favour a specialist placement, an assessment is completed by Connexions taking into account the young person's needs and how they will be met by the chosen placement. If the college agrees to take the young person, the assessment is taken before an internal Westminster panel. If funding for placements outside Westminster is being sought, Connexions have to justify why provision cannot be found locally for that young person. If the internal panel approves, an application is made to the YPLA for funding.

In some cases, if the YPLA agree to fund the placement and the young person is looking for a placement post-18, Adults Services may be asked to contribute towards the funding. The application needs to go to the panel in the year before the young person requires the placement. For some colleges and placements with long waiting lists, however, decisions and applications will need to be made further in advance. A decision from Adults Services is only formally needed towards the end of the funding application process but Connexions provides relevant leads in Adults with a forecast of those likely to consider specialist placements. It is also brought before the Young Persons' Transition (YPT) Operational Group (refer to section 5.2.3 for more detail). The numbers involved are small, but due to the implications for financing and service provision it vital that Adults Services are involved in decision-making at an early stage.

²² <http://www.ypla.gov.uk/aboutus/> The Young People's Learning Agency (YPLA) was established by the Apprenticeships, Skills, Children and Learning Act 2009 and launched in April 2010. They are sponsored by the Department for Education and exist to support the delivery of training and education to all 16 – 19 year olds in England.

5.1.2 Health and Social Services

Responsibility for social care and health funding transfers from Children's to Adults Services at the age of 18. Although responsibility transfers at 18, some young people may continue in education until the age of 19. As such, many of their support needs may continue to be met at school. Responsibility for extra-curricular support, such as short breaks, respite and activities during holidays etc. will, however, fall to Adults Services. It is important, therefore, that these needs are flagged in advance to allow the services to plan.

The level of support provided, the level of funding, and the contributions of Health and Social Care to care packages and placements, are allocated according to outcomes of Continuing Care and FACS assessments. Some services are funded through direct payments or personal budgets, as discussed in section 3.6. Some packages in Children's Services may be jointly funded by Health and Social Care (or tri-funded with Education). Child and Adolescent Mental Health Service (CAMHS) contributions may also be arranged to support additional therapy within school packages for some individuals. In Adults funding is largely lead by either Health or Social Care, although there can be joint contributions to care in some cases.

5.1.3 Looked after children (LAC)²³

The Council has a statutory responsibility for children within their care (looked after children) until the age of 21. If the young person is in full time higher education (university) the responsibility continues until the age of 24.

If the young person has a disability (physical and/or learning disability) and is eligible for Adult Services the situation is slightly different. If they attend a day college or school or they are not in school, the young person would transition to adult services when they reach the age of 18. If the LAC are in a residential special school for either 38 or 52 weeks a year, and have a statement of special educational need, they would transition to adults at the end of the academic year (September-July) in which they turn 19²⁴. If the young person decides to leave school, however, sometime after their 18th birthday and their statement of special educational need lapses²⁵ they would move over to Adult Services as soon as it could be arranged.

If a looked after young person develops a mental health problem and goes on to need adult mental health services at 18 (regardless of whether they had been supported by CAMHS), Children & Families funding would cease at aged 18 as the young person is deemed an adult. Funding responsibility would be assumed by Adults Services (unless in a residential special school when the episode commences).

23 The term 'looked after' was introduced by the Children Act in 1989. A child is looked after by a local authority if he or she is in their care or is provided with accommodation for more than 24 hours.

24 If the young person's 19th birthday takes place after the start of the new academic year in September, funding would continue until the end of that academic year (July). If the young person's 19th birthday occurs before the September term has commenced (for example in August) funding would cease at the end of the preceding school year.

25 An explanation of why a young person's statement might lapse is provided in Appendix C.

Depending on the need of the looked after child, a child's placement may be solely funded by the Children & Families Department, or it can be joint or even tri-funded. Other contributors to the support package/placement include the Special Educational Need (SEN) department and NHS Westminster.

The number of disabled young people in care in Westminster remains low. This is due to the high level of family support that is offered to parents and carers in the community. Over the last 4 years only around 2-4% of the LAC caseload had a disability identified as their primary need when they became looked after (WCP 2010).

As at August 2010 there were 14 young people looked after between the ages of 3 and 19 with a disability of the severity which means they are likely to transition to adults services for specialist support. Seven were of transition age and 5 were in residential schools jointly funded with SEN (and some tri-funded with health). These represent around 5% of the total LAC caseload²⁶. This figure includes individuals with profound learning disabilities, autistic spectrum disorders or physical disabilities. It does not take account of looked after young people who may have social, emotional or behavioural issues, attention deficit hyperactive disorder (ADHD) or those who may receive services from CAMHS.

Looked after children in general are a vulnerable group, for example having higher than average drug and alcohol use, lower educational achievements and poorer health outcomes. Due to complexities surrounding this population and the fact that their needs can deteriorate very rapidly, individuals outside those with recognisable disabilities but who still have potentially high needs, who may require ongoing support as adults, such as mental health support, can be difficult to predict during the transition period. The Westminster Looked After Children team works to try and alert relevant adult teams as soon as needs are known. On a regular basis lists of LAC children with disabilities, whose current diagnosis suggests that they are likely to transition, are shared with the relevant adult services.

5.1.4 Other funding contributions - Independent Living Fund

The Independent Living Fund (ILF) is an executive non-departmental public body of the Department for Work and Pensions. The ILF is dedicated to the financial support of disabled people to enable them to purchase care so they can choose to live in the community rather than in residential care. A contribution towards care costs is in the form of regular four-weekly payments to individuals used to buy personal care in the community. Recipients may use care agencies or employ personal assistants, but may not employ relatives who live in the same house.

The eligibility criteria requires people to be of working age (between 16 and 65) to work 16 hours or more per week, and to need more personal and or domestic care help than their local authority is able to provide. Funding is not for equipment adaptations or mobility equipment.

(<http://www3.westminster.gov.uk/weldis/organisationdetails.cfm?contactid=6478>)

[accessed November 2010]

26 As at the end of March 2010 there were 247 children looked after by Westminster City Council.

The Government recently announced that the ILF will be phased out by 2015. It is currently closed to new applicants but there may be some individuals locally who are in receipt of funding. Payments to existing users are set to continue until 2015.

<http://www.bbc.co.uk/news/uk-11985568> [accessed February 2011]

5.2 Westminster's transition teams: strategic and operational

Westminster has a 'virtual' multi-agency transition team; staff are not co-located but come together for joint transition planning and sharing of information. This transition team includes service managers, case workers, therapists, Connexions Personal Advisers from Locality Teams and commissioners with responsibilities for transition across Children's and Adults Services²⁷. The team structure is supported by two joint multi-agency transition groups: an overarching Transition Strategy Group and a Young Persons Transition (YPT) Operational Group. These groups focus mostly on the transition of young people with physical disabilities, learning disabilities and sensory impairment. The transition of young people with mental health problems, without other disabilities, between child and adult mental health services, is, in the main, managed through a separate process, which is considered in section 9.

5.2.1 Multi-Agency Transition Protocol

Work has taken place within Westminster to develop a transition protocol governing the transition arrangements for young disabled people who require specialist support services as adults. The protocol is currently being finalised. It provides a framework outlining the involvement of different agencies in the transition of young people who have a statement of special educational need and/or impairment (physical; learning; sensory; chronic health; mental health need) that substantially impacts on their daily lives.

The protocol is designed to clarify responsibilities of the different agencies and ensure the smooth transition of all young people. The initial draft of the document has been developed for use by the relevant services as an internal document. The intention is for separate guidelines to be produced in due course for young people, parents and carers clarifying what they should expect throughout the transition process. These guidelines can be expected in 2011.

Published literature suggests that having a strategic multi-agency protocol helps to facilitate good transition. Some research advises that the protocol should include reference to financial agreements between agencies for supporting transition, such as commissioning, transfer of funding and pooled budgets (Singh et al. 2008). This is not something that the Westminster protocol currently details but could be considered for insertion at the protocol's 6 month review.

²⁷ The following professionals contribute to transition planning and assessment for young people: Children's and Adults' Social workers, Adult Services Clinical Psychologists, dedicated transition workers, Connexions Services, Community Paediatricians, Community Nurses, School Nurses, Specialist Child and Adolescent Mental Health Services (CAMHS), Occupational Therapists, Physiotherapists, Speech and Language therapists, Local Authority and school-based special educational need (SEN) support, class teachers, Education Support Services, Housing Teams, Youth Services, Young People's Learning Agency, Supported Employment and voluntary organisations.

5.2.2 Transition Strategy Group

The Transition Strategy Group is a multi-agency group with a responsibility to develop person-centred policies, procedures and protocols covering the transition from childhood to adulthood. Membership spans Children's and Adults Services, including representatives from the Special Educational Needs Department, Locality Young Peoples Services, which includes Connexions, the Children with Disabilities Team, commissioners and providers in Adults Services, voluntary and community sector organisations and representatives from the local special schools. It monitors the work of the Young Persons Transition (YPT) Operational group and meets on a monthly basis.

Service users and parents are not currently represented on the strategy group, which is something advised as good practice in the national *Transition Guide for Services*. The Transition Strategy Group has identified this as an area for development in its Self Assessment Questionnaire and there are plans in place to invite a couple of representatives to join the group (WCC 2010b).

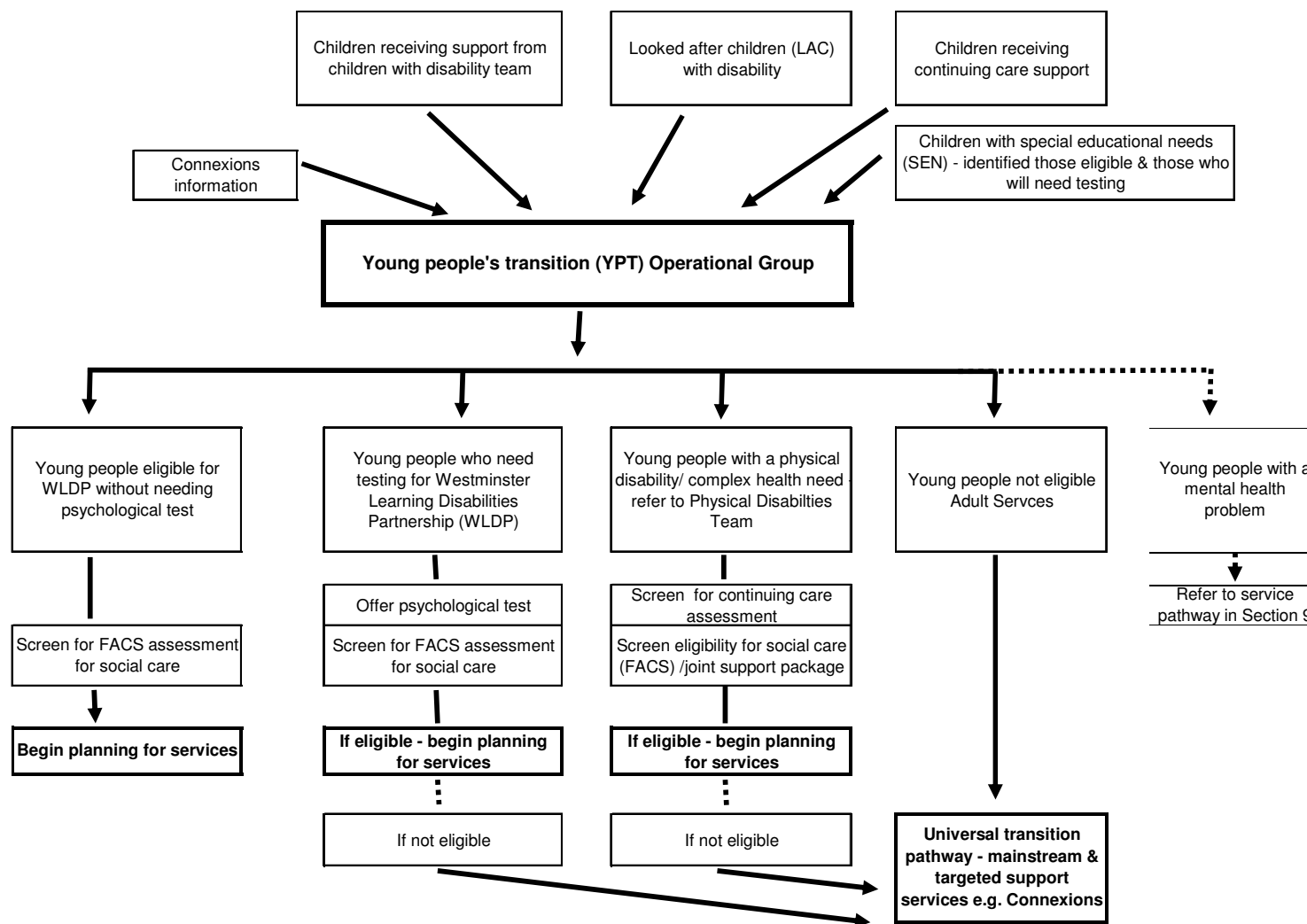
5.2.3 Young Persons Transition (YPT) Operational Group

The YPT Operational Group meets monthly to discuss young people going through transition, their care needs, their case worker allocation and the level of transition planning which has taken place. The group has a role to identify young people with a disability or complex health need who are currently known to services in Westminster, including the Special Educational Needs Team, who are approaching transition age (Year 9 onwards) and potentially eligible for Adults Services. This includes young people who are educated both in and out of borough. They also have a responsibility to ensure that relevant departments in Adults Services (e.g. Learning Disabilities and Physical Disabilities) are aware of, and engaged with, those young people as necessary. They identify gaps in service provision for young people going through transition and pass these onto the Transition Strategy Group and commissioners of services as necessary. Individuals who are not eligible for Adult's Services are fed into the 'universal' transition pathway, with support from Connexions.

The YPT Operational Group has a wide membership across relevant teams in Children's and Adults Services in contact with young people going through transition. These include representatives from local special schools, the Children with Disabilities Team, the Westminster Learning Disabilities Partnership, Locality Young Peoples Services/Connexions, the Special Educational Needs Team, care managers, occupational therapists and physiotherapists. It is jointly chaired by the Children with Disabilities Team, the Westminster Learning Disabilities Partnership and Connexions. There is a group of core members and quarterly representatives from Child & Adolescent Mental Health Services, Westminster Leaving Care Team (WALC), Looked After Children and Adults' Physical Disabilities Team are invited to attend. The agenda is agreed in the month preceding the meeting and each quarter focuses on a specialist area, such as Connexions, Adult's Services.

Figure 8 shows these different teams work together around a young person's transition.

Figure 8: An overview of the work of the Young People's Transition Operational group and the information that feeds the group



5.3 Financial planning

One aspect of transition planning that has been noted within previous local strategies and needs assessments has been the need for a 'fair warning' system. It has been recommended that a better system to warn Adult's Services of the severity of young people's disabilities who will be reaching transition should be developed. This would enable Adult's Services to allow for adequate planning (NHSW, WCC 2009). Anecdotally there is good communication between commissioners in Children's Services and Adult's Services around complex cases with expensive support packages who are likely to transition. However, the system needs to be formalised to ensure that all cases are carefully accounted for during financial and service planning. As will be discussed in section 5.4 this may be something to be considered for the future when looking at improving data sharing between teams.

Financial planning for the following financial year takes place between October and December. In order to budget, Adults Services need to forecast potential costs incurred by new referrals to the services. Although some people may move into the area at age 18, the transition group are in the majority a 'known population'. It is useful for financial planning to have as much information as possible about those likely to transition. As well as the budget for the forthcoming year, summary budgets have to be made for the following 2 years. Anyone not included in cost forecasts becomes an in-year cost pressure.

Although it is acknowledged that the needs of young people may change around transition, and current needs and service usage are not necessarily going to remain the same once the young person leaves education, information on current needs does provide an indication of likely future needs.

For financial planning in Adults Services, it is therefore useful to have an indication of:

- numbers of young people likely to transition to which service in the next financial year
- an idea of when that young person will turn 18 (date of birth)
- the current placement of the young person, whether it is in or out of borough and whether it is likely that they will remain in their current placement beyond the age of 18
- whether it is likely that Adult Services will have to contribute to funding the current placement at 18
- an idea of current costs of placements and additional care packages, along with current funding sources
- an indication of whether the young person is likely to require a low, medium or high cost support package on transition to Adult Services
- if the information in the assessment or transition plan could build in information around type of accommodation or care packages expected.

As noted above, the ages at which young people might transfer, and tracking whether they will be eligible/have been tested for Adults Services is complicated. Different teams hold different information on the young people. A further complication is that the numbers of young people transitioning each year varies, although the majority are

known to local services. Forecasts have to be based on combinations of young people who are known about and young people who have come through in the past. It is important therefore that information on young people likely to transition is shared across teams and also between teams within the same departments to allow financial and support planning to be initiated.

Currently, some assumptions are made within the planning process. For young people transitioning to the Westminster Learning Disabilities Partnership (WLDP), for example, it is assumed that the young person will transition mid way through the year, unless the exact date is known. Similarly if the young person is likely to require residential support then an estimated cost of £2,000 per week is forecast. The more information is shared on current need and estimated future need, the more accurate these estimates can be.

Despite adequate planning, it is likely that there will be some surprises. It is possible that support needs may change and the circumstances and future plans outlined in a young person's transition plan may no longer work on transition. To help prevent surprises, where possible it is important that as much information is shared, as early as possible and that this is updated as needed, for instance if new individuals move into the borough in-year.

5.4 Data sharing and data storage

Evidence collected for the literature review highlighted the importance of having good information systems for data collection and systems in place for data sharing to prevent losing vulnerable young people at transition. Young people with physical disabilities without learning difficulties and those educated out of borough were highlighted as a group who were most at risk of being missed through not being on a centralised list. The implication is that these young people may have unmet needs – including medical, therapeutic, equipment, social care needs (Ko & McEnry 2004). (Refer to the literature at the end of the document for more detail).

Information on young people who are in the process of transition in Westminster is stored in different places and, sometimes, using different software. Information is separately recorded, for slightly different purposes, by the:

- Children with Disabilities Team
- Looked After Children Team
- Children's Commissioner for Continuing Care in the NHS
- Special Educational and Additional Needs Services
- Locality Young Peoples Services/Connexions.

The Westminster Learning Disabilities Partnership (WLDP) in Adults also maintain a transition database, which monitors the young people currently known to services or to education who will likely to be eligible for their services when they turn 18. This enables the WLDP to do adequate forward planning. It does not currently, however, contain any cost information.

Whilst these databases serve the purposes of individual teams, and contain information which would not be of relevance to other teams, there is an

acknowledgement locally that a pooled database is needed with key information about young people with disabilities aged 13 to 25 going through transition in Westminster. It is suggested this should include both key personal information and details of the services they are currently in touch with, as well as whether the level of transition planning which has taken place. Initial discussions have begun around what information needs are common to the different teams and what needs to be in the shared database. However, IT solutions for the proposed model are yet to be realised. Access to the database would need to be tightly controlled and managed to maintain client confidentiality.

Initial discussions for data to be included have suggested the following headings:

- SWIFT id (Adult Social Services database)
- name
- date of birth
- age
- gender
- ethnicity
- address (residential and young person's address if different)
- lead professional
- diagnosis
- whether the young person has been tested for learning disability/ needs to be tested
- statement of special educational need
- Coreplus reference (individual reference on Connexions CCIS database)
- whether they have a person centred plan
- whether they have a health action plan
- school/other educational, employment, training currently receiving
- borough of school
- cost of education/placement
- outreach/ short breaks provision.

Introducing a form of data sharing whereby the data held on these young people by different teams can be shared, updated and checked by a range of people will make the process of transition between services more efficient and ensure that young people are not missed. It will also help enable future planning for Adults Services around the numbers of people coming through, their level of need and the cost of their support packages.

In the interim, the Westminster 'Moving on Protocol' highlights the importance of the Children with Disabilities Team, Special Educational and Additional Needs (SEAN) Services, Looked After Children Team and Children's Commissioners continuing to pass information about disabled young people known to them, and currently in years 9 and above, to the relevant Adult Service Teams and commissioners (in social care and health) on a regular basis. This will enable the planning and provision of services for disabled young people when they reach the age of 18/19 on a regular basis. Where teams in Children's Services are aware of young people moving into the area during the transition years they should forward that information on to relevant Health and Social Services in Children's and Adults. It is important this process is established and documented both for young people with learning disabilities but also physical disabilities.

It is noted in *Aiming high for disabled children better support for families* that a number of Local Authorities have developed methods of collecting data for disabled children and their families in a successful way. They cite the example of Halton which uses a single data set, which includes all health, social services and education data available on their vulnerable children population to improve communication, eligibility assessment and commissioning of services. At its core, the Local Authority maintains pupil-centred data relating to pupil service, early years, grants and benefits (Free School Meals), Common Assessment Framework, Special Educational Needs and Admissions. However, beyond its core, it utilises information from a very wide range of organisations and information sources which affect the lives of children, including Youth Offending Teams, Colleges, Looked-After Children, the Traveller Service, exclusions, PCT 0-3 year olds, Connexions (including children not in education, employment or training), non-Halton schools, academic performance, and many more. Whilst this database serves a wider purpose than the database solution proposed for Westminster it may be useful in planning what is required locally to consider how other Councils have developed data sharing systems around transition (DH, DCSF 2008a).

6 Transition for children with special educational needs

Young people who make the transition to Adults' Learning Disability Services will have had statements of special education need whilst at school. Statements of special educational need (SEN) enable children and young people with particular needs to access special educational provision to support them in their learning, whether in mainstream or special schools. Not all young people with a statement have a cognitive impairment or learning disability. SEN statements can be provided to young people who have sensory or physical impairments or complex medical conditions which impact on their ability to learn at school without support. Some of the young people who make the transition to Adults' Physical Disability Services will have had SEN statements.

This section focuses on the transition of children with special educational needs, particularly those with moderate and severe learning disabilities. It provides a profile of both the SEN population and the population who make the transition to the Westminster Learning Disabilities Partnership (WLDP). Young people with physical disabilities and sensory impairments, with or without SEN statements are discussed in more detail in section 7. Although it is recognised in this section that a large proportion of the Children with Disabilities Team's caseload is made up of young people with learning disabilities, the profile of the caseload as a whole is discussed in more detail in section 7.

6.1 Definition of special educational need

Children with special educational needs (SEN) are defined in the Special Educational Needs Code of Practice (2001) as children who 'have a *learning difficulty* which calls for *special educational provision* to be made for them.' The code of practice goes on to explain that:

Children have a *learning difficulty* if they:

- a) have a significantly greater difficulty in learning than the majority of children of the same age; or
- (b) have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority
- (c) are under compulsory school age and fall within the definition at (a) or (b) above or would so do if special educational provision was not made for them.

Children must not be regarded as having a learning difficulty solely because the language or form of language of their home is different from the language in which they will be taught (DfES 2001).

Local Education Authorities (LEA) have a statutory duty to identify and make an assessment of the children for whom they are responsible who have special educational needs and who may need a statement²⁸. The majority of children with special educational needs will not need a statutory assessment; their needs will be met

²⁸ Sections 321 and 323, Education Act 1996

effectively within mainstream settings through *Early Years Action* and *Early Years Action Plus* or *School Action* and *School Action Plus*.²⁹ More information about the SEN statement process is given in appendix C.

The number of young people receiving *School Action* or *School Action Plus* is much larger than the cohort with statements of special educational need. This group of young people however are very unlikely to have needs of a severity which will meet the eligibility criteria for Adults Service, and are therefore not explored further within this needs assessment.

Children receive SEN statements for a wide variety of reasons and many will not transition to Adults Services.

6.2 Transition process for young people with special educational needs

All young people with a statement of special educational need (SEN) are required to have an annual review. The review considers the educational and other support needs of the young person, their progress at school and whether any changes are needed in specialist provision to support the young person, and thus to the statement. It is the responsibility of the Local Authority SEN Department to ensure this happens. The annual SEN review from year 9 onwards provides a framework for many of the transition processes for statemented children, including the development of their Transition Plan. The flow chart in Figure 9 shows the transition process for young people with SEN statements diagrammatically.

6.2.1 The year 9 SEN annual review

The year 9 annual review offers the opportunity for individuals closely involved with the young person to address concerns and identify any special support required to achieve the young person's future goals and aspirations. The aim of the annual review in year 9 and subsequent years is to:

- review the young person's statement
- draw up and subsequently review the young person's Transition Plan (DfES 2001).

It is the school's responsibility to convene the annual SEN reviews for their statemented pupils. If the young person is educated outside a school setting this responsibility falls to the SEN team (DfES 2001). This process is required for statemented children who are educated locally, in Westminster, and those out of borough.

²⁹ *School Action* is used when a child is identified as needing interventions that are in addition to or different from those provided as part of the school's usual curriculum and strategies. *School Action Plus* is established when the child's needs are such that the school needs to seek advice and support from external support services, which may be provided by the local Education Authority (LEA) or other, outside agencies. <http://www.charteredpsychologist.co.uk/education-learning/special-needs.htm> [accessed December 2010]

The review should involve agencies which play a major role in the young person's life currently and in the future (multi-agency). A representative from the Connexions Service is required to contribute to the year 9 review. If the statemented young person is subject to a care order, accommodated by the local authority or is a 'child in need', social services departments are required to ensure that a social worker attends the review and contributes to the transition plan (DfES 2001). Looked after children have six monthly care reviews, which if possible, should be coordinated with the SEN review for those with a statement (WCC 2010i).

The following individuals should attend the review:

- Young person (where possible attend part of the review)
- Parent/Carer of the young person (or relevant representative for looked after child)
- SEN representative
- Key teacher at school
- Connexions.

The following should be invited (as relevant) or asked to contribute to the review in other ways:

- Health professionals, such as school nurse
- Social services
- Other professionals working closely with the young person

If invitees are not able to attend in person they are encouraged to send written information to inform discussion at the meeting and any relevant reports. The outcomes of the reviews are shared with the participants and contributors to the review.

The SEN code of practice explains that health professionals involved in the management and care of the young person should provide advice towards transition plans in writing and, wherever possible, should attend the annual review meeting in year 9. They should advise on the services that are likely to be required and should discuss arrangements for transfer to adult health care services with the young person, their parents and their GP. They should facilitate any referrals and transfers of records, which may be necessary, subject to the informed consent of the young person and parents, and should liaise with the Connexions Service as appropriate (DfES 2001).

6.2.2 The SEN transition plan

The Code of Practice for Special Educational Needs (DfES 2001) stipulates that the transition plan should draw together information from a range of individuals within and beyond school in order to plan comprehensively for the young person's transition to adult life. Transition plans when first drawn up in year 9 are not only about post-school arrangements but should also plan for on-going school provision, under the statement of SEN as overseen by the Local Education Authority.

The statutory transition plan, drawn up as part of the annual review process, is shared with individuals participating in the annual review. The plan is primarily an education document but it is also supposed to include some information about future support

needs and have person-centred components around aspirations of the young person. National guidance and strategies such as *Valuing People Now* have, however, seen the transition plan as a document which is ‘person-centred’, more inclusive and covers wider aspects of a young person’s life in addition to training and education, such as employment, housing, leisure, personal and social development, transport needs and health needs (this is discussed in more detail in section 3).

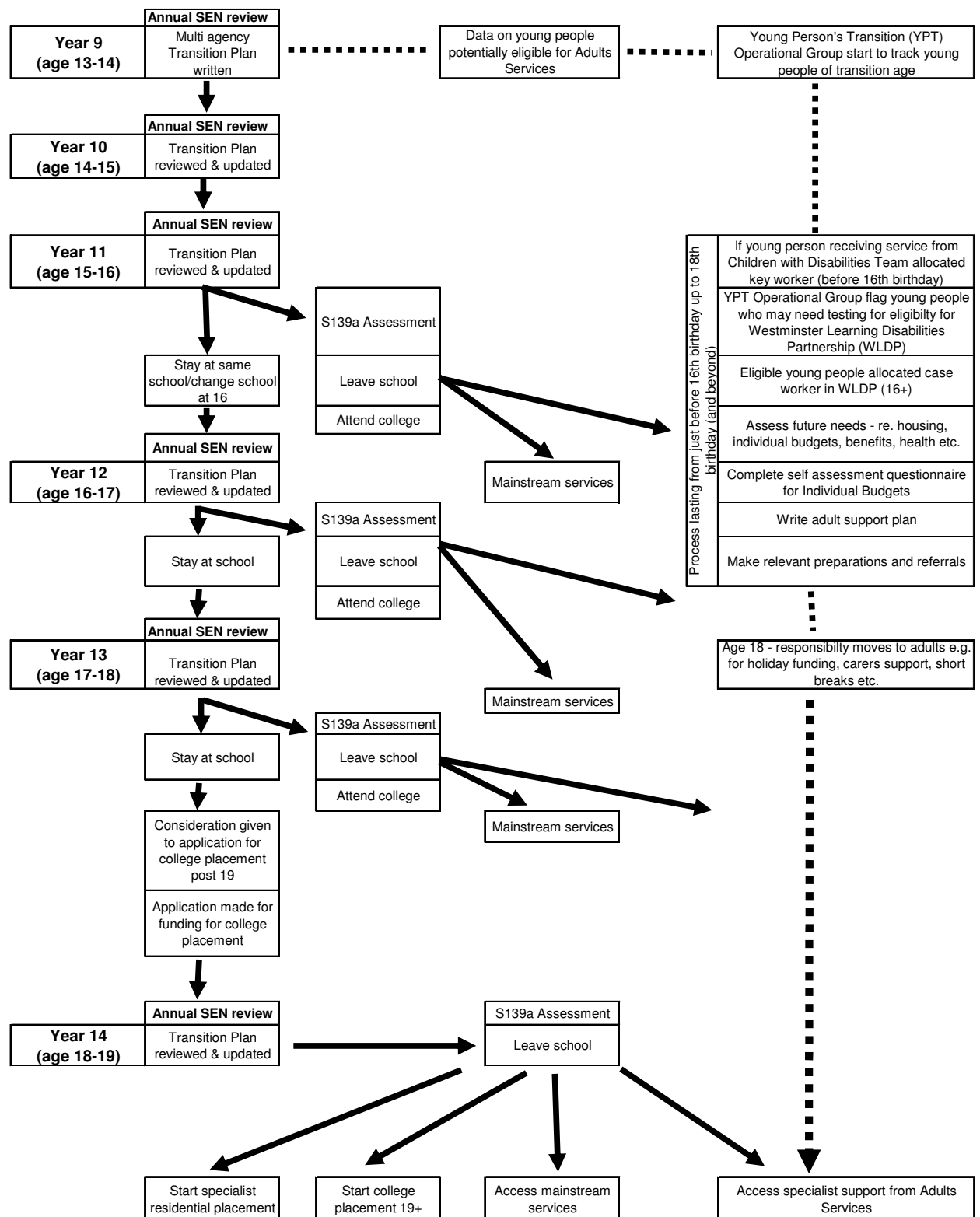
All children who are looked after by the Local Authority (LAC), including those with a SEN statement, are required to have a pathway plan in place on their 16th birthday. This builds on their Care and Personal Education Plans and maps out their pathway to independence, including education, training and employment. As the pathway plan fulfils a similar function to the Transition Plan it is seen as good practice that they should be included in the same document to avoid unnecessary duplication for the young person (DfES 2001).

6.2.3 Year 11 and subsequent reviews

The year 11 annual review is also significant within transition planning. This is because year 11 is the last statutory school year; it may also be a year in which the young person changes school or moves to college. If this is the final year of school and the young person intends to move into training or education the Local Authority has a duty to complete a S139a assessment around future training needs and provision (outlined in section 6.2.4 below); in Westminster this duty is discharged by Connexions. Consequently a representative from Connexions is expected to attend the year 11 review.

Where post-16 educational provision for the young person has already been identified, the SEN code of practice indicates that it is good practice for a representative from the future training/education provider to be invited to attend the annual review meeting in the final year prior to the change. Similarly, if the young person is transferring to Adult Services it is encouraged that a representative from the service attend the review in the year of transfer, if not before.

Figure 9: Flow chart showing the statutory SEN annual review process and elements of the multi-agency support through transition for young people with learning disabilities³⁰



³⁰ The pathway for young people with physical disabilities is similar, discussed in more detail in section 7.6.

6.2.4 Connexions responsibilities for children with SEN statements

Connexions is part of Locality Young Peoples Services within Westminster. As discussed in section 3.1.2 the service offers access to universal support for young people aged 13-19 and a more targeted service up to aged 25 for young people with learning disabilities and difficulties (LDD). There are Connexions Personal Advisers (PAs) in Westminster with responsibilities for working with pupils at the two special schools within the borough, College Park and Queen Elizabeth II Jubilee; the PAs also work closely with the Children with Disabilities Team and Adults Services. Where Westminster residents with complex needs are educated out of borough the expectation is that the 'host' Connexions service leads on transition information, advice and guidance.

The Local Authority has specific statutory duties for children with statements of special educational need (SEN) around transition, some of which are discharged by Connexions in Westminster. For instance, section 139a of the Learning and Skills Act 2000 requires the Local Authority, discharged by Connexions, to make a formal assessment of a pupil's learning and training needs and requires that appropriate post-16 provision is identified. Connexions PAs have to attend year 9 transition reviews and should be involved at further reviews to ensure that the pupil's transition plan is created and updated appropriately (DfES 2001).

When the young person with a statement leaves school to progress to education or training the Local Authority/Connexions PA has statutory duties to ensure an S139a assessment is carried out. This should be completed in the pupil's last year of school. It is intended that the Section 139a Assessment includes a realistic recommendation for the future provision of education and/or training for the young person, considering a range of factors which may impact on the choices open to the pupil, including tuition, independence, personal care, therapy and counselling and equipment. It should incorporate the professional opinions of those involved in transition planning and support for the pupil, such as the Special Educational Needs Coordinator (SENCO), parents/guardians, educational psychologists, health professionals, social workers and teachers. It should be prepared in conjunction with the annual SEN statement review and the transition plan started in year 9. On completion, the plan is shared with the young person and their parent and carers; with their consent future education/training providers; and, if relevant, the SEN department. This duty exists whether the person is educated in Westminster or outside borough.

Connexions PAs attend annual reviews and undertake S139a assessments for all statemented young people in Westminster Schools (i.e. not just Westminster resident pupils). Where a young person from Westminster is in out of borough educational provision, Westminster's Connexions service will liaise with the host (out of borough) Connexions service over the provision of information and guidance, and to support their successful transition at the end of their statutory schooling. It is expected that the Connexions PA linked to the host placement will provide the ongoing support for the young person and their family (WCC 2010i). Due to national changes to Connexions services and funding, however, this support is variable. In addition to working through the host Connexions service, the Westminster Connexions PA will contribute to the annual reviews where necessary to ensure the transition process is

running smoothly and invite the young person and their family to local appointments outside of term-time to explore local provision opportunities for the future.

If the young person is intending to leave school at the end of Year 11, the transition plan should clarify whether the young person wishes to attend a local college and whether this local facility can meet his or her needs. If a specialist college is likely to be required the Connexions Personal Advisor can support the process of applying for a college placement and support the process of funding applications (this is discussed in more detail in section 5.1.1).

6.2.5 Children with Disabilities Team

Many of the children and young people on the caseload for the Children with Disabilities Team have a learning disability and have a SEN statement. The Children with Disabilities Team are engaged with these young people throughout their transition to Adult Services. (More detail on the Children with Disabilities Team is provided in section 7.2).

The Children with Disabilities Team aims to allocate all potential transition cases within their caseload to the Transition Social Worker, another social worker within the team or the Connexions worker attached to the team before the age of 16. The role of this worker is to help facilitate the transition planning until the age of 18 and the handover to Adults Services. This includes raising the young person and their family's awareness of the changes at transition, introducing them to their appointed case worker in Adults Services and providing support in the completion of the self assessment questionnaire and help in drafting the Adults support plan for the young person.

These responsibilities exist for young people in contact with the service placed in and out of borough. For children with SEN statements educated in local special schools, where possible, their allocated social worker/ another representative from Children with Disabilities Team aims to attend their reviews in years 9-11 (NHSW 2010).

These responsibilities are outlined in the transition protocol between the Children with Disabilities Team and the Westminster Learning Disabilities Partnership. A similar written transition protocol is not currently in place between the Children with Disabilities Team and the Physical Disabilities Team in Adults Services. The Children with Disabilities Team, however, provide similar support in the transition of young people on their caseload who have a physical disability or complex health need but do not have a learning disability to that detailed above.

6.2.6 Receiving teams in Adults Services

The Young Person's Transition (YPT) Operational Group in Westminster has a role to ensure that a named worker from Adult Services is appointed to monitor progress of disabled young people known to education or other services, with a view to identifying the need for additional services to be undertaken prior to their 18th birthday, such as:

- Consideration of a psychology assessment (for learning disabilities)
- Making the arrangements for continuing support

- Determining any need for housing.

These young people may be those who are currently receiving support from Children and Families, including Children with Disabilities or Looked after Children but also those not receiving an additional service but known to the SEN team through the child's statement.

6.2.7 Westminster Learning Disabilities Partnership

Support for adults with learning disabilities in Westminster is coordinated by the Westminster Learning Disabilities Partnership (WLDP). The WLDP is an integrated health and social care service for adults aged 18 and over (including those aged 65 and over). The team includes occupational therapists, physiotherapists, speech and language therapists, nurses, psychologists and psychiatrists as well as care managers. The multi-agency team supports those with a learning disability who meet the eligibility criteria, some of whom may also have complex needs and challenging behaviour and individuals with a dual diagnosis of mental health and learning disabilities. The WLDP provides some services for people with autistic spectrum conditions, providing they meet the eligibility criteria.

The Partnership has recently been restructured in order to better meet the needs of adults with learning disabilities and their carers. Provision is based around three teams, all of which include health practitioners:

- Team 1 - has responsibility for all new users, young people in transition and people on review services³¹. All people in Team 1 have an allocated case worker or a person directly responsible for their reviews.
- Team 2 - has responsibility for all housing and support options, and responsibility for those people in residential care and supported living.
- Team 3 - has responsibility for the support and management of all those who additionally have a mental health diagnosis, including those with complex and continuing health needs, and the support and care planning of those who meet criteria of the Flexible Response Service³². This team also works with people with complex challenging behaviours who need ongoing case management/Care Programme Approach (CPA) coordination and intensive/flexible support services (WLDP 2010).

Through Team 1 the Westminster Learning Disabilities Partnership tracks potential transition cases from the age of 14. The team aims to allocate all eligible transition cases to an Adults' case worker when the young person is 16 years old, who helps with support planning. If there are questions as to the young person's eligibility they are referred to psychology for testing prior to allocation. These processes should happen whether the young person is placed within or outside the borough.

³¹ Service users living with their families or independently and whose care package is working well (those who do not need an active case manager or a new assessment for services) are transferred to 'Review Services'. A named worker in team one is responsible for carrying out the reviews for this group.

³² The Flexible Response Service is an integrated assessment and intervention service that provides direct support for day opportunities as well as short-term, long-term and ongoing clinical support to individuals with learning disabilities living in Westminster who have challenging behaviour.

The role of the case worker is to:

- Work in partnership with the designated social worker from the Children with Disabilities Team and Connexions Personal Advisor (PA);
- Provide information and advice about Adult Services and resources;
- Ensure any additional information is obtained for the purposes of community care services e.g. housing needs, short breaks, employment, colleges
- Consider whether a Continuing Healthcare assessment will be needed
- Consider an Independent Living Fund application
- Consider the use of a personal budget and support the service user to complete the Self Assessment Questionnaire.
- Offer Direct Payments
- Offer a Carers Assessment
- Prepare Adults Support Plan prior to 18th birthday (WCC 2010i).

Where it is thought that a young person may leave school prior to year 14, if social care services are required, then an Adult Care Services representative should attend the school annual SEN review in the pupil's last year (DfES 2001).

The intention is that all eligible young people in transition will be supported with self directed care and a self assessment questionnaire. It is the responsibility of the named case worker from the Westminster Learning Disabilities Partnership to set up (if necessary) the care package for when the disabled young person reaches 18 and transfers to Adults Services. The agreed support plan, together with any care package, should be ready to be put in place at least 12 weeks prior to the young person's 18th birthday. The service's principles stipulate that all support plans and care plans need to include plans about getting paid work (in particular), voluntary work, work experience, training and education, developing independence and being full members of the local community. They also plan that the young people coming through transition should also have a Health Action Plan in place (WLDP 2010).

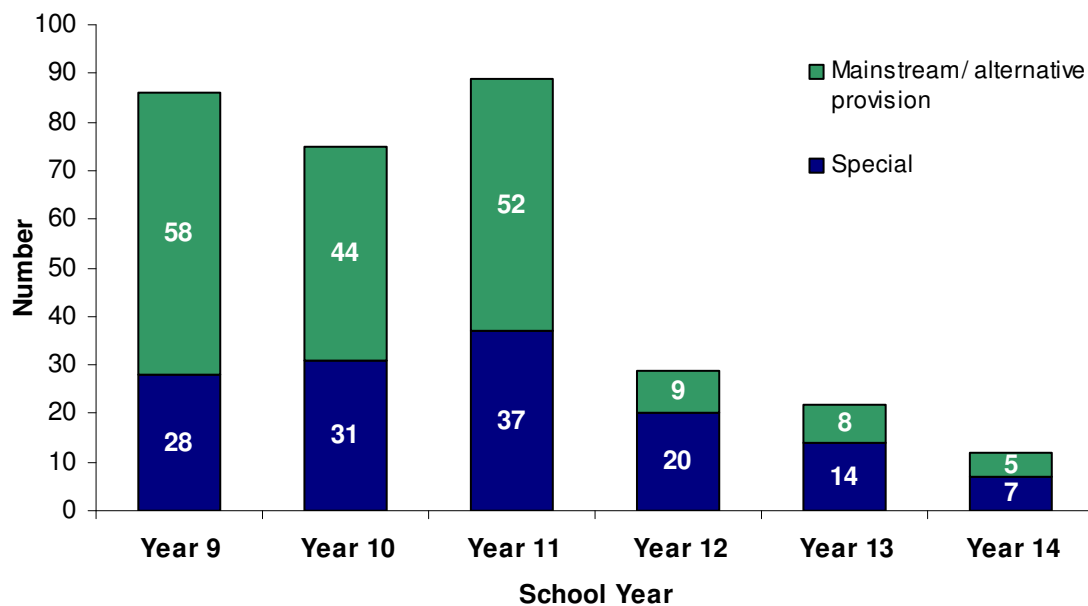
An informal Fair Access to Care Services (FACS) assessment is conducted by the YPT operational group at age 16+ to consider potential eligibility for a social care package. It is useful at this age for parents/carers to have an early warning regarding FACS criteria (refer to section 4.1 for more detail). All clients may be offered an assessment but not all will be eligible for services or meet the FACS criteria for a social care package. For instance, some young people assessed for a learning disability may have health needs and be referred to a clinician but may not meet FACS criteria. The formal FACS assessment is done when the young person transitions to Adult Services at age 18.

6.3 Profile of SEN transition population in Westminster

Westminster City Council currently (as at 9 November 2010) administers the statements of 313 pupils in school years 9-14. Just over half of pupils are educated in mainstream schools, with a further 43% in special schools and around 5% in alternative provision³³.

33 All of the pupils in 'alternative' provision have some form of educational, social and/or behavioural difficulty. This group are excluded from this needs assessment as they do not have a disability or complex health need but they are included in the total SEN population data here for information.

Figure 10: Total cohort of pupils with SEN statements (Westminster) by type of school provision, years 9-14 (n=313)



Source: SEN Department, Westminster City Council, November 2010

There is a clear decline in the number of pupils with SEN statements in years 12-14. These pupils are past the statutory school age and this drop is likely to reflect pupils:

- leaving school
- moving to employment
- moving to further education provision (colleges) whereby they are no longer funded through a statement but through the Young People's Learning Agency (YPLA)
- moving to a specialist residential placement, whereby they are no longer funded through a statement but through the YPLA.

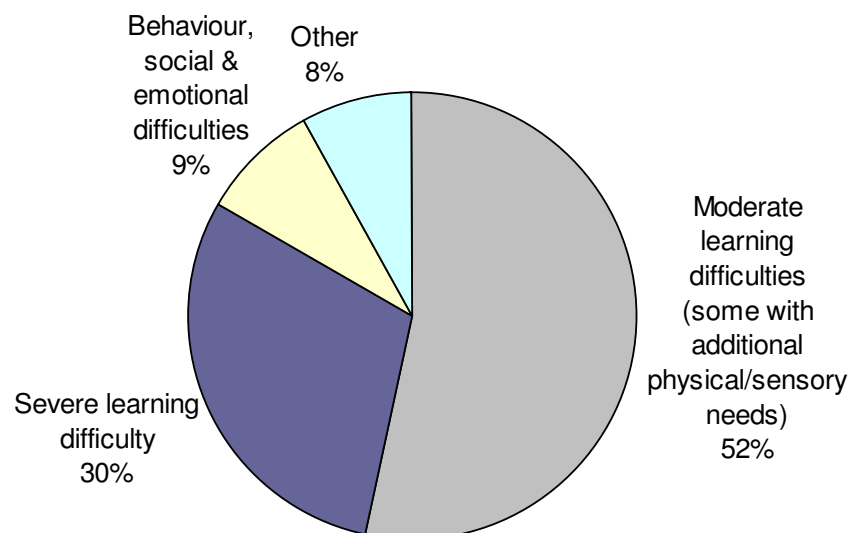
Most of the young people with a SEN statement who are educated in mainstream schools will not have a disability of the severity that would entitle them to transition to Adult Services. A much greater proportion of young people educated in special schools will transition to Adults Services due to the severity of their disability. That being said, not all pupils at special schools will make the transition.

The majority of the pupils at special schools (52% (n=71)) (Figure 11) are classed as having moderate learning difficulties (some of whom may have additional physical or sensory needs). Only a proportion of this group will meet the criteria for the Adult's Learning Disability Services; some may meet the criteria for the Adult's Physical Disability Team. 9% of the special school population have behaviour, social and emotional difficulties and are therefore unlikely to meet the criteria for Adult Services.

Only those young people with a severe learning difficulty, who represent 30% (n=41) (Figure 11) of the pupils, by virtue of the type of school they attend and their level of disability, are highly likely to meet the criteria for Adult Learning Disability Services. This includes a few individuals with severe autism. The remaining 8% of pupils

described in Figure 11 as 'other,' include those with sensory impairments, dyslexia and speech and language difficulties, as well as a couple for whom no primary need was detailed. Among this group it is likely that those individuals with sensory impairments may have some ongoing needs.

Figure 11: Breakdown of primary needs of pupils with SEN statements in special schools, years 9-14 (n=137)



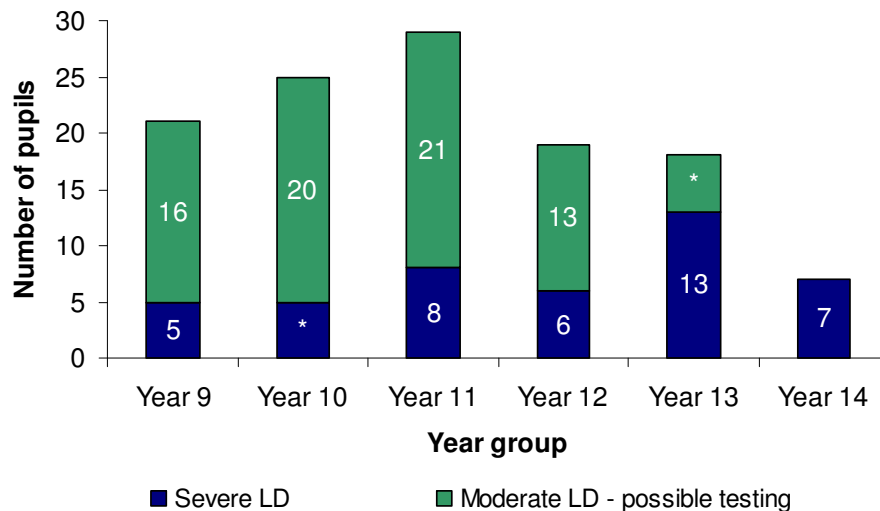
Source: SEN Department, Westminster City Council, November 2010

Refer to appendix D for a breakdown of the primary needs of all pupils with SEN.

Figure 12 provides an indication of the pupils with SEN statements educated in special schools that are likely to transition to Adult Learning Disability Services. It divides the population between those with a severe learning disability and those with a more moderate learning disability who may require a psychology assessment before their eligibility for Adult Services can be confirmed.

There is a historic understanding between the SEN department and the Westminster Learning Disabilities Partnership (WLDP) that pupils identified by the SEN department as having a severe learning disability will not need testing and will qualify for services from WLDP (by virtue of their disability and the type of provision required to meet their needs). Those with more moderate learning disabilities attending special schools are likely to need testing. This refers to potential eligibility based on psychological testing. Although the psychological assessment may indicate the young person has a learning disability these individuals may not meet the additional eligibility for receiving a specialist service, as examined through NHS Continuing Care or Fair Access to Care Services (FACS).

Figure 12: SEN pupils in special schools indicating the likelihood of eligibility for Adult Learning Disability Services (n=113)



Source: SEN Department, Westminster City Council, November 2010

Note a few of the young people here classed as having moderate learning difficulties for ease due to their school provision; they may have physical disabilities and may transition to the Physical Disabilities Team as adults rather than Learning Disabilities.

* refers to boxes where there are ≤ 5 young people in this category but the exact number cannot be disclosed to protect confidentiality.

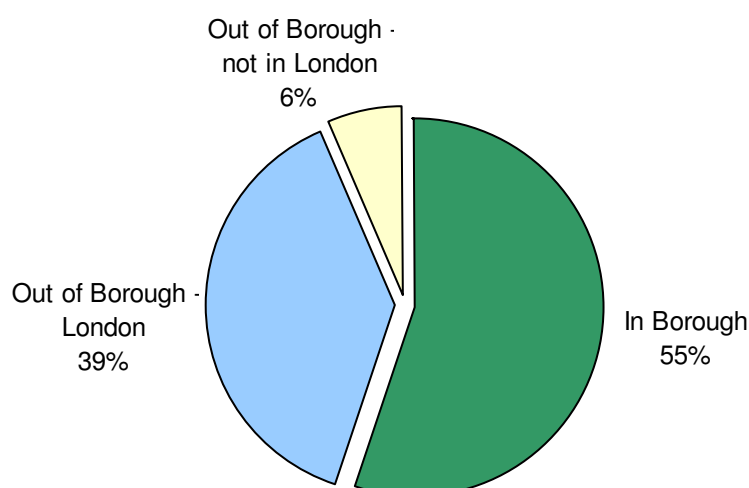
Schools for young people with special educational needs are chosen based on their ability to meet the specific needs of the young people as identified in their SEN statement. Where possible suitable places are found within the local borough's special or mainstream schools. Residential placements are only sought in exceptional circumstances. Generally young people in residential provision fit into one of the following categories:

- the child has severe or multiple special educational needs that cannot be met in local day provision
- the child has severe or multiple special educational needs that require a consistent programme both during and after school hours that cannot be provided by parents with support from other agencies
- the child is looked after by the local authority and has complex social and learning needs, and placement is joint-funded with the social services department
- the child has complex medical needs as well as learning needs that cannot be managed in local day provision and the placement is joint-funded with the health authority (DfES 2001).

The location of a young person's school is important for their transition. Returning to Westminster if their school placement has been outside of Westminster (especially if it was outside London) brings additional challenges to the transition process. Some of these are discussed in the literature review at the end of this document. As Figure 13 shows, the proportion of young people who are schooled outside of London in residential placements is small, but for these young people the transition process is more complex. Over half of the pupils attend one of the two local special schools

either College Park (n=42) or Queen Elizabeth II Jubilee School (n=19). The remaining pupils attend a range of 24 different schools, related to individual need; the schools with ≥ 5 pupils on this list include Richard Cloudesley in Islington, Woodlane High in Hammersmith and Field Heath in Hillingdon. The majority of these pupils are in day school provision, with only 6% attending residential schools.

Figure 13: Young people with SEN statements and learning disabilities educated in special schools in years 9-14 by location of school (n=113)



Source: SEN Department, Westminster City Council, November 2010

Note this graph does not include pupils who attend a special school for the deaf.

Detail of the cost of placements for young people with SEN statements is provided in appendix E.

6.4 Profile of learning disabilities transition population in Westminster

The Westminster Learning Disabilities Partnership (WLDP) maintains a list of young people who are potentially eligible for their service who are currently in year 9 and above in school (or equivalent age). This database includes those who are certain to meet the adults criteria based on where they are currently schooled and their SEN statement, and those who will require testing. It tracks them through the transition process. This list is fed by information from the Children with Disabilities Team and the SEN department as well as the Looked After Children Team, which are provided on a regular basis.

This database provides the best pooled information about the prospective learning disabilities transition population. All the individuals on the list have a perceived learning disability which needs to be/has been verified by psychological test or another method. It is not thought that a similar list exists for tracking young people with physical disabilities or young people with mental health problems.

An idea about numbers of people with learning disabilities transitioning can also be collated using data from SWIFT, the adult social care database, on new referrals to the

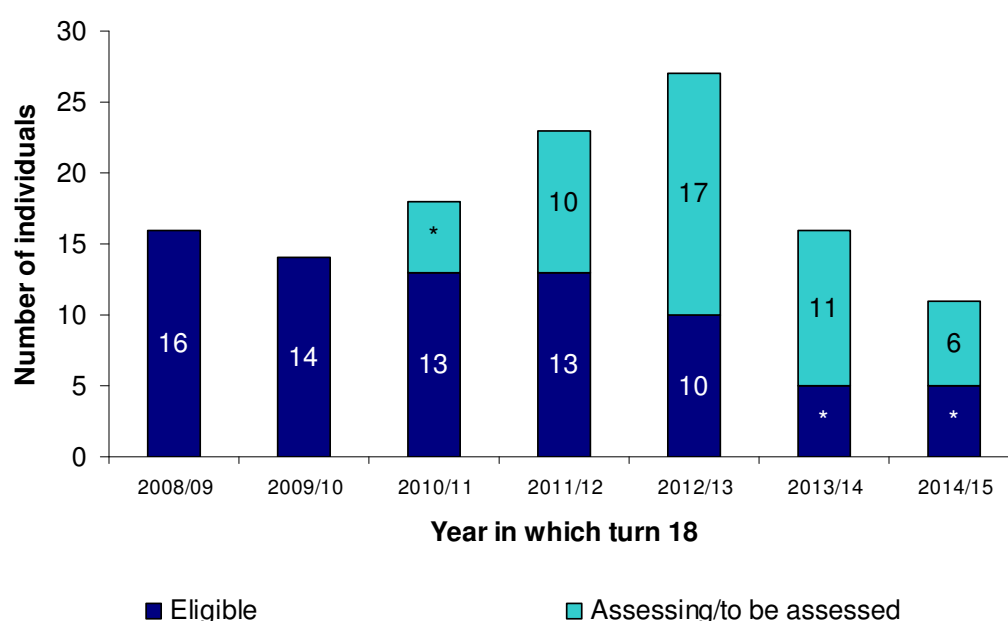
services over the last 5 years to different teams within Adults Services. This will be used to provide a retrospective picture of transition.

6.4.1 Westminster Learning Disabilities Partnership transition database

Figure 14 shows the number of young people being tracked by the Westminster Learning Disabilities Partnership (WLDP) through transition. It breaks down the numbers who have had a psychological assessment or have otherwise been found to be eligible for Adults Services and those who are currently being assessed or awaiting an assessment. All of those who were 18 in 2008/09 and 2009/10, who were found to be eligible, are recorded on SWIFT as new referrals for Adults WLDP (more detail below).

It should be noted that this database is constantly being updated and the contents reflected here are as at the beginning of October 2010. The information for the new intake in year 9 in special education is not added to this list, which is why the columns towards the right are smaller than might be expected. The WLDP team aim to assess young people at or around the age of 16. Not all the young people on the tracking list are likely to be eligible for transition; over time, therefore, as more young people are assessed, the number of eligible young people is likely to be lower than the total list of potential transition cases currently on the list.

Figure 14: Tracked transition cases and eligibility for WLDP by year in which turn 18



Source: Westminster Learning Disabilities Partnership, October 2010

* refers to boxes where there are ≤ 5 young people in this category but the exact number cannot be disclosed to protect confidentiality.

Figure 14 does not include a further 17 cases which continue to be tracked by the WLDP despite being recorded as 'closed' transition cases. These cases were closed for a variety of reasons including being assessed as not having a learning disability, or the assessment being refused, as well as other individual reasons. They are kept on the list so that their details can be passed to other teams who may need to provide an

ongoing service, or in case they decide to return to the service at a later date. Due to the life-limiting nature of some of the conditions young people with learning disabilities have, every so often cases may also be closed due to death.

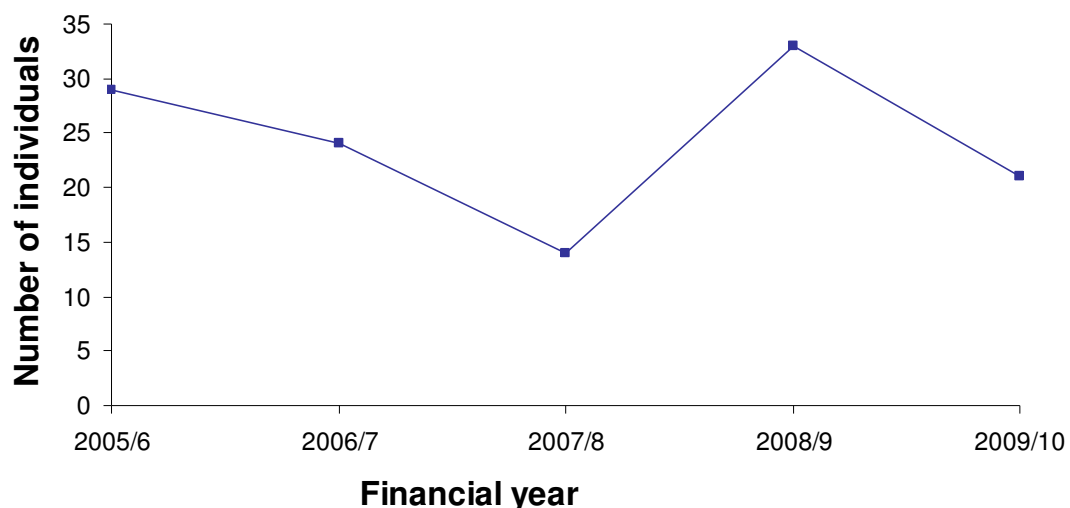
At the time this data was analysed it was unknown how many of the individuals awaiting assessment and turning 18 in 2010/11 or 2011/12 were likely to be eligible. It is clear that at least 26 young people turning 18 in the next year and a half are likely to transition to WLDP.

The database currently does not indicate the likely level of future need of these young people (i.e. low, medium or high). Recent work undertaken by the Clinical Psychologists within the WLDP, based on early assessment data, has indicated that there may be as many as 21 young people transitioning to Adults Services in 2011/12 with behaviours described as ‘challenging,’ some of whom will need support sessions from the Flexible Response Service and others are likely to require specialist clinical input. This is likely to stretch current capacity within the team. Although this information was collated for a specific piece of work, it would be useful for this information to be built into the data recording on a regular basis, to facilitate service planning. Data recording is discussed in more detail in section 5.4.

6.4.2 Westminster Learning Disabilities Partnership – new referrals (adults)

Figure 15 shows new referrals made to the Westminster Learning Disabilities Partnership over the last five complete financial years, who were aged 18-25 on referral, taken from SWIFT (the adult social care database). As the graph shows, the numbers of new referrals have fluctuated widely between years from a low of 14 in 2007/8 to 33 in 2008/9. This highlights the difficulty in projecting numbers based on past referral numbers.

Figure 15: New referrals aged 18-25 by financial year to the WLDP (n=121)



Source: SWIFT data, Westminster City Council, October 2010

As Figure 16 below shows there were a total of 121 young people aged 18-25 who were referred to the Westminster Learning Disabilities Partnership over this time

period. The majority (72%) were aged 18 on referral. Although not shown in the graph in Figure 15 the trend for new referrals 18 closely follows that of 18-25 year olds as a whole.

Figure 16: New referrals aged 18-25 over the last 5 years to Westminster Learning Disabilities Partnership

Age	Numbers
18	87
19-20	15
21-22	11
23-25	8
Total 18-25	121

Source: SWIFT data, Westminster City Council, October 2010

It is not straightforward to ascertain whether these new referrals transitioned from Children's Services. The 'referral source' code on SWIFT is rarely completed and, when it is, often displays the 'receiving team's name as opposed to the team who referred the person. It is important that this code is correctly used, to aid a better understanding of the flow of young people between Children's and Adults Services and allow mapping of service use over time. It is likely that the majority of the 18 year olds were also supported by the Children's Services in Westminster. Although the number of referrals varies massively between years they are broadly comparable to the numbers predicted to go through transition in the WLDP prospective transition spreadsheet.

Nearly a third of the individuals referred between 2005/6 and 2009/10 are now closed to the service (32%; n=39). Around half of these were closed after only a few months, which possibly indicates a lack of eligibility for the services or that individuals just required one-off support packages.

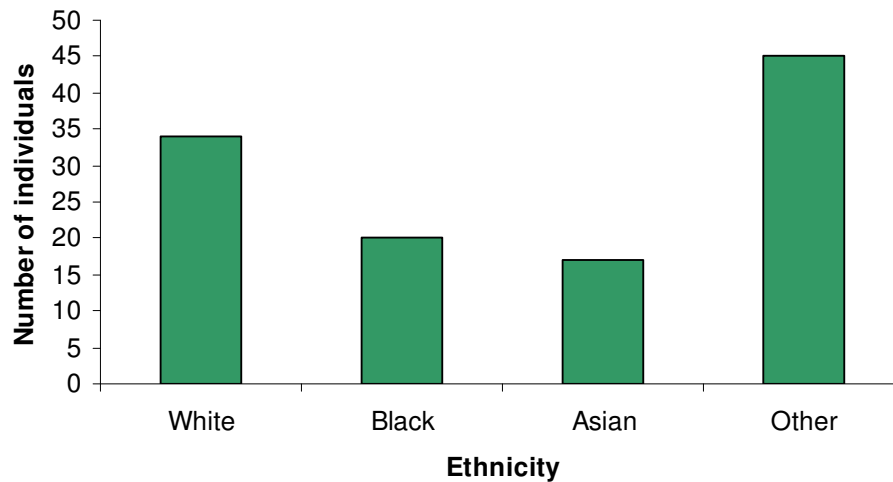
6.4.2.1 Demographic data

40% of the new referrals were female and 60% were male. The data from SWIFT also indicates the ethnic diversity of this population, shown in Figure 17. The largest group were classified as 'Other' ethnicity, making up 39% of referrals. 71% overall were from Black and Minority Ethnic Groups (BME). This is much higher than the proportion of the Westminster population of a similar age group estimated to be from BME groups. Greater London Authority (GLA) population estimates for the borough for 2009 indicate that around 34% of 15-24 year olds are from BME groups and 6% from 'Other' groups³⁴ (GLA 2007 Round Ethnic Group Projections - PLP Low for 2009). It is important to interpret these population comparisons with caution, since they are based on 2001 Census data on ethnicity, which is now nearly 10 years old. It

³⁴ GLA population estimates for ethnicity are given in 5 year age bands; for these estimates the numbers for the 15-19 and 20-24 age bands were pooled.

is likely that ethnic composition of the borough has changed within the intervening time.

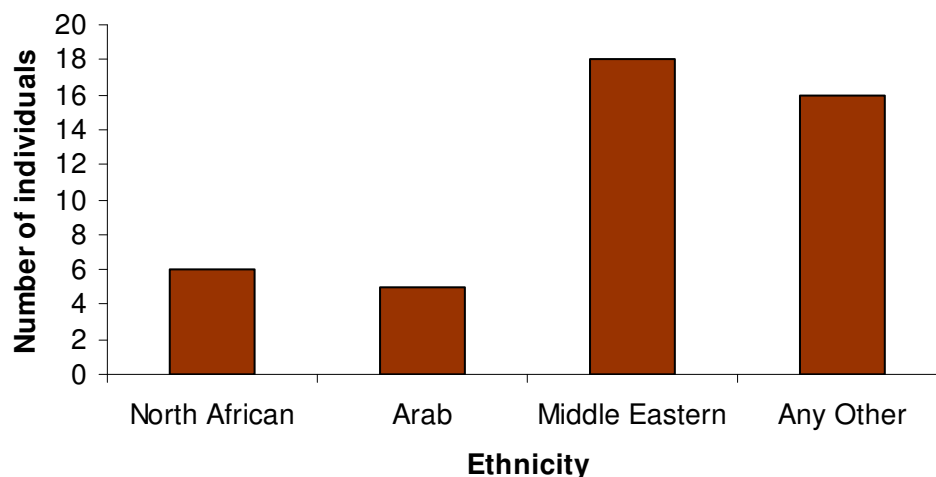
Figure 17: Ethnicity of new referrals to WLDP aged 18-25 years (2005/6-2009/10)



Source: SWIFT data, Westminster City Council, October 2010

Figure 18 shows a further breakdown of the 'Other' ethnicity category showing that two thirds were Middle Eastern, North African or Arab.

Figure 18: Breakdown of 'Other' ethnicity in new referrals to WLDP aged 18-25 (2005/6-2009/10)



Source: SWIFT data, Westminster City Council, October 2010

It is not possible to compare these Adult Service figures with the ethnicity of young people in Children's Services. Although the principle datasets used within Children's Services do record the ethnicity of service users that data is not currently transferred to the teams' data sets shared for the purpose of transition (these were also used for the JSNA data). Anecdotal information from the teams working with young people with disabilities indicates that the population is similarly ethnically diverse. As

discussed in section 5.4, the proposed new pooled data set for transition will include information on ethnicity.

Research has indicated that there is some variety in the prevalence of learning disabilities amongst different ethnic groups, which may partly explain the high proportion of service users from BME groups. For instance several studies have shown that South Asian minority ethnic communities have a higher prevalence of learning disabilities among young people (principally Bangladeshi and Pakistani) (Emerson & Hatton 2004). Other studies have also shown that the pattern of service use varies across different ethnic groups. For instance some studies have found that South Asian families caring for individuals with learning disabilities may be less likely to use psychiatric services, residential care and respite care services than those from a White background. Some of the patterns in service use however are thought to relate more to socio-economic status and family support, such as two parent families, than ethnicity specifically (Durà-Vilà & Hodes 2009; Emerson et al. 1997).

Given the ethnic diversity of the population accessing services, it is important to ensure that services are sensitive to the family organisation, culture, language and religion of service users in order to provide culturally appropriate services to best meet the needs of service users and their families. The consultation held with providers and commissioners on transition in Westminster in 2008 found that cultural, and especially language barriers, were a big factor in preventing families from seeking and accepting support (WSPLD 2008).

7 Physical Disabilities Transition Process

This section focuses on the transition young people with physical disabilities, sensory impairments and complex health needs to Adults' Physical Disability Services, including those in receipt of NHS Continuing Care. This includes some young people with long term conditions, where their condition is of a severity which affects their ability to carry out day-to-day activities. For instance, a few but not all young people with epilepsy may fit this definition, and require additional support from the Adults' Physical Disabilities Team.

Many, but not all, of the population who make the transition to Adults' physical disability services will have had statements of special educational need (SEN) whilst at school. There is therefore some overlap between the transition population and transition process discussed in Chapter 6, and the population discussed in this chapter. Similarly, although the profile of the Children with Disabilities Team caseload is discussed here it is acknowledged that the majority of the service users in contact with the team have a SEN statement.

7.1 Children with a medical diagnosis or physical disability: statements of special educational need (SEN)

A child with a particular medical diagnosis or disability will not necessarily have a special educational need. As such it may not be necessary for them to have a statement or any form of additional educational provision. A SEN statement reflects the child's educational need rather than their medical diagnosis. That being said, in some instances, medical conditions may significantly impact on a child functioning at school. In such cases, the Local Educational Authority (LEA) may consider assessing the child for a statement (DfES 2001).

There is a wide spectrum of what might constitute a sensory, multi-sensory or physical difficulty. The SEN Code of practice advises that for the children with the most complex physical needs and the most severe sensory losses it is likely that the LEA will consider a statutory assessment of SEN to be necessary. The governing factors are likely to be the extent of specialist teaching or aids and adaptations which are required. For many children with a lesser level of sensory or physical needs, intervention at *School Action Plus*³⁵ will be sufficient.

Some of the young people with SEN statements discussed in section 6.3 have a physical disability, complex health problem and/or sensory impairment in addition to a learning disability. Depending on the severity of their learning disability they may or may not make the transition to the Westminster Learning Disabilities Partnership (WLDP). Due to the multiple needs of this population, it is important that there is good communication between the different Children's and Adults' teams to ensure that young people are not missed between services and that they receive the most appropriate support.

³⁵ Refer to section 6.1 for an explanation of *School Action* and *School Action Plus*.

In addition to the individuals discussed in section 6.3, Figure 19 shows that there are around 13 individuals in years 9 and above with SEN statements and a primary need indicated as either a visual impairment or hearing impairment, educated in special/mainstream schools, who do not have an additional learning disability recorded (4% SEN population) and around 5 individuals with a physical disability/medical need (2% SEN population). However, as outlined previously, there is a wide spectrum of children who may have a sensory, multi-sensory and/or physical disability, not all of whom will have a statement of special educational need. Furthermore the SEN statement and recorded 'primary need' reflects a child's educational need rather than their medical diagnosis. As such, the SEN statement can only be used to identify a few individuals within this population.

Figure 19: Additional young people with statements of special educational need (SEN) in years 9-14 (aged 13-19) with a physical disability, medical need or sensory impairment indicated as primary need for SEN

Population group	Number of people
Young people with hearing impairment as primary need for SEN	6
Young people with a visual impairment as primary need for SEN	5
Young people with a physical disability/ medical need as primary need for SEN	5

Source: Special Education Department, Westminster City Council, November 2010

7.2 Overview of the Children with Disabilities Service

The Children with Disabilities Team is a multi-disciplinary team providing social work and other support services to children (aged 0-18 years) and their families. The Team supports children who are resident in Westminster and who have severe learning and/or physical disabilities, long-term chronic illnesses, autistic spectrum conditions or sensory impairments. In order to be eligible for services the young person's disability must be of a severity which substantially impacts on their daily lives.

In some cases young people receiving services from the Children with Disabilities Team may be known to other Children and Families Teams (such as the Looked After Children Team or Westminster Accommodation & Leaving Care Team). Some of the care packages offered are jointly funded with the PCT through children's NHS Continuing Care funding (discussed in more detail in section 4.2).

The Children with Disabilities Team is principally made up of social workers, including a transition social worker, occupational therapists, a welfare benefits worker, a health development worker and a Connexions worker, as well as service managers. The Team has close partnerships with the Child Development Service and Children's Community Nurse Team, the Special Educational Needs Team, Penderals

Trust for direct payments support and Paddington Green Child and Adolescent Mental Health Services (CAMHS).

The team provides a range of services including:

- Family support work – assessments completed jointly by health and social services teams; ongoing support provided to families where necessary.
- Welfare benefits advice – information and advice in applying for a range of disability benefits.
- Occupational therapy – assessments, aids and equipment to help children live more independently and advice on alterations required in the home.
- Behavioural support – therapeutic support in the home for families experiencing difficulties managing their child's behaviour.
- Short term breaks – care for a disabled child at home or in a different setting to give parents a break.
- Funded play provision/ activities for children/ young people – information and advice to help in accessing local and specialist play services.
- Direct Payments – money given to parents/ carers or disabled young people (from the age of 16) to purchase the services they want themselves.
- Transition support – help for young people with the transition to adulthood.

http://www.qe2cp.westminster.sch.uk/page_viewer.asp?page=The+Children+with+Disabilities+Team&pid=117 [accessed December 2010]

The Transition Social Worker works with young people between 14 – 18 years on the Team's caseload and provides a mentoring role for other social workers within the Team undertaking transition work, as well as being the main point of contact for transitional issues that arise within the Team. The role also supports young people and their parents/carers plan for their futures post 18years/ post full time education and liaises on their behalf with the different services throughout the young person's transition. The Transition Social Worker works one day a fortnight within the Westminster Learning Disabilities Partnership (WLDP) in order to facilitate the links between the teams with regards to all areas of transition.

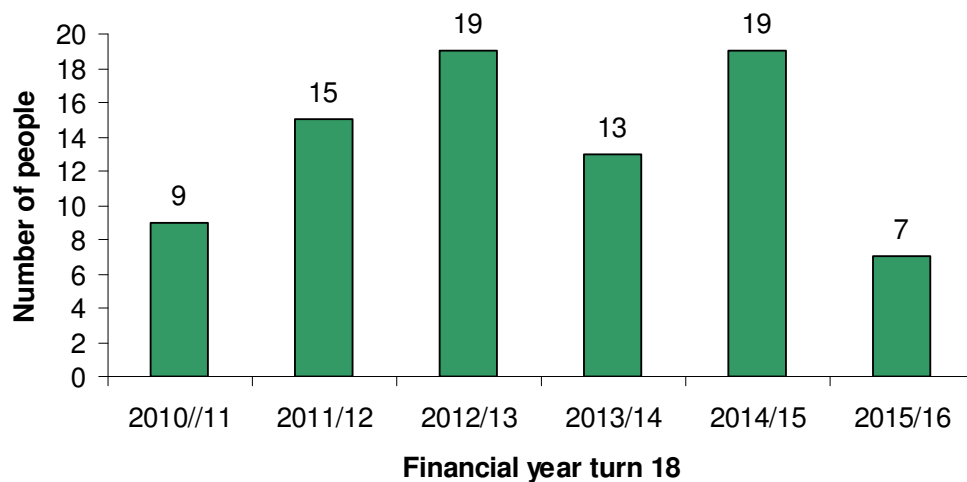
Children referred to the service receive an assessment of their needs and eligibility for the service. This assessment is different to, and independent of, the SEN assessment. If they are eligible, a care plan will be developed, outlining how the service will support their needs. The child's care plan is reviewed annually and amended accordingly. Some young people referred to the service at a young age may not initially meet the criteria; this situation may change as they get older and their disability becomes more pronounced and starts to impact on their daily life.

7.2.1 Profile of Children with Disabilities Team caseload

There is yearly fluctuation in the number of young people on the Children with Disabilities Team caseload. Figure 20 below provides an overview of the total number of children of transition age in touch with the Children with Disabilities Team in Westminster (as at October 2010). Data on this cohort is presented by the year in which they will turn 18 (the graph shows those young people aged 13-18). It should be noted that the columns for 2010/11 and 2015/16 are likely to under represent the caseload in these year groups; the data is from October (a mid-year point) and some

young people would have turned 18 and been removed and others are yet to turn 13 and so are not yet included. The numbers receiving a service and turning 18 between 2011/12 and 2014/15 provide a more accurate picture of average caseload numbers.

Figure 20: Children with Disabilities Team caseload aged between 13 and 18 years (as at October 2010)



Source: Children with Disabilities Team, Westminster City Council, October 2010

Individuals receiving a service from the Team have a wide range of conditions or multiple conditions, many of them unique. This makes a generalisation of the needs of the caseload difficult. The detail recorded on each child's diagnosis or disability also varies between individuals. An indication of the range of needs supported by the team highlights the complexity of this service provision; of the 57 individuals aged 14 and over who have some form of health need recorded:

- a minimum of 26 have a learning disability (8 of which have a severe learning disability)
- 26 have a probable autistic spectrum condition (ASD) (including asperger's); there is some overlap between those indicated as having a learning disability and those with ASD
- a minimum of 6 have a sensory impairment, with or without another condition recorded
- 6 have epilepsy and another disability
- a few have a genetic disorder such as down's syndrome
- some have medical conditions such as hypothyroidism
- a few are oxygen dependent
- some require gastronomy feeds
- a few are wheelchair users.³⁶

For some of the children supported by this team these conditions are life limiting and mean they may not survive into adulthood.

The service estimates that around 6 individuals currently receiving a service and likely to transition over the next 5 years have a physical disability/ complex health need without a significant learning disability.

³⁶ The last five bullet points relate to numbers lower than five and therefore cannot be reported.

At least 10 of the young people aged 14+ (n=68) supported by the team are currently receiving speech and language therapy, mostly provided through their schools. At least 6 receive physiotherapy and/or occupational therapy support. At least 17 have additional involvement from CAMHS. Some young people receive support from more than one specialty.

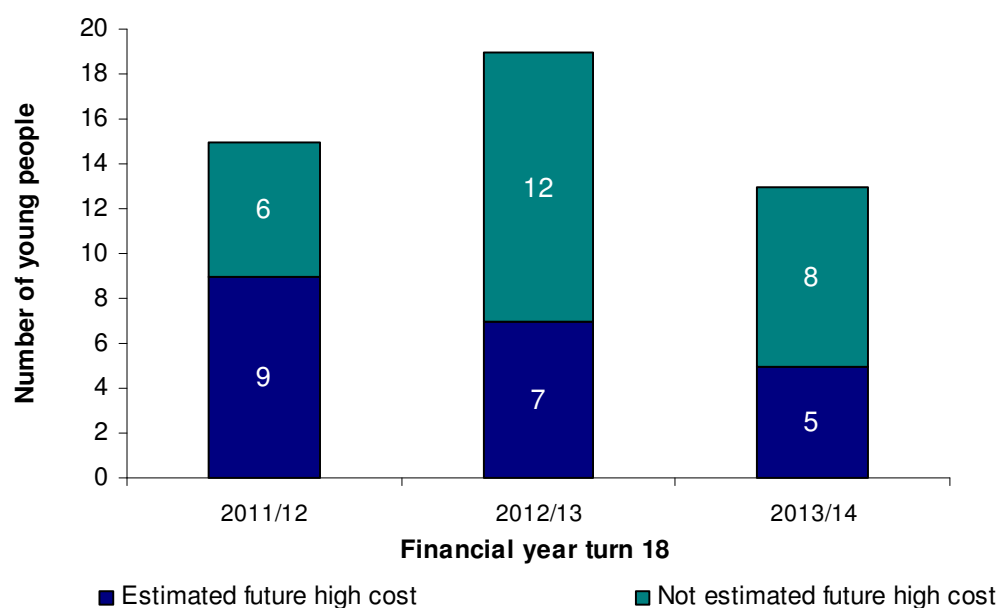
7.2.2 Care packages

Care packages for children with disabilities are arranged to meet the needs identified in the young person's care plan. These may involve carers to help with washing, dressing and providing of medication; leisure activities; or short breaks. Not all young people in touch with the service currently have a care package (33 out of 68 young people aged 14+).

Care packages for some individuals may be funded through direct payments, either partially or entirely. At least 15 young people of transition age have care packages at least partially funded using direct payments. Care packages usually range from between 4 and 24 hours of care per week. Some young people receive respite care which is calculated by nights of support. These vary from between around 18 and 40 nights per year. Care packages are arranged with a range of agencies in Westminster. These include Westminster Carers Services (at least 5 individuals) and Special People (at least 8 individuals) for carers, and Buckets and Spades for respite services. Young people in touch with the service may also attend Lisson Green Playscheme, Caxton Youth or Rainbow Youth services. (Information on the cost of these care packages is included in appendix E).

7.2.3 Estimates of future need: Children with Disabilities Team

Figure 21: Children with Disabilities Team caseload of transition age (turning 18 between 2011 and 2014) – with an estimation of their future need (as at October 2010)



Source: Children with Disabilities Team, Westminster City Council, October 2010

Figure 21 provides a rough estimate of the potential future need of young people receiving services from the Children with Disabilities Team, who will turn 18 between 2011 and 2014. This graph should be interpreted with caution, however; the estimates of the numbers of individuals who may be high cost and those who may not are based around the current Children with Disabilities Service provision and the severity of the child's disability. Those for whom there was uncertainty have been categorised as not being a high cost in the future. This may therefore be an underestimate of true future need. High cost provision refers to the potential future care package needs within Adults Services. This information is useful for service planning and, as discussed in section 5.3, is something that should be developed for future data sharing agreements and pooled data sources.

7.3 Children with complex health needs (Continuing Care)

Care packages for children and young people who have 'needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone' are funded through children's Continuing Care. Primary Care Trusts are responsible for leading the Continuing Care process. However, a child with continuing care needs may require additional services commissioned by other organisations such as the local authority or other partners (DH 2010c).

Generally, a child or young person will develop continuing care needs due to having a congenital condition, a complex and long term deteriorating condition or a sudden unexpected need, such as the after-effects of a serious illness or injury or due to an accident. These needs will typically be one or more of the following: communication, mobility, nutrition, continence or elimination, skin and tissue viability, breathing, drug therapies and medicines, psychological and emotional needs, or seizures. Challenging behaviour may result from some of these needs and may exacerbate the need. Assessment of these needs and the delivery of bespoke packages of care to meet them takes place alongside services to meet other needs, including education and social care (DH 2010c).

7.3.1 Profile of children receiving Continuing Care in Westminster

There are currently 27 young people aged 0-16 receiving children's Continuing Care support from NHS Westminster. Fewer than 5 are approaching their transition to adulthood (NHS Westminster, September 2010).

Figure 22: Children receiving Continuing Care by age (September 2010)

Age	Number of children
0-5 years	13
6-10 years	9
11-16 years	5
Total	27

These individuals have high and sometimes complex and multiple medical needs, due to rare congenital disorders, or as a result of acquired brain injury, premature birth and/or organ failure. As a result of their conditions, some are technology dependant (such as requiring dialysis or oxygen) and some require gastronomy feeding. Some, but not all of these individuals have a learning disability as well as a physical disability/complex medical need.

Several of those currently receiving Continuing Care have rare genetic disorders which are life limiting conditions and may mean that they will not survive into adulthood. It is not possible to predict how many of these children will survive to transition to Adult Services, as it will depend on the severity and complexity of their conditions. Those surviving, however, are likely to continue to need high levels of support as adults. Many of these children have been receiving Continuing Care support for a significant number of years, some since birth.

Continuing Care is used to purchase additional services such as paid carer support, which are not provided through other means, for example through the Child Development Team or school-based provision. Funded carer support for these children may range, for example, from 8 hours per week, to combinations of full overnight, as well as day and weekend support. The care packages received are tailored according to the young person's individual needs and the support needs of their family, and are unique to every case. The majority of packages are jointly funded between health and social care and many of these young people are, therefore, also on the caseload of the Children with Disabilities Team. (An idea of the cost of these care packages is provided in appendix E.)

A small number of children who meet Continuing Care criteria also reach palliative care thresholds, which for children includes life limiting conditions. The Kaleidoscope children's palliative care service provides home support, specialist nursing and trained carers as well as bereavement services to approximately 12 Westminster children in their homes. This is by far the preferred option for families, although occasionally funding is provided for respite in a children's hospice. This is in response to need and parental wishes.

The children currently receiving Continuing Care and of transition age are also known to other services including Children with Disabilities, Special Education and the Westminster Learning Disabilities Partnership (for transition tracking purposes). As stated earlier, it is important that those individuals with a physical disability or complex health need without a learning disability are picked up within the transition process, and screened for Adults Continuing Care and other services if relevant.

Children's Continuing Care funding stops at 18, when young people are eligible to apply for Adult's Continuing Care. At 18 eligible children may be put forward for an assessment. This is discussed in more detail in section 4.2.

7.4 Physical Disabilities Team in Adults Services

People who have a physical disability, long term condition or sensory impairment can access support services through the Adult Services (Physical Disability) Team. This team offers a care management service to adults with a physical disability or long term illness aged 18 to 65 years.

The main function of the Adults Physical Disability Service is to assess needs in line with relevant legislation and guidelines, to promote independence and support disabled people to realise their potential and live in the community. The Physical Disability Team will commission services where people have been assessed as needing home care, day care, residential or nursing home provisions.

People who have a physical disability, long term condition or sensory impairment can access health care services through primary, secondary or specialist services, depending on their individual assessed needs. These are universal services, however some individual services may have their own eligibility criteria.

The Physical Disabilities Joint Commissioning Team commissions a wide a range of support and specialist services including:

- Community nursing services
- Community Specialist Rehabilitation and reablement³⁷ services
- Equipment services such as wheelchairs (including specialist seating and electrically powered indoor/outdoor chairs), home adaptations, deaf and hard of hearing equipment, community equipment, telecare, environmental controls
- Specialist services such as spinal injury services, specialist and local neuro-rehabilitation inpatient services and prosthetic limb fitting
- British Sign Language/Interpreting Service
- Low vision services
- Advocacy services.

For more detail refer to the Physical disabilities strategy *Our Say, Our Way Joint Commissioning Strategy for Physical Disabilities and Sensory Needs 2009 – 2012*.

7.5 Physical disabilities transition population

Depending on the level of need, a young person with a physical disability or complex health condition may be assessed for Continuing Care. Data of new referrals to the Physical Disabilities Team can be examined in two ways: those who have been assessed for NHS Continuing Care and those who are recorded as new referrals on SWIFT, the adult social care database. Data from registers such as the *deaf and hard of hearing register* also provides additional ideas of numbers of people receiving support from the Adults Physical Disabilities Team. Information from other services such as the Westminster Equipment Service is detailed in Appendix B.

³⁷ Re-ablement involves the provision of planned, short term intensive services that work with individuals who require assistance to regain independence and confidence in carrying out everyday activities, for example following an illness or crisis.
http://www3.westminster.gov.uk/docstores/publications_store/Re-ablement.pdf

7.5.1 NHS Adults' Continuing Care

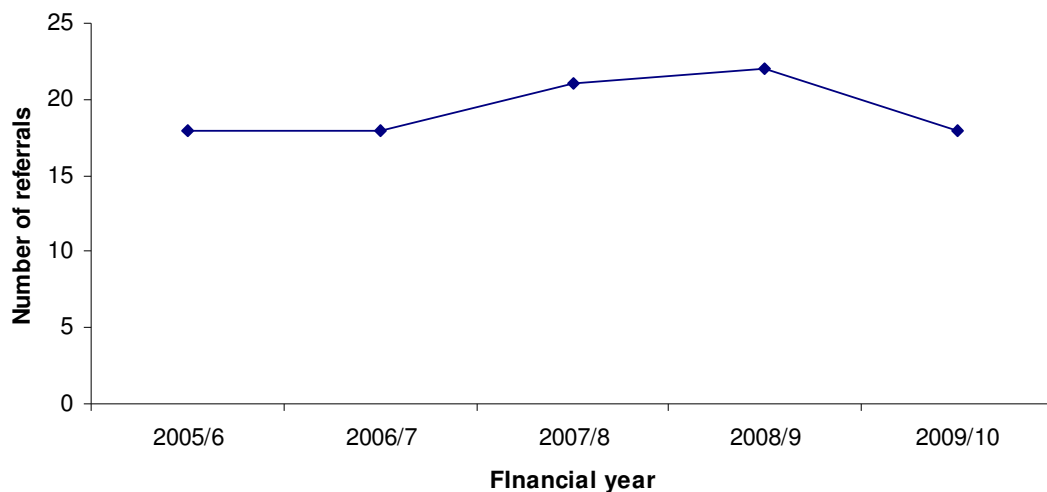
Data for Westminster shows that there have been fewer than 5 young people aged 18-25 who have been assessed as meeting NHS Continuing Care criteria over the past 4 years. Although small numbers, these are complex and unique cases, requiring very high cost placements. The numbers are too small to provide further detail.

All those who were put forward for a Continuing Care assessment over the past 4 years received a Continuing Care package. This suggests that the staff working with these young people are very accurate in gauging who will meet the criteria. It could, however, also indicate that some individuals with less high needs are being missed, and that more people should be screened for Continuing Care.

7.5.2 Physical Disabilities Team – new referrals

Over the past 5 financial years, there were 97 referrals made to the Westminster Adults' Physical Disabilities Team, recorded on SWIFT (the adult social care database). The number of referrals have fluctuated slightly between years from 18 in 2006/7 to 22 in 2008/9 (Figure 23). 11 of the referrals over this five year period were repeat referrals. As with the data for the Westminster Learning Disabilities Partnership, discussed in section 6.4.2 it is not known what proportion of these new referrals were known to Westminster's Children's Services.

Figure 23: Referrals per year to the Physical Disabilities Team aged 18-25 years (n=97)



Source: SWIFT data, Westminster City Council, October 2010

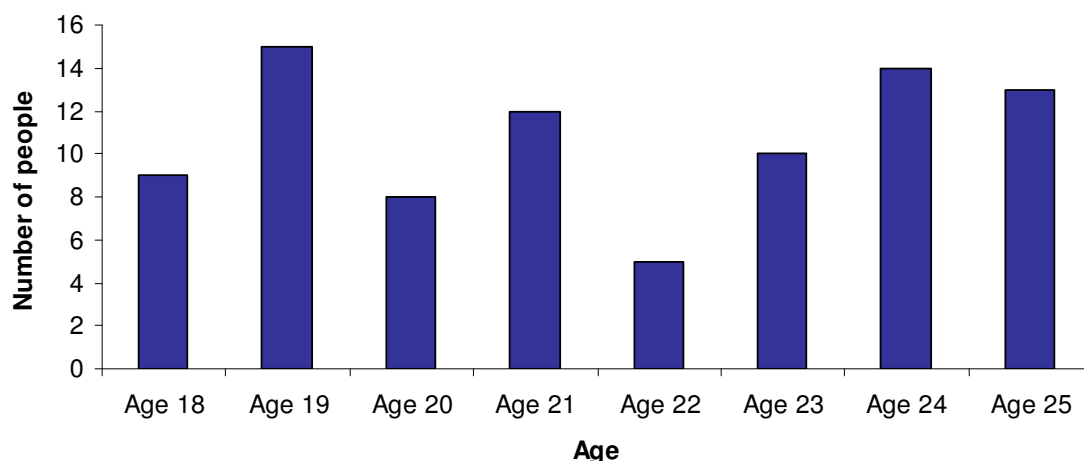
These numbers are relatively low, reflecting the fact that the majority of clients do not meet the eligibility for adult social care provision.

Of the new referrals over the last five financial years only 28% of cases are still 'open' to care management, indicating the service user is receiving an on-going service. The remainder are currently closed cases. The Physical Disabilities Team reviews all open cases each year. Cases are closed after the review process is complete and the care package has been established. Similarly new cases are added to the open caseload while their care package is sorted out, and then closed when the

package has been established. If the client contacts the Care Management Team in the intervening time, for example for a new adaptation, their case will be reopened (hence some clients show on SWIFT as repeat referrals). Clients may come back several times over several years for different pieces of specialist equipment.

Figure 24 shows a breakdown of the age of young people when they were first referred to the service (i.e. not including the repeat referrals). Only a small proportion were aged 18 on first referral. On average, over the last five years, only two people aged 18 were referred to the service each year and three aged 19. This may reflect people moving into the area late into transition or returning later from education. It may reflect people having degenerative neurological illnesses and not needing care previously. It could also indicate that people are being missed at transition and accessing services late.

Figure 24: Age of first referral to physical disabilities team aged 18-25, referrals during financial year 2005/6-2009/10 (n=86)



Source: SWIFT data, Westminster City Council, October 2010

For the closed cases, where there is a date of case closure, 10 were closed after less than 1 month and a further 6 were closed after between 1 and 2 months.

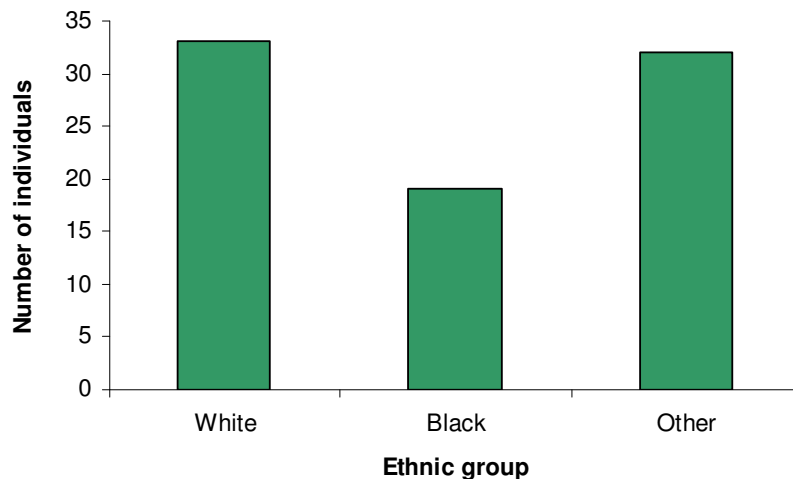
7.5.2.1 Demographic data

Of the new referrals to the Physical Disabilities Team, 64% were female and 36% were male. This is a different pattern to that seen in the referrals to the WLDP where there were more males than females. The SWIFT data also indicates the ethnic diversity of this population (shown in Figure 25). The largest group were 'White' but overall 60% were from Black and Minority Ethnic (BME) groups. As with the population accessing the Westminster Learning Disabilities Partnership (WLDP), this is much higher than the proportion of the Westminster population of a similar age group estimated to be from BME groups. Greater London Authority (GLA) population estimates for the borough for 2009 indicate that around 34% of 15-24 year olds are from BME groups and 6% from 'Other' groups³⁸ (GLA 2007 Round Ethnic Group Projections - PLP Low for 2009). As discussed in section 6.4.2.1 for the

³⁸ GLA population estimates for ethnicity are given in 5 year age bands; for these estimates the numbers for the 15-19 and 20-24 age bands were pooled.

learning disability population, is important to interpret these population comparisons with caution, since they are based on 2001 Census data on ethnicity, which is now nearly 10 years old. It is likely that ethnic composition of the borough has changed within the intervening time.

Figure 25: Ethnicity of new referrals aged 18-25 over 5 years to the Physical Disabilities Team (2005/6-2009/10)

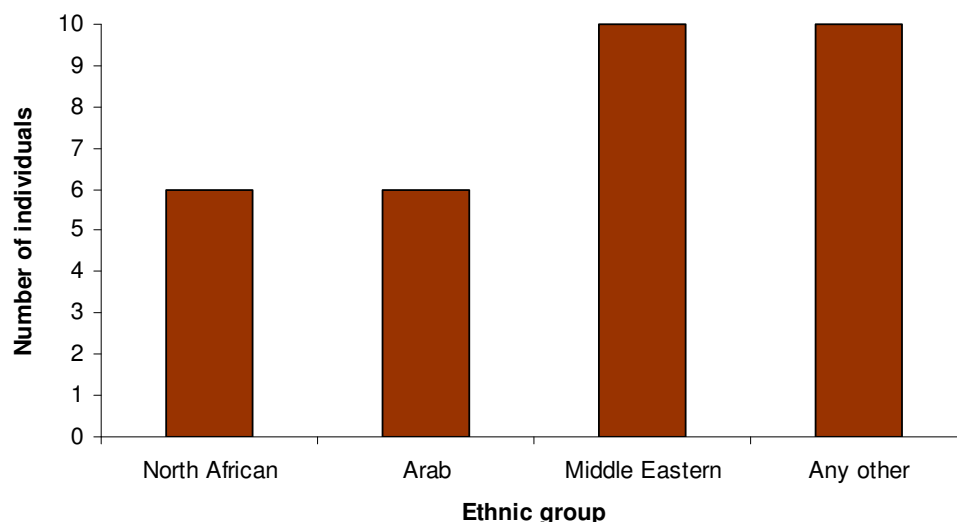


Source: SWIFT data, Westminster City Council, October 2010

Note: Due to small numbers clients of an Asian ethnicity have been included here in 'Other'.

Figure 26 shows below a further breakdown of the 'Other' category; two thirds were either of a Middle Eastern, North African or Arab ethnicity.

Figure 26: Break down of 'Other' ethnicity in new referrals aged 18-25 years to the Physical Disabilities Team (2005/6-2009/10)



Source: SWIFT data, Westminster City Council, October 2010

Given the ethnic diversity of the population accessing services, it is important to ensure that services are sensitive to the family organisation, culture, language and religion of service users in order to provide culturally appropriate services to best meet the needs of service users and their families.

7.5.3 Deaf and hard of hearing register

There are currently 8 people aged between 18-24 on the deaf and hard of hearing register (WCC October 2010).

7.6 Transition process for young people with physical disabilities

As noted above, many of the structures and process in place to support the wider transition population and young people with SEN (discussed in sections 5 and 6) also support young people with physical disabilities and sensory impairments. A named representative from the Physical Disabilities Team attends the Young Person's Transition (YPT) Operational Group every quarter. In the intervening time young people known about to other teams who are likely to need support from the Physical Disabilities Team in Adults are reported informally to the named representative.

Clients are assessed via the Care Management Team prior to them becoming an adult so that their needs can be identified. When they are assessed the Fair Access to Care Services (FACS) criteria is applied. If the client is eligible for care they will then go through the care management process and be offered a care package, including the option of a direct payment or individual budget. If they have health needs that might meet the Adults' Continuing Care criteria then a joint assessment is undertaken with the Physical Disabilities Continuing Care Team and Care Management Team. Eligible clients will receive either health or social care funding (under Continuing Care guidance funding cannot be 50:50). All clients irrespective of funding source also have a right to community services e.g. primary care, district nurses, occupational therapy and physiotherapy.

Although an informal process is in place between services, and with the YPT Operational Group, there is currently no written protocol around the process for transition for young people with physical disabilities or complex health needs. This may be something that should be considered developing in the future due to the complexity of provision within Adults Physical Disabilities and the different services involved. It may be that the written guidelines which exist for transition between the Children with Disabilities Team and Westminster Learning Disabilities Partnership could be adapted for this purpose.

8 Summary of the transition population: learning and physical disabilities

As discussed in section 5.4 each team working with the transition population holds a different list on their individual caseloads, kept for slightly different purposes. In order to capture the transition population for the purposes of the needs assessment the different data sets were merged into one list. It should be noted, however, that due to the different level of detail contained in the lists provided for individual teams, which does not allow for a perfect comparison, these figures should be taken only as a rough estimate.

Some of the differences between the data sets, indicating the difficulties of capturing the whole transition population are as follows:

- The special educational needs (SEN) database holds information on the SEN population. As noted in section 7, not all young people with physical disabilities and complex health problems have SEN statements. When young people with disabilities leave school, including when they move to college or another specialist placement funded through the Young People's Learning Agency, they are no longer recorded on the SEN list, since they will no longer have a SEN statement.
- The Children with Disabilities Team database records data on people in touch with the service or receiving packages of care. Since not all young people with disabilities use the services provided by the team, their list does not include all young people with disabilities in the borough.
- The Connexions database holds information on a wider group of young people with 'learning disabilities and difficulties', many of whom will not transition to Adult Services.
- The NHS Children's Continuing Care team hold a database on young people in receipt of Continuing Care (discussed in section 7.3)
- The Looked After Children Team keep a database on young people in the borough who are looked after, with and without disabilities.

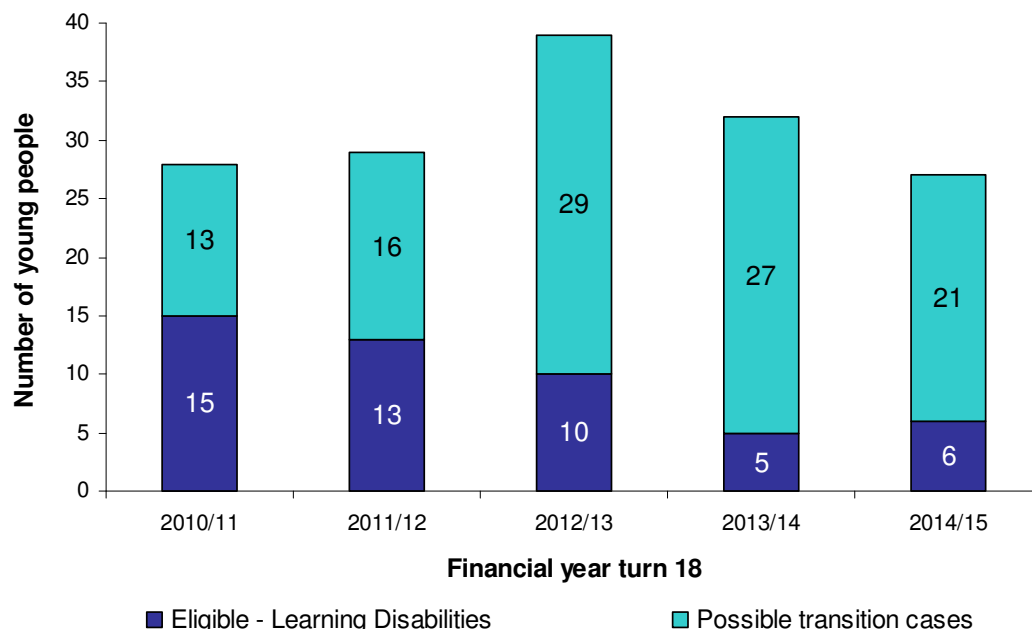
As discussed in section 6.4.1 the Westminster Learning Disabilities Partnership (WLDP) maintains a database to track young people in year 9 onwards who are potentially eligible for Adult Learning Disabilities Service. The list is fed by information from the Children with Disabilities Team (CWDT), the SEN Department, Connexions and the Looked After Children Team. This database offers the best profile of young people in transition. Its focus is on young people learning disabilities rather than the total population, although where known to the service young people who have physical disabilities without learning disabilities are sometimes retained on the list.

In order to gauge an idea of the size of the transition population, the WLDP database from October 2010 was used as a baseline. As this list had been last updated prior to information on the new SEN intake being gathered from the start of the school year, this information was added. Similarly, as the WLDP database focuses on young people with learning rather than physical disabilities there are a few individuals from the Children with Disabilities Team caseload who were not included on the WLDP

list, who have been added.³⁹ These pooled data are displayed in Figure 27 and the totals are shown numerically in Figure 28. Where information from the baseline WLDP database indicated that individuals were eligible for Adult Services, they are shown in the graph in dark blue. To these numbers were added new cases from the SEN list who had severe learning disabilities (for whom an understanding exists with the WLDP that these individuals are unlikely to need testing.) The remainder are shown as ‘possible transition cases.’ Individuals transitioning to Adult Mental Health Services are discussed separately in section 9.

Since the information provided on different teams’ lists did not always allow a clear differentiation between young people with physical disabilities, complex health needs and/or sensory impairments without learning disabilities, and individuals who also had learning disabilities all of these individuals have been included in the category of ‘possible transition cases’.

Figure 27: Pooled estimate of potential transition numbers (from data on SEN special schools population, WLDP and CWDT data)



Source: Children with Disabilities Team, Westminster City Council, October 2010; Westminster Learning Disabilities Partnership, October 2010; Special Education Department, Westminster City Council, November 2010

Note: The date of birth of the SEN pupils was not provided; where individuals were not on the lists of other teams the year they will turn 18 was estimated from their school year.

This data includes cases that have been closed by the WLDP (discussed in section 6.4.1) since the reason for case closure was not always recorded and there is a possibility they may return to the service at a later date.

³⁹ To avoid double counting these, extra individuals from the Children with Disabilities Team were only included when they were not already included on the SEN list (for example due to reasons such as attending a college or not having cognitive impairment etc.) Individuals on the Looked After Children list and NHS Continuing Care lists were already included on other lists, as were the young people attending specialist placements funded by the Young People’s Learning Agency (discussed in section 3.1.8).

Figure 28: Summary table of potential transition numbers

Year turn 18	2010/11	2011/12	2012/13	2013/14	2014/15	Total
Overall transition numbers	28	29	39	32	27	155

The data displayed in Figure 27 indicates that the number of transition cases over the next 5 financial years may lie somewhere in the region of between 49 and 155 individuals. The majority of this data relates to young people with learning disabilities, although some may transition to the Adults Physical Disabilities Team

As discussed in section 7.1 there are also a few individuals who have a SEN statement for a medical need, physical disability and/or sensory impairment. Some of these are already captured in other lists, due to being in touch with other teams. The SEN data indicates there are likely to be at least another 14 individuals not included already, but it is unknown how many have disabilities of a severity that mean they are likely to transition. They are therefore noted as an additional group, but not included in the graph in Figure 27. It is important that these individuals are signposted to relevant support services at transition.

One final caveat to note is that the new SEN intake includes those individuals with learning disabilities and/or physical disabilities educated in special schools rather mainstream schools; additional individuals educated in mainstream schools have not been added, since it was less clear which individuals may have a disability of a severity which may meet the eligibility criteria for Adults Services or need testing. This may exclude a few additional individuals, but the numbers are unlikely to be large; some individuals in mainstream education are already tracked by the WLDP or receiving services from the Children with Disabilities Team (and therefore included already).

The numbers displayed in Figure 27 are lower than the new referral data from Adults Learning and Physical Services over the last 5 years, taken from SWIFT (refer to sections 6.4.2 and 7.5.2). Data extracted from SWIFT showed that during this time period there had been 121 new referrals aged 18-25 to the WLDP and 97 to the Physical Disability Team (total of 218). This is likely, however, to be an overestimate of transition figures; only 96 across both teams were aged 18 at referral. As discussed in sections 6.4.2 and 7.5.2, it was not possible for the purposes of the JSNA to interrogate these figures in great detail, and find what proportion of these cases were 'transition' cases, and what proportion represent referrals of young people who went on to receive a service (were not closed immediately after referral). As suggested above, it is likely that the data in Figure 27 underestimates the number of potential transitions to the Physical Disability Services. Furthermore, as discussed in section 7.5.2 some of the physical disability referrals aged 18-25 may have conditions which have deteriorated, and who may not have needed specialist care previously.

Although this information provides a guideline as to the range of potential transition numbers, it highlights the need for a pooled transition database within the borough, with an agreement across teams of the different headings the database should contain, and as much clarity as possible as to whether young people have been found to

eligible for Adults Services (and which service) and an indication of their future level of need for service planning. The fact that different lists are updated at slightly different stages (indicated here by the new SEN intake) also highlights the importance of teams sharing information on new clients with other relevant teams on a regular basis, while the pooled transition database is in development.

As the numbers of likely transition cases in each financial year varies year by year, and the needs of the different cohorts of cases similarly varies, it is less important to be able to model likely transition numbers over the next five years, as to be able to accurately track numbers coming through on an annual basis and have an accurate picture of their likely level of service need.

9 Mental health transition process

Child and Adolescent Mental Health Services (CAMHS) provide services for children and families with a range of mental health problems. CAMHS works to a very different service model to Adult Mental Health Services (AMHS). Very few individuals receiving CAMHS go on to meet the eligibility criteria for AMHS. Although some conditions may present for some individuals around transition age, many of the more common adult mental health problems, including those at the more severe end, develop for most people in early adulthood. As such, these adult service users may not have needed support from CAMHS previously. For instance the prevalence of psychosis is highest in men aged 30-35 years old and in women aged between 35-44 years old, although some experience their first episode from the age of 14 (WCP 2009). The numbers of young people with mental health problems going through transition is therefore relatively low.

Although numbers of transition cases are low, nationally there is evidence of poor transition arrangements from CAMHS to AMHS. Many people who are in receipt of CAMHS services fall through the gap and are deemed not eligible for Adult Services. The findings of the TRACK multi-perspective study on the process, outcome and experience of transition in mental healthcare, which have recently been published, confirmed this pattern and made some recommendations for how transition could be improved in mental health (Singh et al. 2010). More detail is provided in the literature review at the end of the JSNA. Since transition in mental health services in Westminster has not been considered in the detail provided in the TRACK study, it may be useful for local services to consider the findings of the TRACK study and discuss them further in the context of local service provision.

Since 2005 Westminster has had a protocol for transition. Locally there are processes in place for transition planning to begin at age 17 for children receiving CAMHS support who will need ongoing support from AMHS. In this section an overview of the local mental health services will be given as well as a profile of the transition population and an outline of the transition processes and how they are working in Westminster.

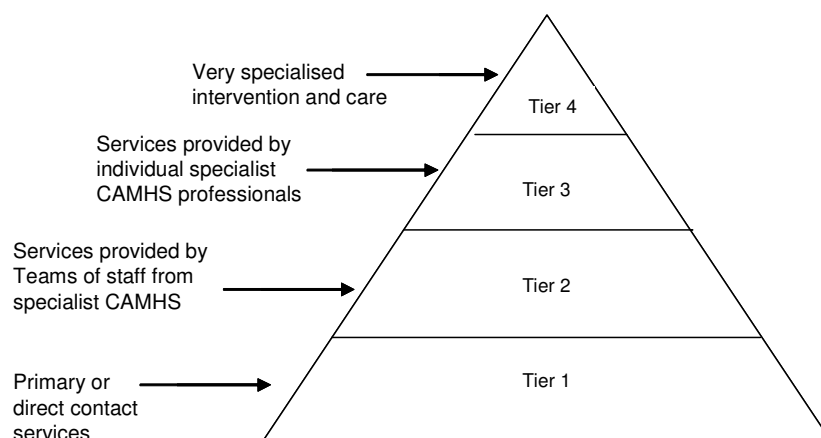
9.1 Child and Adult Mental Health Services in Westminster

Central North West London (CNWL) Mental Health NHS Trust provides both child and adolescent (CAMHS) and adult mental health services (AMHS) for the Westminster population. CAMHS services are provided for young people up to the age of 18. Each year there will be a few young people who continue to have significant mental health needs which require ongoing treatment, care and case management, who will transition into AMHS at the age of 18.

CNWL CAMHS services are spread across several multi-disciplinary teams within the borough, offering both generalist and specialist CAMHS support. Treatment models offered by CAMHS for young people and their families include family

therapy, marital therapy for parents, individual psychotherapy, art therapy, behavioural/cognitive therapy and a medical/psychiatric model of therapy.⁴⁰

Figure 29: The conventional 4-tier framework for children's mental health services



Source: WPCT, CNWL, WCC 2006

CAMH services are arranged on a tiered model along the lines of the diagram in Figure 29. Tier 1 services include services provided by professionals who are not necessarily employed for the main purpose of promoting mental health but who directly and indirectly influence the mental health of children and young people through their work. These services include but are not limited to schools, Connexions, Youth Workers, Social Services, GPs, Youth Offending Teams, School nurses and others. Tiers 2-4 represent services provided through CNWL. CNWL has one Tier 4 CAMHS unit, Collingham Child and Family Centre, which offers day and inpatient interventions for children with a wide range of more complex and severe mental health problems. Westminster also has a Tier 4 consortium contract with The Priory.

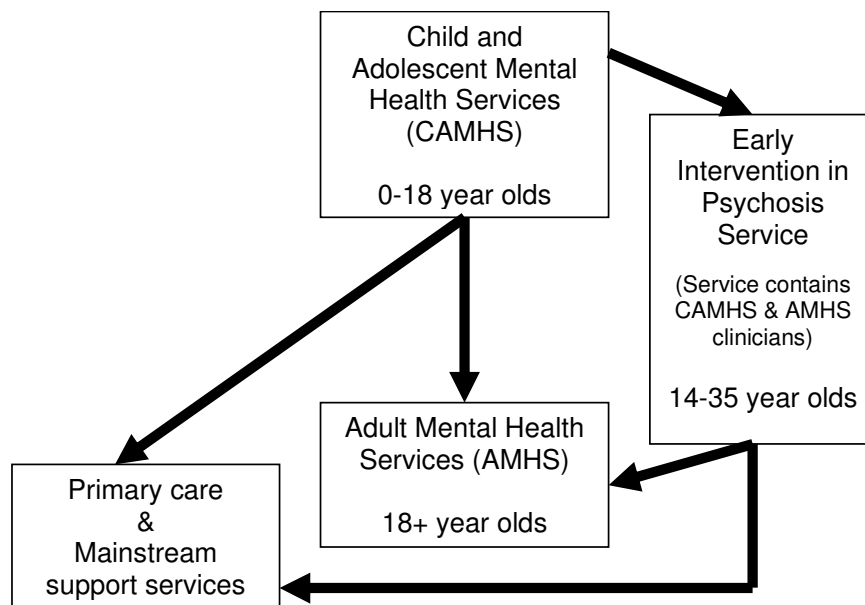
CNWL also provides secondary inpatient/hospital care and specialist mental health services for adults in Westminster with severe and enduring mental illness. Other mental health services for more common mental health disorders such as stress, depression and anxiety are provided in primary care, through GPs, counselling services and the new Improving Access to Psychological Therapies (IAPT) services⁴¹. Young people who have been in receipt of CAMHS services who do not meet the criteria for Adult Services will be referred to these services in primary care or mainstream support services such as youth counselling service or Connexions. These transition pathways are indicated in Figure 30.

⁴⁰ For more information refer to:

([http://www.cnwl.nhs.uk/Child Westminster Child and Adolescent Mental Health Service.html](http://www.cnwl.nhs.uk/Child_Westminster_Child_and_Adolescent_Mental_Health_Service.html))

⁴¹ IAPT offers Cognitive Behavioural Therapy (CBT), psychological assessment or signposting to other services, where appropriate.

Figure 30: An overview of the transition between CAMHS and Adult Mental Health Services



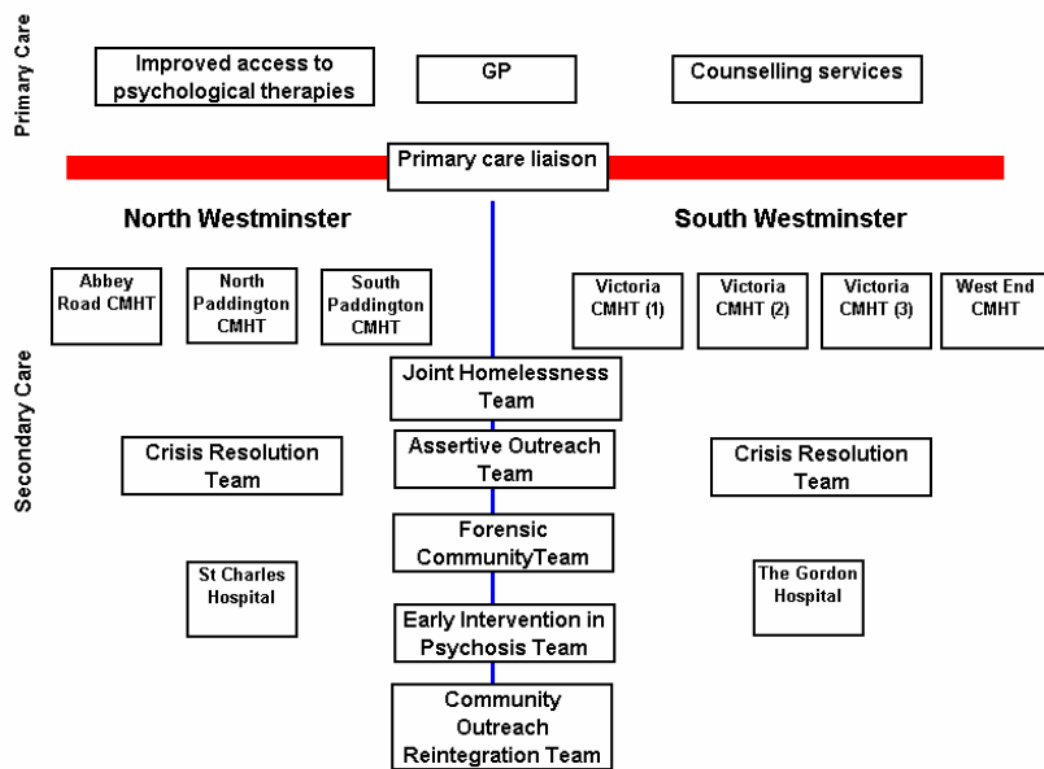
Adult mental health services are provided in the community by a number of providers, as shown in Figure 31. Community Mental Health Teams (CMHTs) are multidisciplinary, locality-based teams that provide core community care. They have 3 main functions:

- to provide professional advice to other healthcare providers;
- to provide specialist treatment and;
- to provide care for those with time limited disorders or those with more complex and enduring needs.⁴²

CNWL runs a specialist Early Intervention in Psychosis Service (EIS) which provides multi-disciplinary support for people aged between 14 and 35, diagnosed with having experienced a first episode of psychosis. The service provides a care package and pathway for these people for up to three years. The service includes a dedicated Consultant Adolescent Psychiatrist who works with clients who are referred to the service prior to their 18th birthday, and continues to work with them during their full three year care package with the service (up to and beyond 18 as necessary). If clients require ongoing support after their three year care package and are aged 18 and over they are referred into Adult Services. If they are under 18, they will remain with the service until their 18th birthday and at that point transition into Adult Services (conversation with the Early Intervention Service, October 2010).

⁴² For more information on other mental health services refer to Westminster's Adult Mental Health Joint Strategic Needs Assessment (WCP 2009).

Figure 31: Adult Mental Health Services in Westminster



Source: WCP 2009

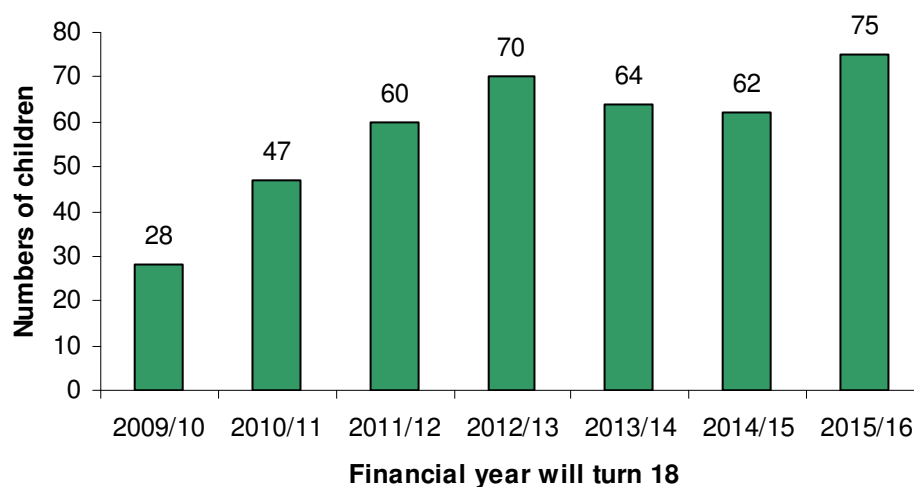
In addition to the services indicated in Figure 31 above, there are also some other, specialist units providing care for Westminster residents, such as the Vincent Square Clinic which offers a range of dedicated services for women and men aged 18 years and over suffering from anorexia nervosa, bulimia nervosa and other eating disorders.

9.2 The transition population: mental health

Data on the mental health transition population and the outcomes from transition is not readily available. It is not a requirement in AMHS to record whether new young patients have transitioned from CAMHS. Similarly, CAMHS databases do not record where young people receiving their services are referred onto at 18. Therefore, there is limited data available on the numbers of young people who transition between CAMHS and AMHS and their conditions. A quick scan of CNWL data from Adults showed that there were only 11 transition cases over the past 5 years. This is felt by the service to be an underestimate, and highlights the problems with the recording system. A conversation with the Early Intervention in Psychosis Service (October 2010) indicated that around 15 of a current caseload of around 190 individuals are aged under 18. As explained above, under 18s within the EIS remain within the service for the duration of their care and, if relevant, 'transition' within the same service. The researchers within the published TRACK study of transition in mental health also had difficulty using trust databases to identify transition study participants in the trusts they worked with; in the end they abandoned their database search in favour of using individual clinicians to identify cases (Singh et al. 2010).

To get a sense of the numbers of young people receiving a CAMHS service around transition age Figure 32 shows the number of young people from Westminster who had CAMHS appointments in 2009/10 by the year in which they will turn 18. It does not cover the whole CAMHS caseload but only those of transition age. Unfortunately it does not provide any indication of the proportion of young people who are likely to need support in Adults' Services. Additional data on the CAMHS population from the Child Health Mapping programme, including the primary needs of young people in CAMHS is provided in Appendix F. Both data sets show that the number of young people receiving services from CAMHS decline as they approach 18.

Figure 32: Age profile of transition age young people on Westminster CAMHS caseload 2009/10



Source: CNWL activity returns 2009-10, NHS Westminster

This graph consists of community contacts at Paddington Green, Marlborough Family Service, Violet Melchett Clinic, Harrow CAMHS and Westminster CAMHS intervention. There were 841 individuals seen by the services with 6,180 appointments over the course of the year.

Information on the conditions of young people transitioning from CAMHS to AMHS in Westminster was not possible to collect for the JSNA. The TRACK study showed that those with psychosis or severe mood disorder were more likely to transition to Adults' Services than those with neuro-developmental disorders and emotional disorders, including conduct disorder, attention deficit hyperactive disorder (ADHD), borderline learning disability, or autistic spectrum disorder. This was found to be an issue because three quarters of teams surveyed in the study had no provision for continuity of care for those not accepted by Adults' Services. Patients with eating disorders were excluded from the study (Singh et al. 2008; 2010).

9.3 The transition process for mental health

The term 'transition' for mental health is used here to describe the total process involved in planning and bringing about transfer of care from CAMHS to AMHS. The exact nature of transitional care will depend upon the individual service user's needs and views. As the local mental health transition protocol indicates, it should be based on a full and informed discussion between CAMHS, AMHS and the client,

including the person or persons with parental responsibility where appropriate (CNWL 2005).

There has been a transfer of care policy in CNWL since early 2005, which sets out the guidance for transition between CAMHS and AMHS. It is subject to two-yearly review. The detail from this policy is summarised here. A flow chart summarising the process was agreed by CNWL, Westminster City Council and NHS Westminster in 2006. It is reproduced in Figure 33.

CAMHS has a role to identify those service users aged 17 onwards who will require secondary care from Adults Mental Health Services and ensure the timely and comprehensive hand over of care within the Care Programme Approach (CPA) framework.

A Care Programme Approach (CPA) sets out that all users of specialist mental health services must have:

- a comprehensive assessment of their health and social care needs
- a single care plan that addresses identified needs drawn from the assessment
- a designated care co-ordinator responsible for overseeing the delivery of care
- a systematic and regular review of the care plan to reflect any change that occurs.

The CAMHS key worker should discuss with the service user as early as possible (ideally before their 17th birthday) the implications of their continuing care needs and that transfer to Adults Services is likely. This should be recorded in their written care plan (or CAMHS equivalent) with an agreed review date. CAMHS should consult those with parental responsibility and the extended family/carers where appropriate, whilst respecting the young person's rights to confidentiality.

Unless it is the young person's choice, a young person should not simply receive an appointment in Adults Services without a transition plan agreed between CAMHS and Adult Services. In agreement with the young person CAMHS should have early discussions with Adult Mental Health Services to consider the options and other possible alternatives.

Where it is clear that a young person is suffering from a first episode of psychosis they should be transferred from CAMHS to the Early Intervention in Psychosis Service. For others, the receiving adult community mental health team (CMHT) will be identified by CAMHS based on geographical location and GP registration. It is the responsibility of the team manager (team coordinator) of the referring CAMHS to identify this team and initiate the onward referral and request for a transfer of care.

The manager of the receiving CMHT has a role to appoint a care coordinator before the official handover of care to ensure:

- a) a smooth and unbroken transition of care
- b) the comprehensive application of the CPA framework including the undertaking of a needs assessment and the development of a CPA care plan with particular attention to risk, crisis and contingency planning and carer's needs

- c) appropriate monitoring and management of service users placed in the private sector.

The care co-ordinator should meet the young person as early on in the transition planning as possible, preferably at CAMHS and via an introduction by the CAMHS key worker to facilitate agreement.

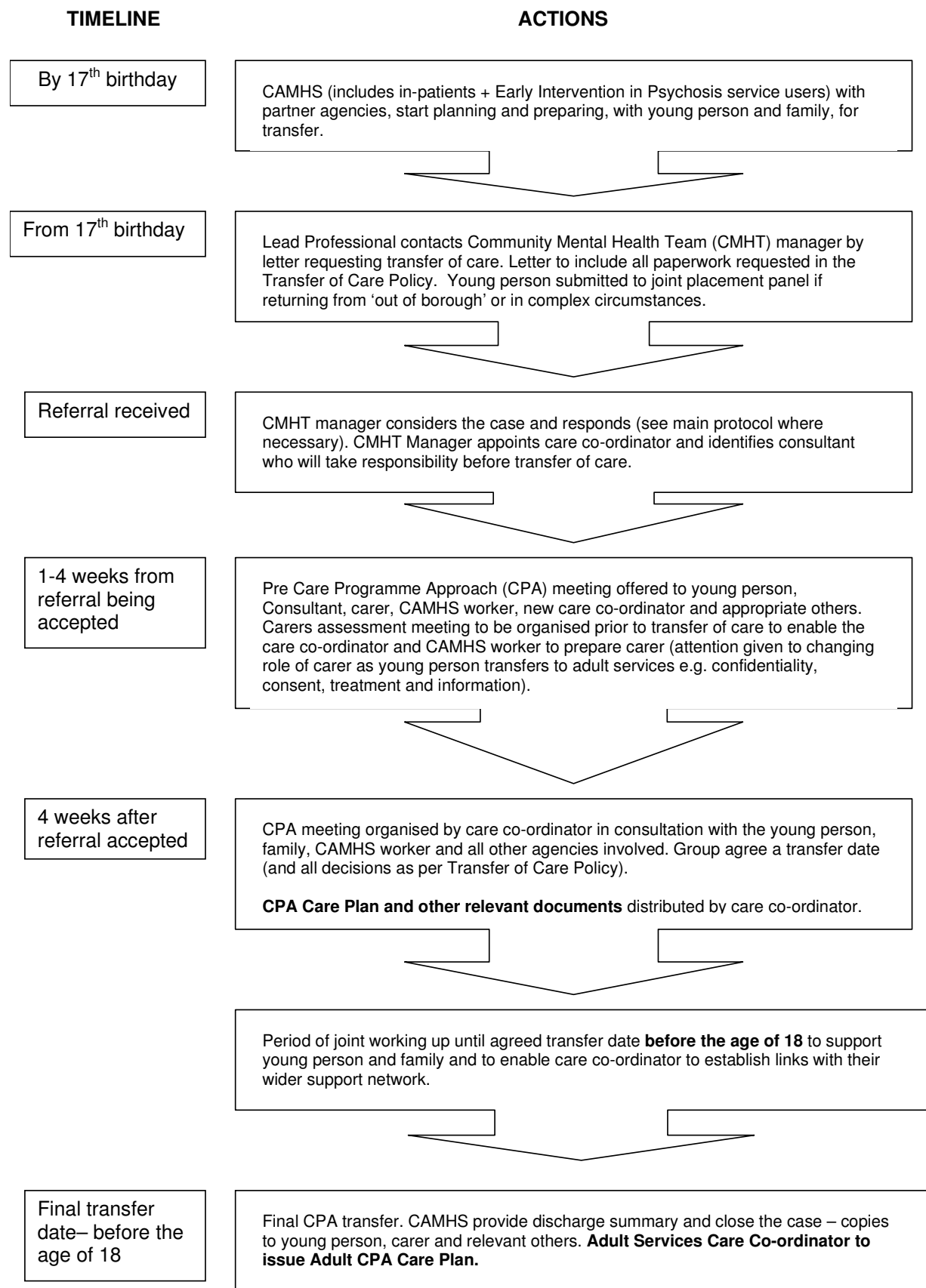
With the client's agreement, CAMHS and Adults Services should maintain a full and open dialogue which will generally entail a joint meeting between adult services and members of the CAMHS multidisciplinary team and any other agencies involved e.g. responsible parents, carers, primary care, child and family social services, mentors, youth services etc. The young person may wish to attend this joint meeting to be involved in the planning of their care. If not, they should be given feedback, including a written summary of the transitional care plan.

An optimal point/date for the transfer of lead clinical responsibilities should be agreed. Once the young person is discharged from CAMHS, the new care-coordinator will be provided with an up to date summary of CAMHS involvement.

As with adults with learning and physical disabilities, adults with mental health problems may be eligible for receipt of services under NHS Continuing Care or eligible for social services assessed under FACS (Fair Access to Care Services). Assessments for Continuing Care and FACS are separate to CPA assessments but if they are both being carried out by the same service the protocol suggests they should be completed at the same time (for more information on FACS and Continuing Care refer to sections 4.1 and 4.2).

A brief survey was conducted on the CNWL transition flow chart and its use locally for the JSNA. Five individual responses were received from a mixture of clinicians across CAMHS and AMHS, and other services in touch with young people seen by CAMHS, and notes were also taken during a CMHT team meeting. As transition cases are infrequent and individual to each case, it was felt to have been useful for clinicians to discuss and familiarise themselves with the protocol, across both Adults and Children's Teams. Respondents commented that having a period of joint working and a planned hand over was beneficial for both the young person and the services, and also helped to manage parents' expectations around transition. In terms of improvements that could be made to the current process, it was felt to be particularly important to have clarity on what happens for young people who access CAMHS during transition age, for example aged 17.5 years, something the protocol does not currently specifically draw attention to. Similar to responses made in the recently published TRACK study, there was felt to be concern within CAMHS around the different levels of support in Adults and Children's, particularly for clients with conditions such as ADHD and autism and that more detailed pathways are needed for young people who do not meet the threshold for adults services. More detail on all the responses received is provided in appendix I.

Figure 33: Flow chart showing the timeline and actions for transfer of care from CAMHS to Adult Mental Health Services



10 Conclusions and recommendations

Transition can be a difficult time both for young people with disabilities and complex health needs and their families, and also for the services that support them. Although the number of young people receiving support from Children's Services, including Special Education, transitioning to Adults Services is small, they are a diverse group with high and sometimes complex needs. It is vital that their transition is well planned and managed for all concerned: Children's and Adults Services need adequate information in order to plan for the transfer of responsibility in plenty of time, both in terms of finances and service provision; and the way young people are supported at transition is crucial to their continued wellbeing and their independence, as well as their continued engagement with services and treatments.

There has been a major push in public policy over the last decade to improve the transition process for young people with disabilities; most recently with the launch of the three year Transition Support Programme in 2008. Improving transition has also been identified as a local priority.

Recently there have been many improvements to transition in Westminster in terms of service delivery, inter-agency communication and the identification of, and transition planning for, young people in Westminster. Despite these developments this needs assessment has identified some areas where transition in Westminster could benefit from further improvements. Twenty-two recommendations have been suggested. These recommendations, as well as a summary of what Westminster does well at transition are outlined in more detail below.

The recommendations are arranged thematically, rather than in order of priority. As the JSNA has indicated, the key area for improvement is in the data on the transition population. There has been discussion for some time locally about developing a pooled dataset for transition, which can be used to track young people throughout the transition process. This would help reduce the risk of young people being overlooked within transition planning, which has potential cost implications for services and may result in poorer outcomes for the young person. In the meantime it is vital that the informal data sharing agreements between the teams working with young people with disabilities in transition continue, and that the teams update each other as and when they are aware of new young people moving into the area during the transition years. In addition, better recording of the referral source for new referrals to Adults Services and the destinations of closed cases within Children's Services would facilitate better mapping of service use over time, for future study of trends within the transition population.

This JSNA has looked at young people with learning disabilities, physical disabilities, sensory impairments, complex health needs and mental health problems aged 14-25 years who make the transition between Children's and Adults Health and Social Services. It has been noted that there are a large number of potentially vulnerable young people on the edges of this group, who do not meet the criteria for specialist support as adults and who warrant further research.

The JSNA has focused on the transition process and the needs of young people at transition. It should be noted that there are other needs assessments and strategies which link closely with this JSNA, and provide more information on the broader needs of the population groups discussed within the JSNA and the services that support them. These are given in the table below.

Learning disabilities	The Westminster JSNA and strategy for adults with learning disabilities, <i>The Big Plan 2009-2012</i> (NHSW, WCC 2009; NHSW, WCC, WLDP 2009)
Physical disabilities & sensory impairments	The Westminster strategy for adults with physical disabilities and sensory needs, <i>Our Say, Our Way, 2009-2012</i> (NHSW, WCC 2009)
Autistic spectrum conditions	The Westminster JSNA and strategy for adults with autistic spectrum conditions and Asperger syndrome for 2010-13 (NHSW, WCC 2010a; WCC, NHSW 2010)
Mental health	The Westminster JSNA and strategy for adults with mental health needs (WCP 2009; WMHP 2010)
	The Westminster <i>Child and Adolescent Mental Health Strategy, 2006-08</i> (WPCT, CNWL, WCC 2006)
Children & young people	The Westminster <i>Children and Young People's Plan 2009-11</i> (WCC, NHSW 2009)
	<i>The Health and Wellbeing of Children and Young People aged 0-19 in Westminster: A Population Profile</i> (WCP 2010)
Carers	The Westminster JSNA and strategy for carers for 2010-13 (NHSW 2009; NHSW, WCC 2010b)

What works well in Westminster and should be continued

(The sections of the JSNA which the recommendations relate to are given in brackets after each recommendation.)

Westminster has a **multi-agency Transition Strategy Group**, which makes strategic decisions regarding transition in Westminster. This has improved inter-agency communication and helped to streamline the transition process within Westminster. *(Section 5.2)*

Westminster has a **multi-agency Operational Transition Group** (Young People's Transition (YPT) Operational Group), which helps plan young people's transition between Children's and Adults Services. This has improved service delivery, inter-agency communication and the identification of, and transition planning for, young people in Westminster. *(Section 5.2)*

Westminster has a **commissioner in Children's Services and a commissioner in Adults Services with named responsibility for transition**. This has helped to raise the profile of transition and the importance of getting the transition process right for young people and their families. *(Section 5.2)*

Westminster has developed a **multi-agency Transition Protocol**. This has helped clarify the responsibilities for different teams working with young people at transition. *(Section 5.2)*

Westminster has a **transition pathway for young people with learning disabilities** which identifies the key stages that young people must pass through during transition from the Children with Disabilities Team to the Westminster Learning Disabilities Partnership. (*Sections 6.2.5, 6.2.6 & 6.2.7*)

Central North West London Mental Health NHS Trust, which provides specialist mental health services for Westminster residents, has a **transition flowchart and transfer of care policy for young people with mental health problems** moving between Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services. (*Section 9.3*)

Westminster has two **specialist Connexions Personal Advisors** (PAs) who work with young people educated at the two local special schools. One of the PAs also offers access to information, advice and guidance services for young people and their families educated out of borough in special education. The PAs work directly with the young people to help plan their future education, training and employment. The specialist Connexions Careers contract also has 0.5 full time equivalent learning difficulties and disabilities (LDD) PA allocation, as well as providing services to all the mainstream schools. This is a valuable resource for young people to help them during their transition whilst preparing for adulthood. (*Section 6.2.4*)

Many children with more moderate disabilities will be educated in mainstream schools and will not be eligible for Adults Services. Although not transitioning between Children's and Adult's Services these children are making the transition 'to adulthood' without continued social or health support, which may increase their vulnerability compared to their peers. The **Connexions teams** help them prepare for adulthood and their future through their **universal offer**, with support for continuing into education, training or employment. (*Section 3.1.2*)

Westminster has a dedicated **Transition Social Worker** in the Children with Disabilities Team who works with young people between 14–18 years and provides a mentoring role for other Social Workers within the Team undertaking transition work, as well as being the main point of contact for transitional issues that arise within the Team. The role supports young people and their parents/carers to plan for their future post-18/ post full time education and liaises on their behalf with the different services throughout the young person's transition. (*Sections 6.2.5 & 7.2*)

There is a **dedicated team within the Westminster's Learning Disabilities Partnership** supporting new users to the service, including **young people in transition**. The team aims to allocate all young people that will be eligible for Adult Services to a case manager when they are 16 years old. The case worker, together with Children's Services, ensures that all assessments and referrals are in place prior to the young person's 18th birthday so that there is a smooth transition into Adult Services. (*Section 6.2.7*)

Work has taken place to embed **person-centred-planning** and person-centred-input into transition reviews at Westminster's two special schools. Key teachers have been trained in person-centred-planning. This is likely to enable young people to feel more involved in the decisions that are made about and for their future during transition. This is seen as best practice. (*Section 3*)

A **written health referral pathway** has recently been developed for young people with learning disabilities going through transition. This will help young people, their families and the services that support them better understand the health transition process and their different roles and responsibilities. This is seen as best practice. *(Section 3.7)*

In Westminster, it is considered a priority to increase the number of young people receiving **self-directed support** as adults. As such, the self-assessment questionnaire for personal budgets is embedded within transition planning for people with disabilities. All young people making the transition to the Westminster Learning Disabilities Partnership and Adults' Physical Disabilities Team are offered supported self assessments. Self-directed support allows the young person greater control over the services they receive to ensure that they best suit their personal needs. *(Section 3.6)*

Suggested improvements to the current transition processes

Data: Data sharing

Each team involved in transition in Westminster currently has their own database. These databases are not compatible. As such data transfers between the different teams are difficult, inefficient and time consuming. The different systems increase the risk that a young person would be overlooked within transition planning; this has potential cost implications for services and may result in poorer outcomes for the young person.

Recommendation: A single pooled database is developed which can be accessed by all relevant teams in both Children's and Adult's Services (according to a strict access protocol to maintain client confidentiality). This database should include key personal information, details of the services they are currently in touch with and their transition status. To enable more robust financial planning this database should include the current costs of a young person's placements and additional care packages and an indication of whether they are likely to require a low, medium or high cost support package on transition. *(Sections 5.3 & 5.4)*

Recommendation: Westminster has informal data sharing agreements between different teams (including Special Educational Needs (SEN), Looked After Children (LAC), Children with Disabilities Team, Connexions/Locality Young People's Service and the Westminster Learning Disabilities Partnership) for sharing of data on the transition population on a regular basis. It is important that this continues until a single pooled transition database is established. *(Section 5.4)*

Data: Data recording

Children's and Adults' Health and Social Care Services use different database systems for recording information about their service users. Currently Adult Services (both Local Authority and NHS) do not regularly record whether a young person has entered their service through transition from Westminster Children's Services or elsewhere. It is also not consistently recorded where children leaving Children's Services are referred onto. Regular recording of referral source and destination would

enable better understanding of the flow between Children's and Adult Services and the needs of those young people who transition. This would allow mapping of service use over time.

Recommendation: Accurate completion of the 'referral source' code on SWIFT, the adult social care database, and the adult mental health database should be mandatory on data entry for a new referral. (Section 6.4.2 & 7.5.2)

Recommendation: Accurate completion of where young people are referred on to from CAMHS and other Children's Services should be mandatory on data entry for closing an old case. (Section 9.2)

Pathways

The transition process and service planning for transition is extremely complex. The use of a written pathway ensures that no aspects are forgotten and all parties are aware of the different stages and responsibilities. A transition pathway has worked well for the teams working with young people with learning disabilities during their transition to Adult Services.

Recommendation: A written pathway for transition is developed for the teams in both Children's and Adult Services working with young people with physical disabilities. This should include clear information around which young people, and when, will be put forward for a Continuing Care Assessment. The transition pathway for young people with learning disabilities could be adapted to suit this purpose. (Section 7.6)

Recommendation: Consultation with staff at Central North West London NHS Mental Health Trust highlighted the fact that transition across mental health services is a relatively rare occurrence. There is an agreed transition protocol for mental health. It is vital that staff across both Children's and Adults' Mental Health Services continue to be aware of the protocol and their respective roles and responsibilities in transition, as well as which documents to refer to for more information. This is particularly important for young people who access services for the first time close to age of transition (for example 17 ½ years). (Section 9.3)

Financial and service planning

Service planning for transition is complex and involves many different agencies. Some decisions made regarding service provision, placements and funding arrangements made during adolescence have an impact on Adults Services.

Recommendation: The process for arranging educational placements for young people with disabilities should continue to be based on the principal of young people being educated locally where possible/appropriate. It is important to have a transparent decision-making process for these arrangements; where the decision may impact on Adults Services they should be involved early on in the process. Any decisions around changes to funding agreements should be agreed at director level, following agreed pathways, and cascaded to all relevant teams. (Section 5.1.1)

Preparing for adulthood

Transition is more than the move from Children's to Adults Services. It is the time when a young person should be supported to prepare for adulthood. This is especially important for young people who will continue to be accessing care in a very different service model from what they been used to in Children's Services. Support for young people preparing for adulthood should be holistic and include practical person-centred skills as appropriate.

Recommendation: Being able to travel on one's own or with minimal supervision is an important part of developing independence in adulthood. Travel training in Westminster is provided through a number of different agencies and at different points during transition. It is recommended that local provision is reviewed to ensure a joined-up process in commissioning services, that quality is consistent and young people access training when most appropriate. (*Section 3.5*)

Recommendation: Short break provision is commissioned separately for children and adults. Through sharing of information on the short break services commissioned by Children's Services, Adults Services would be better placed to commission age-appropriate short breaks for young adults. (*Section 3.4*)

Recommendation: Continued development of personalisation and self-directed support should be encouraged across the services for young people with disabilities delivered by Westminster. Any learning from the pilots on personal health budgets and use of personal budgets within Children's Services should be embedded into service structures. (*Section 3.6 & 3.7*)

Transition planning

Within national guidance around transition, there is increased emphasis that the school transition plan (for children with special educational needs) should address wider aspects of the young person's support needs, aspirations for the future and practicalities for moving to Adults Services. As well as education the transition plan should include housing, employment, advocacy and peer support, health and social interests. It therefore requires multi-agency input. It should involve the young person themselves and be person-centred.

Recommendation: The current person-centred transition planning for young people educated at special schools who are to transition to Adults Services should be expanded to include other services and agencies. This will broaden the plan to cover all aspects of a young person's life after transition and whilst preparing for adulthood (including employment, leisure, travel, independence etc.). It is acknowledged that person-centred planning is resource intensive, but important for young people. Therefore to ensure that this planning occurs, a named individual would need to take ownership of the co-ordination of this broader plan alongside each agency having a named individual to contribute. (*Sections 3 & 6.2.2*)

Recommendation: Improve communication links between local services and pupils in out of borough schools to determine the quality of person-centred transition planning and preparations for adulthood that young people are receiving. This should

include (but not be limited to) discussion and preparation for employment, work experience, independence, travel training, sexual health etc. (*Section 3*)

Healthcare support

Many young people with disabilities coming through transition between Children's and Adults' Services have additional and sometimes complex health needs which require ongoing support and management. It is important for their successful transition between services and their general wellbeing in adulthood that there are no barriers to accessing services at any point during their transition.

Recommendation: Young people going through transition from Children's to Adults Services should have a health action plan. This plan will detail their health needs and how those needs will be met in adulthood, including named services/individuals where appropriate. The process of developing a health action plan enables young people and their families to get a better understanding of adult health services and how and where they will receive support and care. The health action plan also assists services to plan the healthcare provision for these young people; this plan should be shared with the young person's GP. This seen as best practice. (*Section 3.7.1*)

Recommendation: A named health facilitator is identified to support a young person and their family in the co-ordination of transition between Children's and Adult's Health Services. (*Section 3.7*)

Recommendation: Young people with disabilities may have minimal contact with their GP during childhood; often they are treated principally by paediatricians or through their school health team. This is particularly the case for young people who are schooled out of borough. An added complication is that some services such as the Child Development Service are based on resident population rather than GP registration. It is vital that young people and their families understand the importance of being registered with a local GP practice during transition. GPs are the gatekeepers for access to secondary care services as well as the first point of contact for primary healthcare services. (*Section 3.7*)

Recommendation: The Westminster Learning Disabilities Partnership has a local enhanced service with local GPs to provide annual health checks for people with learning disabilities aged 18+. It is important that young people who transition to this service are supported to get an appointment for this health check shortly after transition. In order for this to happen a young person must be registered with a Westminster GP. (*Section 3.7.2*)

Engaging parents

The transition process can prove to be a very emotional and difficult time for parents. On their child reaching maturity many parents may find themselves excluded from their care. Improved engagement with parents will enable them to better understand the transition process and the changes to expect on their child reaching Adult Services.

Recommendation: Parent representatives should be invited to join the Transition Strategy Group, to enable them to engage in transition at a strategic level. This is an example of best practice and is recommended in national policy. In addition to this, parents should be asked how they would like the local authority to engage with them; it may, for example, be that in addition to having parent representatives on the Strategy Group, the best way to engage a wider range of parents would be to hold a dedicated transition session once or twice a year at the Parent Participation Group's coffee morning. (Section 3.8)

Information for parents and carers

Improving the information given to parents and carers around transition is a development area highlighted during consultations with both parents and services working with young people. It is an ongoing local priority. Recent developments include coffee mornings organised for parents at the local special schools, involving Connexions PAs, the Westminster Transition Social Worker and representatives from the Westminster Learning Disabilities Partnerships.

Recommendation: Information for parents should be provided in a variety of different ways throughout the transition process. Services should be sensitive to the fact that families may find the transition period difficult and may want information at different points rather than all at once. (Section 3.8)

Documenting and acting on service users reports of transition

On occasion, due to the complex nature of transition and the needs of the transition population, errors will occur in the transition process. It is vital that young people and their families are able to highlight these issues to the services involved and for the services to act on these complaints. Services may also identify areas where improvement is needed.

Recommendation: Develop a method to capture, record and share examples of service users and their families' experiences during the transition process and their satisfaction with the care received. These should be both good and bad experiences which can be used to inform future planning for services. PREMS (Patient Related Experience Measures) are currently being used within WLDP to assess the quality of service delivery. The feedback provided via PREM allows individuals with learning disabilities and their carers to raise any concerns or provide positive feedback about their service experience. The information gathered via PREM is discussed at the Team's monthly governance meeting, which allows the team management and clinical leads to reflect and discuss in detail any concerns raised and how they can be resolved. A similar measure could be adapted for the transition cohort. (Section 2)

Recommendation: Following the model of successful events in the past organised through the Young Person's Transition (YPT) Operational Group, joint meetings should be held at least twice a year for the different teams and agencies working with young people in transition across Children's and Adult Services to share learning, reflect on the transition process and refine local protocols. Key messages and issues raised should be fed up to the Transition Strategy Group. (Section 5.2)

Vulnerable groups who do not transition

The JSNA has focussed on young people with disabilities, mental health problems and complex health needs who make the transition from Children's to Adults Services. It has, however, highlighted that there is a large group of potentially vulnerable young people who do not meet the eligibility criteria for specialist support as adults.

Recommendation: Another piece of work is carried out to understand the needs of this population and the support services available. (*Section 4.4*)

Performance monitoring

In order to improve the quality of transition services and outcomes for young people going through transition, it may be worth considering developing some local performance indicators. (*Literature review, section E*)

Other local protocols and national documents have included the following examples which could be adapted for use in Westminster:

- The number and percentage of young people with disabilities aged 14-19 years contributing to/attending their transition review and who are happy with the resulting plan
- The number and percentage of young people with disabilities aged 14-19 years with a transition plan
- The number and percentage of young people with disabilities aged 14-19 years with a health plan
- The number and percentage of young people with disabilities aged 16-18 years with disabilities who are in education, employment or training (EET) and those not in education, employment or training (NEET)
- Number and percentage of young adults with disabilities aged 18-25 years employed for 16 hours a week or more
- Number and percentage of children and young people aged 14-18 years supported by self-directed support (through their parents)
- Number and percentage of young adults aged 16-25 years accessing self-directed support.

11 Abbreviations

ADHD	Attention Deficit Hyperactive Disorder
AMHS	Adult Mental Health Services
BSL	British Sign Language
CAMHS	Children & Adolescent Mental Health Services
CBT	Cognitive Behavioural Therapy
CLCH	Central London Community Healthcare
CMHT	Community Mental Health Team
CNWL	Central North West London Mental Health NHS Trust
CPA	Care Programme Approach
CV	Curriculum Vitae
DCATCH	Disabled Children Access to Childcare
DCSF	Department for Children, Schools and Families
DfES	Department for Education and Skills
DH	Department of Health
DWP	Department for Work and Pensions
FACS	Fair Access to Care Services
GLA	Greater London Authority
GUM	Genito-urinary Medicine
IAPT	Improved Access to Psychological Therapies
ILF	Independent Living Fund
JSNA	Joint Strategic Needs Assessment
LAC	Looked After Children
LDD	Learning Difficulty/Disability
LEA	Local Education Authorities
LES	Local Enhanced Services
NHS	National Health Service
ONS	Office for National Statistics
PA	Personal Advisor
PCT	Primary Care Trust
SALT	Speech and Language Therapy
SAQ	Self Assessment Questionnaire
SEN	Special Educational Need
SENCO	Special Educational Needs Coordinator

UEA	University of East Anglia
WCC	Westminster City Council
WLDP	Westminster Learning Disabilities Partnership
WSPLD	Westminster Society for People with Learning Disabilities
YPLA	Young People's Learning Agency

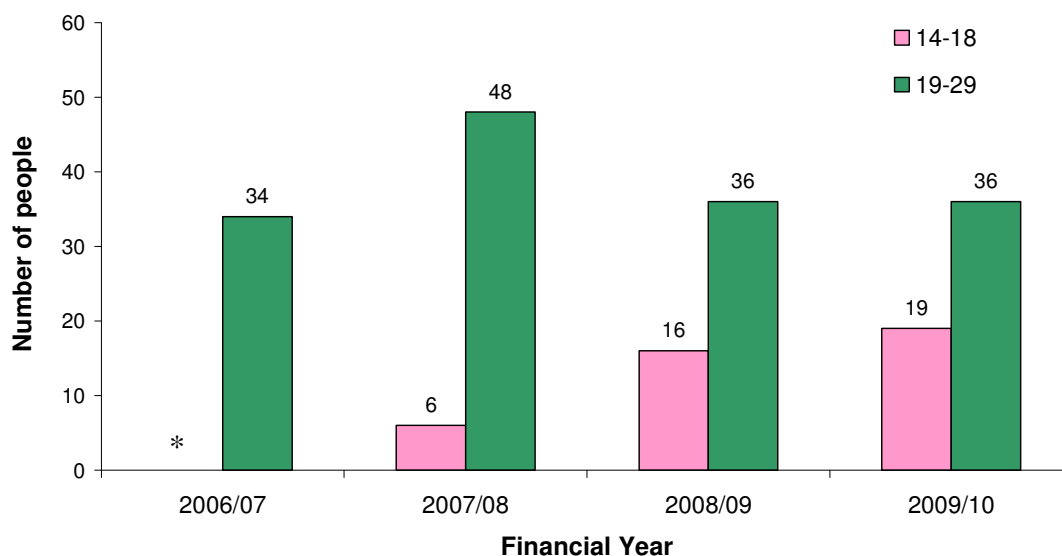
Appendix A – Members of the 14-25 Transition JSNA Steering Group

Fiona Barrett	Area Manager, Locality Young Peoples Services/ Connexions
Amynta Cardwell	Interim Deputy CAMHS, Central North West London NHS Mental Health Trust (CNWL)
Mary Dalton	Head of Commissioning for Learning Disabilities, Transition and Carers (NHSW/WCC)
Jane Derbyshire	Service Development Manager, Children, Young People and Maternity Services (NHSW)
Alison Evans	Social Care Lead/ Workforce Development Officer Westminster Adult Mental Health Services,
Janet Lang	Service Manager, Westminster Learning Disabilities Partnership
Tessa Lindfield	Consultant in Public Health and Assistant Director Public Health and Wellbeing (NHSW/WCC)
Nick Laurence	Service Manager, Children with Disabilities (WCC)
Louise Maile	Service Development Manager, Physical Disabilities and Sensory Impairment (NHSW)
Christine Reeves	Assistant Director of Joint Commissioning Children, Young People and Maternity Services (NHSW/WCC)
Elaine Ruddy	Service Development Manager, Learning Disabilities (NHSW)
June Simson	Head of Commissioning SEN and Inclusion (WCC)
Anna Varela-Raynes	Public Health Programme Manager, Children and Young People (NHSW)
Vikki Wilkinson	Service Manager, Locality Young Peoples Services/ Connexions
Katie Wright	JSNA Analyst (NHSW)

The Westminster Community Equipment Service

The Westminster Community Equipment Service provides a wide range of daily living aids that have been designed to help people who experience difficulties with day to day activities, to remain independent in their own homes. It also provides help to carers to support someone at home. The service is available to permanent residents in Westminster of any age (children and adults), who have a disability of chronic illness. Equipment is prescribed to a service user following an assessment of their need by a health or social care professional.

Figure 34: Number of young people aged 14-29 receiving equipment from the Westminster Equipment Service over the past four financial years.



Source: Westminster Equipment Service, October 2010

* Indicates that there were ≤ 5 service users aged 14-18 in 2006/7

Figure 34 shows the number of people receiving equipment from the service per year, of transition age. The majority of service users within this age group are over 19. Overall the pattern shows a general increase in numbers of young people receiving equipment from the services over the past few years, particularly in the 14-18 age group. Some of the individuals were the same across the different financial years.

Young people were supported with a range of equipment from kitchen equipment to handrails and mattresses. Some young people only required single items; for others a number of different items were provided. The average cost per person per year changes annually depending on the equipment required. Between 2006/07 (£76.49) and 2008/09 (£160.77) an increase was seen but the average cost per person decreased slightly in 2009/10 (£137.90).

⁴³ The majority of the information on the services in this section is taken from NHS Westminster and Westminster City Council (2009) *Our Say, Our Way, 2009 to 2012: Joint Commissioning Strategy for Adults with Physical Disabilities and Sensory Needs*

The Westminster Wheelchair Service

The Westminster Wheelchair Service provides mainstream wheelchairs for around 12,000 wheelchair users of all ages across three boroughs, Westminster, Kensington and Chelsea, and Hammersmith and Fulham. Since September 2008 wheelchair users have helped to inform the development of the service through a user-led wheelchair service user forum.

The Westminster Wheelchair Service provides a basic service for many wheelchair needs. More specialist wheelchairs such as self-controlled chairs or ones for sporting activities, may have to be sought on an individual basis from other services like *Whizz Kidz* (<http://www.whizz-kidz.org.uk/gethelp/getequipment/>).

Data on service users from the Wheelchair Service was not available to be provided for this needs assessment.

Westminster City Council Deaf and Hard of Hearing Service

The service provides the following support:

- Deaf/hard of hearing registration
- Provision of deaf/hard of hearing equipment (such as doorbells, telephones and fire alarms)
- Information on local British Sign Language (BSL)/ interpreting services and letter translation service
- Referral to local organisations who can help secure the rights of service users and represent their best interests.
- Information and advice within and outside Westminster on all subjects relating to deaf/hard of hearing issues, e.g. equipment, support groups, access to printed information and employment issues
- A drop-in session at Westminster City Hall.

There are currently 8 people aged between 18 and 24 on the deaf and hard of hearing register (October 2010).

Westminster Deaf Network Group

The Westminster Deaf Network Group consists of different organisations which offer support, advice, information and services in Westminster to those who are Deaf or Hard of Hearing. Information is shared with one another and the Deaf Community to ensure that the needs of residents in Westminster are being met and to identify any gaps. The group also tries to ensure that the Council is aware of what each organisation does so they can offer better signposting to service users who may require support that the Council cannot offer.

Interpreting services

NHS Westminster commissions a BSL/English Interpreting Service from GRIP Language Service for deaf residents of Westminster. The service is for all health appointments at local hospitals, GP surgeries and other primary care services. This service was expanded in 2008/2009, to fund access to both male and female interpreters and to increase capacity to meet demand, following requests from service users.

Dual Sensory Loss

Deafblind UK provide services in Westminster for people with dual sensory loss. This is a small contract and provides assistance to people to help with activities such as correspondence and escorting to promote independence.

Specialist ophthalmology

NHS Westminster commissions specialist ophthalmology services from a number of acute hospitals in London, including Imperial Healthcare NHS Trust (Western Eye Hospital) and Moorfields Eye Hospital.

Westminster City Council low vision service

The service provides the following support and services:

- Daily living skills training – support with tasks such as making a hot drink safely, general kitchen safety, cleaning and sewing
- Communications – assistance with reading and writing, using magnifiers, telling the time, using the telephone, learning Braille, typing and computer skills
- Mobility – help with getting around safely, indoors and outside. Help offered with aids such as canes and support sticks; advice on how to get help from family/friends and members of the public
- Lighting – advice regarding lighting in your home. This can be assessed and we may be able to suggest improvements
- Information and advice – on all subjects relating to visual impairment e.g. equipment, support groups, access to printed information, employment issues.

Appendix C - The SEN statement process

Some, but not all, potential special educational needs (SEN) are picked up early in a child's development, for example at neonatal screening. If a child has attended an early educational setting they may have had their needs identified and assessed. Others are likely to be identified during primary education (DfES 2001).

In the early years, health service practitioners such as health visitors or the child Development Team may notify their local council as to a child's potential special educational need; this does not count as a referral. Referrals for an assessment of special educational need can only be made to the Council by:

- the child's school or setting
- a parent
- another agency (DfES 2001).

Local Education Authorities (LEA) have a statutory duty to identify and make an assessment of the children for whom they are responsible who have special educational needs and who may need a statement⁴⁴. The majority of children with special educational needs will not need a statutory assessment; their needs will be met effectively within mainstream settings through *Early Years Action* and *Early Years Action Plus* or *School Action* and *School Action Plus*.⁴⁵ Only in a small number of cases will the LEA have to make a statutory assessment and consider whether to issue a statement. Not all children assessed will receive a statement; the information gathered during an assessment may indicate ways in which the school can meet the child's needs without the need for any special educational provision to be determined through a statement (DfES 2001).

An evaluation of a child's special educational need takes account of the following areas and their impact on the child's ability to function, learn and succeed:

- communication and interaction
- cognition and learning
- behaviour, emotional and social development
- sensory and/or physical.

Children must have needs and requirements which fall into at least one of these areas; many will have needs in more than one area. As part of the child's assessment, the LEA considers on an individual basis whether specialist interventions are required to support the child to overcome these barriers to learning and whether those interventions could be provided through *School Action Plus* or whether a statement is required (DfES 2001).

The child's statement usually remains in force until the LEA ceases to maintain it. A statement will lapse in the following situations:

- a young person transfers into further or higher education;
- if the young person leaves school at 16 to seek employment or training;

⁴⁴ Sections 321 and 323, Education Act 1996

⁴⁵ An explanation of School Action and School Action Plus is given in section 6.1.

- if they move abroad for a significant length of time.

Where there is agreement post-16 that the young person should stay in education and the LEA can find the appropriate school provision, the LEA continues to maintain the statement. All statements are reviewed annually (DfES 2001).

Children with SEN statements are eligible to stay at school, if they wish, until the year in which they turn 19. They can leave at any point before that time after year 11 (age 16).

For children with SEN statements moving borough within the UK their SEN statement moves with them. In this instance, the new Local Authority would review and adopt the statement, and arrange the appropriate provision. The case is more difficult with individuals moving into the borough from abroad, for whom there may be little information on previous educational provision and need. If they arrive at 16 it is at the LEA's discretion as to whether to provide a school placement.

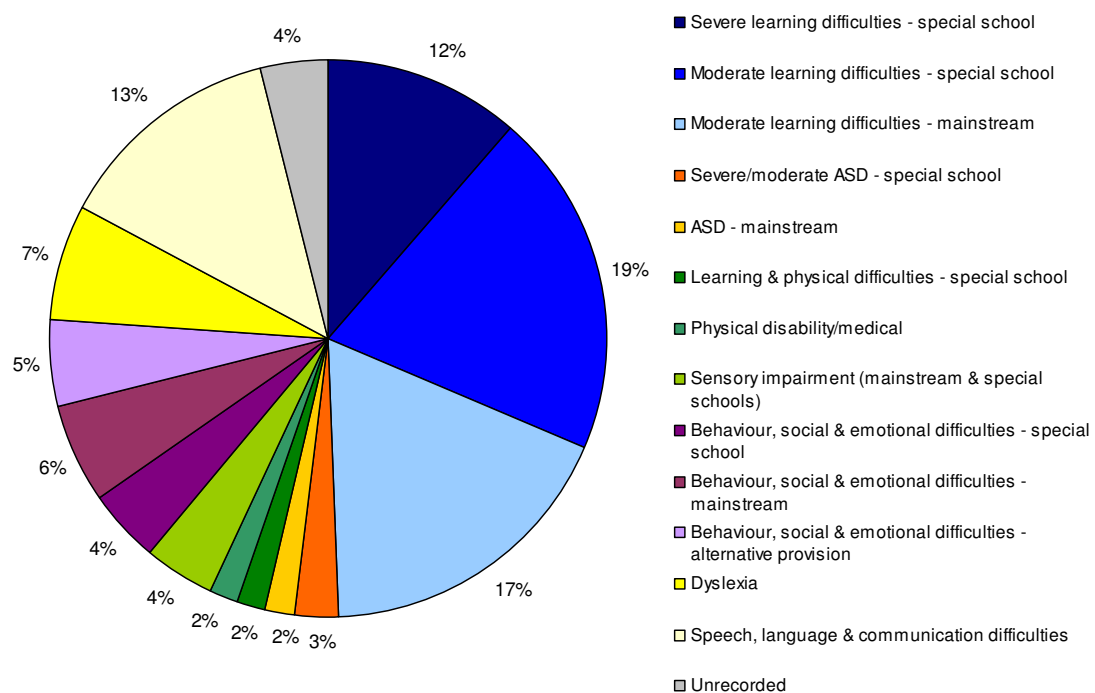
Children with statements of special educational needs may be educated in mainstream provision, in special schools or alternative provision, depending upon need. Parents may also choose to educate their child at home. To access provision in special schools children must have a SEN statement.

Westminster's Local Authority is responsible for the statements of children who are resident in Westminster. Although their home residence is Westminster they may be educated out of borough. In reverse some of the children educated in Westminster schools, will have a SEN statement from another borough, depending on their place of residence.

Appendix D – Additional data on the SEN population

Figure 35 provides an idea of some of the primary needs/disabilities of the SEN population as a whole. It is important, however, to note a few caveats around this data. Special educational need does not necessarily reflect a particular disability or health need and the purpose of the SEN database is not to record people's primary need in this way. Furthermore, although only one need has been included for each pupil, some of the pupils with SEN statements are likely to have multiple needs across several categories. For instance, some of those with a moderate learning disability also have 'complex' needs, which are not given as a category here. Similarly some of those with sensory impairments and/or behavioural, social and emotional difficulties also have learning difficulties. This information is, however, useful in indicating the spectrum of needs within the SEN population and those individuals who may have long-term support needs (continuing into adulthood), who may not be easily identified from other sources, particularly those with a visual or hearing impairment, and other medical/physical needs.

Figure 35: Summary of primary level of need for all young people with SEN statements (school years 9-14) (n=313)



Source: SEN Department, Westminster City Council, November 2010

Note:

- Individuals with a 'language impairment' are included in the category speech, language and communication difficulty; individuals with a 'specific learning difficulty' are included in the dyslexia category; individuals with 'attention deficit hyperactive disorder' (ADHD) and those with emotional needs or challenging behaviour without other disability are included in the category of behavioural, social and emotional difficulty.
- There are ≤ 5 individuals with more severe learning difficulties/disability in mainstream schools who have been included in the category of 'moderate learning difficulties – mainstream' to maintain confidentiality.

Appendix E – Additional information on funding for children with disabilities in Westminster

Education funding for pupils with learning disabilities educated in special schools

The funding of special school placements for young people with special educational needs (SEN) and support for young people with disabilities varies by provision and child. For instance the majority of young people (n=59) with SEN for a learning disability, educated in the local maintained special school sector, will not incur any additional costs. The remaining 51 pupils educated in special schools currently have on average an annual support cost of around £31,200 per child, ranging from between approximately £5,000 and £90,000 per child depending upon their level of need. The total additional educational contribution to special school provision for these 51 pupils is in the region of £1,590,000 per school year. Figure 36 and Figure 37 below provide an indication of the number of pupils receiving additional support packages and the costs of those packages.

Figure 36: Range of additional costs for pupils educated in special schools, who have a SEN statement for a learning disability

Funding per year	Number of pupils
Not funded by pupil-led funding	59
£1 - £24,999	25
£25,00 - £49,999	17
£50,000 - £90,000	9

Source: SEN Department, Westminster City Council, November 2010

Note there were 3 pupils for whom no funding was recorded.

Figure 37: Range of additional costs for pupils educated in special schools, who have a SEN statement for a learning disability by provision

Type of provision	Range of costs (per year)	Number of pupils
Maintained day (with some additional support)	£5,000 - £56,500	29
Non-maintained day	£11,000 - £77,000	13
Residential (all types of provision)*	£31,500 - £90,000	7

Source: SEN Department, Westminster City Council, November 2010

* ≤ 5 of the residential placements are jointly funded placements. This figure represents the education contribution to these placements and therefore underestimates the total cost of these placements.

As well as the support provided at school, 26 of these pupils also receive a care package from the Children with Disabilities Team. Of these children, 15 are educated in-borough at either College Park or Queen Elizabeth II Jubilee School.

It should be noted that this information only provides some of the detail on the cost of SEN provision. The total annual budget for SEN for pupils in years 9-14 is around £3,152,400. Around £1,410,000 goes towards the annual spend of supporting pupils in mainstream and alternative provision. These support packages for the 176 pupils in mainstream and alternative provision cost an average of around £8,000. 57 pupils incur no additional support costs, and the remaining 119 pupils have support packages costing between £1,790 and £28,500.

Young People's Learning Agency funding for pupils with disabilities educated in specialist educational placements

There are currently 6 pupils in specialist (educational) placements of 38 week length aged between 17 and 22, funded through the Young People's Learning Agency (YPLA). These are discussed in more detail in section 3.1.8.

The total annual cost of the placements is around £360,000, with individual placements ranging from £42,300 to £136,000 per year. In a few cases other departments contributed to the placements, in addition to the YPLA funding. All the placements are due to finish within the next 3 financial years, at slightly different points.

Support packages funded by the Children with Disabilities Team

Not all young people in touch with the service currently have a care package (33 out of 68 young people aged 14+). The care packages themselves are discussed in more detail in section 7.2.2. Care packages for some individuals may be funded through direct payments, either partially or entirely.

The total annual cost of care packages for the transition age population (14+) is in the region of £188,000. Packages range from around £250 to £26,000 and have an average support cost of around £5,685 per year. Figure 38 provides an indication of the range of care package costs. Some of these packages are jointly funded with health, through NHS continuing care, described in more detail in section 4.2.

Figure 38: Range of costs of care packages provided by the Children with Disabilities Team – social care costs

Cost of care package per year	Number of children
£1 - £3499	9
£3500 - £6999	16
£7000 - £26,000	8

Source: Children with Disabilities Team, Westminster City Council, October 2010

Support packages funded by NHS Children's Continuing Care

The range of annual costs for care packages for the 27 young people currently in receipt of NHS Continuing Care (discussed in more detail in section 4.2) start at around £6,000 for 8 hours of care per week; in many cases around 50% of the charge is funded by the NHS through continuing care with the remainder through social services. More complex packages involving parenteral feeding or high cost health interventions at home may cost considerably more, as much as £70,000 per year. These costs are entirely funded by the NHS. The total annual Continuing Care contribution to support these 27 children in 2010/11 is around £400,000.

It should be noted that this section does not provide an exhaustive list of all the service costs for children with disabilities. For instance, the additional NHS funding provided for CAMHS support in schools for particular individuals is not included, neither are the contributions to school placements made by the Looked After Children Team.

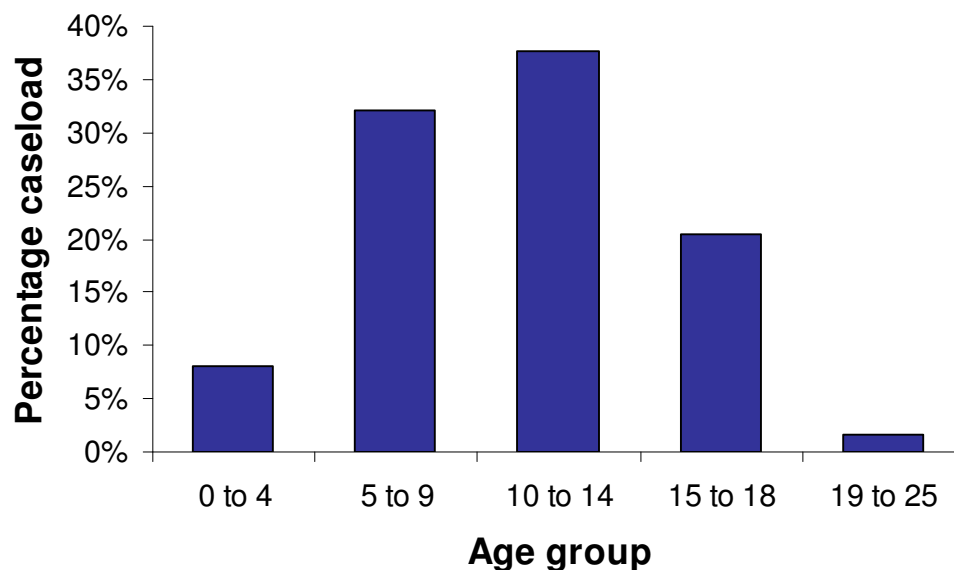
Appendix F – Additional data on CAMHS population in Westminster

Although not specific to Westminster, the Department of Health's Child Health Mapping data for Central North West London (CNWL) NHS Mental Health Trust (DH 2007/8) provides an indication of the size of the population using the CNWL CAMHS and some idea of their needs. This data supplements the data available for Westminster discussed in section 9.2. CNWL is the main provider of mental health services for Westminster residents.

The latest Child Health Mapping data covers all patients receiving tier 2 to tier 4 CNWL CAMH services in 2006/7; the majority were residents of Harrow, Hillingdon, Brent, Westminster and Kensington and Chelsea. A sample annual caseload of 2,308 individuals was used, of whom 598 were from Westminster.

Figure 39 shows the age profile of the total sample caseload. There are significantly more individuals supported in younger age groups than those who would be considered of transition age.

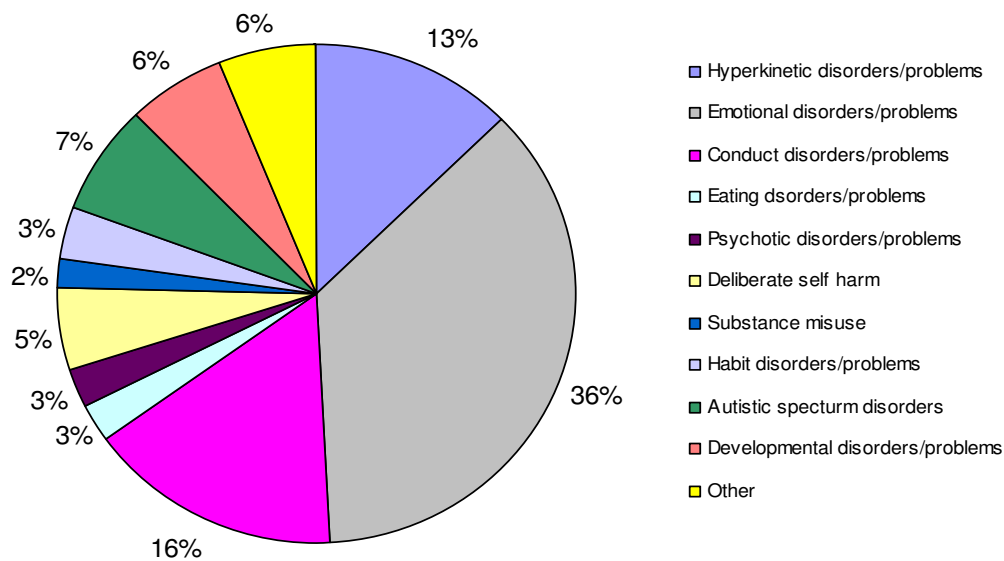
Figure 39: Age profile of CNWL CAMHS caseload 2006/7



Source: Department of Health, National Child Health Mapping Service Exercise, 2007/8: CAMHS Provider Summary for Central North West London Mental Health NHS Trust
<http://www.childhealthmapping.org.uk/> [accessed August 2010]

The data from the Child Health Mapping report also gives an indication of the reason for primary presentation. These are not categorised as diagnoses in a way that Adult Mental Health Services would recognise. The data provides an idea of the range of conditions; it also provides an idea of the proportions of the caseload with some conditions that may require support into adulthood – including eating disorders (3% caseload n=94); psychotic disorders (3% caseload n=97) and autistic spectrum disorders (7% n=264). Unfortunately, however, data is not provided to this level of detail by age or by borough of residence.

Figure 40: Primary presentation of CNWL CAMHS caseload 2006/7



Source: Department of Health, National Child Health Mapping Service Exercise, 2007/8: CAMHS Provider Summary for Central North West London Mental Health NHS Trust
<http://www.childhealthmapping.org.uk/> [accessed August 2010]

The data provided in the report also showed that 14% of the caseload had a learning disability, 12% were looked after children and 6% were youth offending cases. This indicates the cross-over between the CAMHS population and the population receiving support from other support services, such as Special Education, Looked After Children and Children with Disabilities.

Appendix I – Local survey results evaluating usage of the mental health transition flowchart

A short survey was conducted in September 2010 via email as part of the needs assessment to ascertain awareness and usage of the transition protocol and flowchart locally amongst Central North West London (CNWL) NHS Mental Health Trust Child and Adolescent Mental Health Services (CAMHS), Community Mental Health Teams (CMHT) and other support staff such as Locality Young People's Services and whether it was felt that improvements were needed to the process. A copy of the survey questions is provided below.

<p>Questionnaire</p> <ol style="list-style-type: none">1. Have you supported any young people and their carers through the transition between adolescent and adult mental health services over the past few years?2. Are you aware of the Central North West London NHS Trust transition flowchart (with attached glossary)? If yes, go to question 3. If no, go to question 4.3. Have you used the flowchart when supporting individuals through the transition process? Did you find it useful in the transition process? (Please give brief reasons for your answer).4. If you are not aware of the flowchart, have any transitions that you have been involved in followed the process as set out in the flowchart? If not, what process was followed?5. Are you aware of any issues that have arisen that have prevented a smooth transition between adolescent and adult mental health services? (If so, please provide details).6. Please let me know if you have any comments on transition locally or any suggestions for improvements to the flowchart.
--

The number of responses received was relatively low, possibly due to the lack of personal experience within current teams as to transition cases, due to low numbers. Five responses were received, some of which represented discussions individuals had had with their wider team. Notes were also taken following attendance at a CMHT team meeting in October 2010.

Respondents commented that transition cases are infrequent and individual to each case. Lengthy and complex transition cases were felt to be rare occurrences. Respondents in general felt that it was useful to have discussed the flowchart with their team and managers. Although not often involved, Locality Young Peoples Services felt that the process was something that their teams should be aware of. Other comments received are summarised below.

General comments:

- It is valuable when workers in CAMHS and Adults Mental Health Services (AMHS) liaise over cases so that clients do not have to repeat their case histories;

- It is useful for young person to have some time to meet their adult worker in advance of transfer to familiarise themselves with the service;
- It is import to manage family expectations about differences in service provision between CAMHS and AMHS;
- It is important that there is mutual awareness across CAMHS and AMHS that transition planning should begin at 17 years.

Comments on the existing flowchart

- The flowchart is comprehensive;
- There can be difficulties arranging a Consultant CPA (care programme approach) meeting within the timescales presented in the flowchart. A 2 month timescale might give more flexibility;
- There is a risk that with a year to plan transition some individuals may get lost in the system as Adults are unable to take over the case until 18;
- It is important to clarify what is meant by 'joint working' since it is important that there is no confusion over where responsibility lies for providing treatment and prescribing;
- More information could be given on people accessing mental health services during the transition age, for example at 17 ½ years of age.

Other comments made about transition in Mental Health

- For some individuals who are moving between mental health services at the same time as moving from other services such as from Youth Offending Teams to probation, transition can have added difficulties. These young people's experience of transition may be improved if the transition between services was staggered so that all handovers do not happen at the same time;
- There is a difference between the thresholds of care between Children's and Adults Services; CAMHS clinicians sometimes worry about the difference in level of support, particularly for clients with attention deficit hyperactive disorder (ADHD) and autism;
- More detailed care pathways are needed for young people who do not meet the thresholds for adults CMHTs but may have vulnerable mental health need.

Some of the comments raised about transition in Westminster mirror those raised during the TRACK study (discussed in more detail in the literature review at the end of this document) (Singh et al. 2010), particularly the need for clarity about 'joint working' during the transition phase and the concerns amongst Adult Care Coordinators about 'responsibility for someone on your case-load should something go wrong'; the need to involve parents and manage their expectations about Adult Service provision; the need for clear processes for where Adults' Services are not able to accept the referral of young people from CAMHS; and the concern among CAMHS clinicians for young people, such as those with ADHD and autism, who are unlikely to meet the threshold for CMHT services but still have support needs.

Literature Review: Transition of young people

Conducted by Sarah Perman and Colin Brodie, NHS Westminster
October- November 2010

A OUR OBJECTIVES

We searched the literature to identify research into the transition of young people with disabilities from child to adult services. Our objective was to identify (1) studies which identified barriers to effective transition, and (2) studies which found evidence of strategies and practices that promote a positive transition.

B OUR SEARCH STRATEGY

Our focus was on the transition of disabled young people from child health or social services, including special educational services, to adult health or social services. Our search strategy was broken down into separate work streams for different groups of young people. We searched for evidence of effectiveness in the transition of:

- young people with learning disabilities,
- young people with sensory impairment,
- young people with autistic spectrum disorder,
- young people with mental health needs, and
- young people with chronic health conditions and physical disabilities.

We used the following healthcare databases for our search – MEDLINE, PsychInfo, CINAHL and HMIC, accessed via NHS Athens. We searched MEDLINE and at least one other database for each group of young people. We confined our search to literature published in the last ten years in the English language. We also searched specialist collections on NHS Evidence and the Cochrane Database of Systematic Reviews.

The literature includes academic articles, policy documents, and good practice guidelines published by voluntary sector organisations and by the UK government. The academic articles we found include qualitative research, editorials, case studies and systematic reviews. We excluded articles that clearly lacked external or internal validity but we did not conduct a systematic critical review of the literature that we found. This would have been difficult because few articles described their research methodology in sufficient detail. In addition, our time and resources did not permit a systematic review to be carried out.

C LIMITS TO THE EVIDENCE

We found that there is little evidence for factors which ensure a smooth transition and positive outcomes for disabled young people. Little is known about the transition process, models and results, and about who is going through the transition process. There is much evidence about experiences and barriers, and a compelling argument that the status quo is not working (Beresford 2004; Singh et al. 2010).

The transition of some groups of young people with disabilities has received less attention than others. There has been little research into the transition of young people with mental health needs. Those in 'out of area' placements is also a neglected area of research (Beresford 2004). In addition, little is known about the transition of young people with sensory impairment.

There is evidence that some groups of disabled young people receive insufficient support at transition. Some young people with learning difficulties leave school without transition planning, despite transition planning being a requirement under the 1993 Education Act and 1994 Code of Practice for all children with a Statement of Special Educational Need (Heslop et al. 2003).

The evidence mostly provides support for general principles which seem to support effective transition although these have been rolled out without rigorous evaluation (Beresford 2004). These principles have been highlighted by several good practice guides published by the British government over the last few years. They appear generally accepted by academics and professionals working with young people as important for effective and responsive service provision.

D BARRIERS TO EFFECTIVE TRANSITION

Many academic studies provide evidence about the problems and difficulties associated with the transition of young people with disabilities. The transition of young people from children's to adult's services is often not handled well and has been described as leaving the young person and carers "in a void" (Morris 1999).

There is evidence that a poorly planned transition can lead to adverse outcomes. For young people with long term health conditions, a poor transition can lead to an increased risk of non adherence to treatment and loss to follow up. This can increase morbidity and mortality as well as lead to adverse social and educational outcomes (DH/DfES 2006). Many disabled young people have a poor quality of life on reaching adulthood: experiencing loneliness, minimal social opportunities, and a lack of skills for independent life, and with fewer education and employment opportunities than those enjoyed by their non-disabled peers (Hirst & Baldwin 1994).

Common difficulties

Some of the difficulties with transition described in the literature appear specific to particular types of disability. Others are generic problems, common across disability groups. One of the main generic short-comings, frequently cited, is the young person's lack of involvement in the decision-making process. For example, research undertaken by the Home Farm Trust and the Norah Fry Research Centre in 2002 into transition for young people with learning disabilities found that:

- A fifth of youngsters had left school without a transition plan.
- Almost half the young people had little or no involvement in planning for their future.
- The quality of transition planning varied widely.

- The issues covered in transition planning were often not those young people and their parents considered to be important, such as friendships, leisure, and information about benefits and housing (Heslop et al. 2003).

The literature also points to a number of other generic problems, including:

- age points for transfer which are based on institutional need but do not reflect the young person's readiness for transfer (Singh 2009);
- the lack of adult services in some fields: leading to young adults with learning difficulties being inappropriately placed in residential care homes (Heslop et al. 2003);
- uncertainty or ignorance among professionals: arising from the support needs of increasing numbers of children who are surviving into adulthood with chronic conditions. In addition, clinical staff have reported the difficulty in responding to the psychological concerns – often about dying young - of young adults with life-limiting conditions (Iles & Lowton 2008);
- the failure to manage care effectively during the transition period: problems arise from separate care teams, plans and funding;
- the complexity of requirements for some young disabled people, requiring multi-agency packages of care;
- anxiety in young people about leaving a long-term medical relationship and meeting new specialists (Sawyer et al. 1998);
- the role of parents: who often feel worried about the future and about the lack of adult services available to support their children. They may lack understanding of the transition process and not be aware that school-based transition planning should cover all aspects of a young person's life.
- tensions between the child/family centred approach of paediatric clinics and the individual approach of adult services (Viner 2003).

Young people in out-of-area provision

Transition planning for young people attending residential colleges and schools out-of-area is particularly problematic. The involvement of professionals from the 'home' area is hampered by distance, and creates difficulties for meaningfully involving the young person (Heslop & Abbott 2009).

Beresford et al (2009) found that person-centred planning was less likely to be used because of geographical distance. The same study reported some good practice with out-of-area children – such as the early involvement of adult social care staff. However, it found a number of 'unique' problems with the transition planning process including:

- the independent nature of residential special schools – influencing transition practices, such as person-centred planning, was reported to be more difficult given that the schools are not covered by all aspects of national policy and legislation;
- conflicts of interest – situations were described where parents were encouraged by the out-of-area schools to pursue adult residential provision for their child in the same or a related school before the transition planning process had started. This created tension with local authority staff who felt that bringing the young person back to the home authority was a better option;
- transferring health care – including confusion about funding and assessments, and health professionals not allowed to carry out assessments outside their local authority;
- transfer of information – the difficulty of sharing information between schools and the home authority (Beresford & Cavet 2009).

Young people with complex health needs

Much has been written about the support needs of disabled children at transition, but there is less understanding about the issues facing disabled children who also have complex healthcare needs (Abbott et al. 2002). For young people with a chronic disorder, barriers to an effective transition include:

- fear of change in service provision: the reluctance of paediatricians, parents and the young person to be released from normal care;
- lack of an adult specialist service in this area. For example, adult services for cystic fibrosis are not as well developed as paediatric services;
- the young person not being ready to take on the management of his/her illness which comes with the move to adult services;
- the young person's feelings about an adult service – presaging complications with their condition and their forthcoming death (Viner 1999);
- institutional cut-offs: the first between paediatric and adult services at age 16, the second occurring when a young adult goes to college or university at age 18 or 19 (David 2001).

Three main models of transition have been described:

- 1) transfer from a paediatric sub-specialist to an adult sub-specialist: possibly through joint transition appointments with child and adult teams as is the case for patients with cystic fibrosis at Royal Brompton Hospital in London;
- 2) primary care based - usually coordinated by the GP;
- 3) an adolescent health service – of which there are few in the UK (Viner 1999).

It is not known which model is appropriate for which groups of young people. One factor is the nature of the health condition and life expectancy. For example, patients who are unlikely to survive beyond their early 20s might be better treated in their own specific adult clinic (Viner 1999).

Young people with sensory impairment

There is very little evidence around the transition from children's to adult services for young people with sensory impairment. Sensory impairment includes vision and hearing loss and dyspraxia.

A survey of deaf young adults and their parents was carried out as part of the Modernising Children's Hearing Aid Services project funded by the Department of Health (The National Deaf Children's Society 2005). The study found that young people and their families had concerns about the transition process. These concerns included the lack of regular reviews and a switch to poorer quality and cheaper hearing aids after transfer to adult services. The survey also found that many young adults failed to attend the adult clinic after transfer.

This project has led to the publication of a set of 'good practice quality standards'. These include:

- a written transition policy for the transfer of patients between paediatric and adult services;
- an information pack for young people containing details of the transition process and local audiology services;
- a preparatory appointment in adult services, facilitated by the paediatric service;
- a designated transition worker (The National Deaf Children's Society 2005).

In addition, a study by NHS Improvement, based on three national audiology transition pilot sites, found that young people with mild to moderate hearing loss are often lost in transition and do not access adult services until their hearing deteriorates or other issues prompt them to seek support. Further work is planned in the pilot sites to provide a better understanding of young people's views and their experiences of transition (NHS Improvement 2010).

Young adults with mental health needs

There is evidence that the transition of young people with mental health needs is not handled well. Adolescence is known to be a risk period for the development of serious mental disorders, and nationally mental health services are perceived not to respond adequately.

There is evidence of poor transition arrangements from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) in the UK. In 1999 only 23% of mental health services in the UK were found to have specific arrangements for transition between these services (Audit Commission 1999). Groups at particular risk of problems during transition, include young people with black and minority ethnic backgrounds and young people in looked after care (Singh et al. 2007).

The TRACK study is a quantitative and qualitative research project that aims to identify the factors which facilitate or impede effective transition from Child to Adult Mental Health Services. It surveyed the transition process across six mental health trusts in England over one year. It found that many young people who are in receipt of

CAMHS and who have ongoing mental health problems fall through the gap and are deemed not eligible for Adult Services. It estimated that one third of service users who needed transfer to AMHS were not referred to or not accepted by AMHS (Singh et al. 2010). Those with psychosis or severe mood disorder were more likely to get through than those with neurodevelopmental disorders and emotional disorders, including conduct disorder, attention deficit disorder, borderline learning disability, or autistic spectrum disorder. This was particularly an issue because three quarters of teams surveyed had no provision for continuity of care for those not accepted (Singh et al. 2008).

The TRACK study also found that less than 5% of those who made a transition experienced an optimal transition. 'Optimal transition' was defined as:

- good information transfer
- a period of parallel care
- transition planning
- continuity of care.

Suboptimal transition was considered as those who failed to meet one or more of these criteria. However, the study did find that around half the young people interviewed reported attending at least one transition planning meeting, with coordinators from both CAMHS and AMHS in attendance (Singh et al. 2010).

TRACK researchers also found that current information technology systems were not adequate for supporting a successful transition. Information continuity was hampered by different systems and inconsistent documentation (Singh et al. 2010).

Overall recommendations from the study included:

- Protocols should specify the timeframe, lines of responsibility and who should be involved, how the young person should be prepared and what should happen if AMHS are unable to accept the referral.
- Protocols should stress flexibility in the age range to accommodate a range of needs and developmental stages, and have explicit referral criteria and service provision.
- Transition should occur at times of stability where possible; young people should not have to relapse in order to access a service.
- Agencies should try to avoid multiple simultaneous transitions.
- Improved information transfer between CAMHS/AMHS with the standardisation of record keeping or, where this is impossible, clear information of what should be made available.
- Carers' needs and wishes should be respected in the transition process and carer involvement in adult services should be sensitively negotiated between clinicians, service users and their carers.
- Services need to develop for young people with emotional/neurotic, emerging personality and neurodevelopmental disorders wherever there is gap in such provision
- Prospective research is required on the clinical course, service needs, health and social cost implications for the young people receiving little service provision after leaving CAMHS (Singh et al. 2010).

The mental health needs of young people with learning disabilities have been the subject of several studies. Carpenter estimates that as many as 40% of young people with learning disabilities may have mental health needs (Carpenter 2002). There is evidence that these young people have particular problems in accessing mental health support as they move into adulthood. Barriers include the difficulty of making a diagnosis in people with learning disabilities and the lack of suitable services (Simons & Russell 2003; Williams & Heslop 2006).

E KEY PRINCIPLES FOR EFFECTIVENESS

There is a consensus in the literature that services should adopt four key principles in order to support a successful transition for young people with disabilities. These principles are based on the belief that the purpose of transition planning should not be about moving a person from one service to another but should rather support a person while moving from childhood to adulthood. As such transition should be a process not an event, and preparation should start early.

Several authors pick up this theme to distinguish between *institutional* and *developmental* transitions. Institutional transitions involve a change in status for individuals as they move between different services. Developmental transition is the naturally occurring process of maturation (Davis 2003).

Developmental transition can be best supported by service delivery based on the following key principles:

- **A person-centred approach:** young people, parents and other advocates must play a central role in planning and decision-making.
- **A multi-agency and multi-disciplinary approach:** the demands of disabled young people are too complex to be responded to by any one individual or organisation.
- **A long-term view** with sufficient time given for planning, deciding and on-going support.
- **The provision of appropriate services,** facilities and opportunities for young people (Beresford 2004).

A person-centred approach

Much has been written about person-centred approaches. The principle involves putting the disabled young person at the centre of the transition review process. The young person's plans, ambitions and worries form the focal point. Person-centred planning has been heavily promoted and is favoured by young people and their carers.

The principles of person-centred approaches are:

1. The young person is at the centre.
2. Family members and friends are partners in planning.
3. The plan reflects what is important to the person (now or for the future), their capacities, and what support they require.
4. The plan helps build the person's place in the community and helps the community to welcome them.
5. The plan results in ongoing listening, learning and action (DH 2010a).

A review of the impact of person-centred planning (Roberson et al. 2005) found that it had had positive benefits on the life experiences of people with learning disabilities, particularly in terms of community involvement, contact with friends and family and choice, benefits which came without significant additional service costs.

Person-centred approaches are often supported by a push for advocacy for the young person. The literature identifies three forms of advocacy:

- **Case advocacy:** where young people have access to an independent support worker who helps them prepare for meetings and navigate different agencies. This can be particularly important in helping the young person to articulate their concerns and aspirations, separately to those of his or her parents.
- **Self-advocacy:** the young person is supported through training and coaching to represent themselves. In a systematic review of transition arrangements, Forbes et al (2002) identify the importance of developing the young person's skills of self-management and self-determination (Forbes et al.2002).
- **Peer advocacy:** the young person is represented by another young person with a disability.

There are plenty of examples of person-centred approaches in the literature. For example:

- One local authority in Suffolk has adopted the long term goal of person-centred planning for all disabled children in their area. A Person-Centred Planning Manager champions person-centred planning in all special schools in the borough. This is supported by training for parents and for facilitators who take a key role in supporting person-centred reviews. Early evidence indicates that this makes action plans more focused, realistic and holistic⁴⁶.
- Many local authorities support the use of one page person profiles for beginning work around a plan. These are developed by the young person, and cover what people like about the person, what's important to that person, what they want to achieve, and how to support them.
- Westminster has pioneered the use of videos in person-centred reviews to provide information to the review process about the young person's life, everything they like doing, and who is important to them.

A multi-agency and multi-disciplinary approach

The literature strongly advocates multi-agency approaches to the transition of young people. This stems from a recognition that the needs of disabled young people are complex and require the input of a range of agencies and staff who are drawn from different professional backgrounds. Separate care teams and care plans may not promote continuity of care. Multi-agency approaches are also needed to respond to

⁴⁶ National Transition Support team website. www.transitionsupportprogramme.org.uk

the broad goals of transition planning which encompass health, social care, employment, education and leisure.

The National Service Framework for Children, Young People and Maternity Services recommends that a multi-agency Transition Group is established comprising a Transition Champion from the Learning Disability Partnership Board, as well as representatives from Connexions, social care, education and housing, health, voluntary organisations and user representatives (DH 2004).

There are a number of well-researched models of multi-agency and multi-disciplinary care. These include:

- **specialist services and skilled staff dedicated to the transition process:** some local authorities have a multi-disciplinary specialist team – sometimes known as the Young Adult Team (YAT) - developed specifically to facilitate transition from children to adult services. There is evidence that this is cost-effective and leads to higher participation in society by young people (Bent et al. 2002).
- **multi-disciplinary medical services:** for example, the consultant in rehabilitation for children with disabling conditions may work in a team with occupational therapists, speech therapists, physiotherapists and psychologists. This allows wider issues than just health to be addressed, including employment and training, leisure time, and relationships (Kent & Chamberlain 2003).
- **multi-disciplinary training:** for staff who have not been involved in the care of adolescents and who need to develop further their knowledge and skills, including an understanding of relevant conditions and disorders, transitional care, young people's perspectives, mental health issues, communication and leadership, and multidisciplinary working (Royal College of Nursing 2004).
- **liaison with other services:** that are important to young people, including housing, leisure, education and employment (Morris 1999).

Townley et al (2002) highlight the lack of research into the impact of joint working on children with complex health needs and their families. They also emphasise that there are different approaches to joint working and these can be seen as falling along a continuum of multi-disciplinary working, interdisciplinary working and transdisciplinary working.

The need for primary care to be involved in transition arrangements is highlighted by the literature. The role of GPs is seen as particularly important. If the young person has been treated principally by a paediatrician, the GP may have been minimally involved. GPs need to be involved from transition onwards because they will be the gatekeeper for access to specialists for adult care, as well as the first point of contact for primary health services (Viner 1999).

A long-term view

Evidence points to the need for careful and long-term planning for transition. The timing of transition should be based around the needs of the young person not the

institution, and should take into account the evolution of the disease or disability, the person's developmental maturity, and their educational and social circumstances (Sawyer et al. 1998). Preparation is usually required over a number of years following the young person's 14th birthday. A young person's readiness for transition can be assessed using validated questionnaires (Capelli et al. 1999).

The literature also highlights the need to allow sufficient time for the process. Sawyer et al (1998) found it took around four hours per patient to draw up a comprehensive medical record.

Provision of appropriate services

There is a body of evidence emerging specifically about the transition process for young people with complex health needs. More young people are surviving into adulthood with complex needs. This can be a challenge for health services because adult provision for these conditions may be under-developed.

Studies emphasise the importance of holistic approaches to the needs of these young people but also highlight the need to ensure that young people have access to individual specialities for their conditions.

Government guidance recommends that commissioners:

- review local provision against the needs of young people;
- where appropriate, redesign services to meet the complex needs of young people. Issues such as waiting times for assessment and for provision of wheelchairs and other equipment should be considered as part of this review;
- review specialist commissioning for relevant health conditions, including palliative care, considering the benefits of regional partnerships and centralised tertiary services;
- appoint a health transition lead to promote transition arrangements across care groups;
- develop flexible funding and contractual arrangements across children's and adult services;
- have multi-agency transition teams which include core health professionals;
- develop age-appropriate settings for young adults (DH/DCSF 2008b).

Services for young adults with complex health conditions should also include:

- adolescent clinics run jointly with paediatric/adult service staff;
- options for young people to be seen without their parents;
- multi-disciplinary clinics for young people with long-term or life-limiting conditions, with links to palliative care;
- opportunities for young adults to meet peers with similar health problems;
- life-skills programmes starting in adolescence;
- sharing information about a young person's condition with that person, including providing access to expert patients' programmes (DH/DCSF 2008b).

F OTHER STRATEGIES FOR EFFECTIVENESS

Several studies set out specific strategies for supporting a seamless transition from child to adult services. The main elements are included in this section.

Data collection and information-sharing

An important issue is the identification of young people with physical and learning disabilities. One particular difficulty lies with identifying young people with physical disabilities and without learning difficulties. The problem arises because these young people are not on a centralised list. The implication is that they may have unmet needs – medical, therapeutic, equipment, social care. Agencies need better information systems to prevent losing these young people, in addition to local agreements on sharing assessment information (Ko & McEnry 2004).

A further problem is sharing information between agencies. There are particular problems for local authorities in accessing information on young people educated out of borough.

The National Service Framework for Children recommends the development and implementation of a locally based multi-agency database on disabled children, based on agreed definitions, and used for planning and evaluation of services (DH 2004).

Development of a strategic transition protocol

There needs to be a strategic multi-agency protocol on how local services work. There is evidence that services improve where this happens (UEA 2005). Usually local authorities have a strategic planning group for transition, and this is responsible for developing the transition protocol.

The National Transition Support Programme sets out key steps and best practice for development of a protocol (NTSP 2009). The protocol should include reference to financial agreements between agencies for supporting transition, such as commissioning, transfer of funding and pooled budgets. Protocols should be evidence-based and support clinical practice (Singh et al. 2008). Regular monitoring and evaluation should be carried out in order to verify that the protocols are operating effectively.

Development of a local transition pathway

This takes the protocol into practice. It sets out the operational detail: how local services - and individuals within them - will support disabled young people, the legal responsibilities of each service, and performance criteria. The most effective pathways have been developed through a sub group of the Project Board, with input from young people and families, and other agencies such as leisure services and Jobcentre Plus.

Transition review

Studies have highlighted the importance of the transition review. Each young person with a physical and/or learning disability should have a transition review leading to a transition plan. This sets out the young person's aspirations as well as the support they will need. It outlines each agency's commitment and how support will be delivered. This should inform a number of areas including:

- education planning
- employment planning
- planning for access to health services (including those not related directly to disability, for example contraception)

The timing of the review depends on the nature of the disability. For young people with a statement of SEN, the formal transition process starts with a transition review in Year 9.

Studies have also analysed the importance of the role of the Connexions adviser. S/he is responsible for coordinating transition planning from year 7 onwards. One review indicated problems with advisers not having enough skills to work with young people with learning disabilities (Grove B & Giraud-Saunders A (2003).

Evaluation of transition arrangements

There should be quality indicators of performance. The experience of young people and their carers can be measured through satisfaction surveys and quality of life questionnaires. The impact of joint working should also be evaluated.

Involvement of parents and carers

Evidence with regard to good practice on working with families and carers is weak. Research shows that it is a stressful time for families who may feel a loss of control as their child moves into adult clinics (Cowland 2003). Forbes et al (2002) identify the importance of:

- support for adjustment to changed relationships with young people;
- parental involvement in service planning;
- a family-centred approach;
- provision of information to parents; and
- a key worker: a named person who liaises with the young person and family and collaborates with professionals. This might be the children's nurse specialist, a GP or social worker (Forbes et al. 2002).

There is some evidence that a family-centred approach results in greater parental satisfaction with services and psychological adjustment of children in paediatric rehabilitation (King et al. 1996). Research by Ward et al (2003) into transition for young people with learning disabilities shows the value parents place on being actively involved in the transition process.

Direct payments

Direct payments and individual budgets are being used to shift choice and control to service users. Young people with disabilities can receive direct payments for payment for social services, following an assessment from children's services. Direct payments can be made to parents of disabled children up to the age of 18, and from 16 and 17 young people themselves can receive direct payment.

Some local authorities have piloted the use of individual budgets for young people. The aim is to develop a transparent needs-based approach to the allocation of funds, as well as assisting young people in the move to financial independence. Funding from social care and learning budgets and, in some cases, from health services are combined to support young people in developing their own holistic care packages.

There is a lack of evidence regarding direct payments and individual budgets. One evaluation of the use of individual budgets highlighted different models including setting up an Independent Living Trust. This evaluation also highlighted the importance of a facilitator or broker to assist families in the process (Crosby & Fulton 2007).

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