



# Preparing for adulthood for young people with physical disabilities and/or learning difficulties: *Factsheet*

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## Tower Hamlets Joint Strategic Needs Assessment 2015/2016

To be reviewed April 2017

### Executive Summary

The period of life when a young person is approaching adulthood is a time when the individual gains increased independence and makes plans for their future. While this can be an exciting time, it can also be an unsettling time including an element of uncertainty. Young people with physical or learning disabilities have additional needs associated with this period as they transition to adulthood. They must attempt to navigate new systems of support as they move out of the reach of children's services and they may have to overcome additional barriers, associated with their disability, to achieving their goals. The needs of these young people must be considered jointly by specialist children's and adults services and by universal services.

It is currently difficult to provide accurate estimates of the number of young people with physical and learning disabilities in Tower Hamlets who are preparing for adulthood (PFA). However, current estimates suggest that this represent a sizable group; with at least 838 young people in the 14-19 age group. The true number of young people in the transition age group (defined as 14-25) will be greater than this. Evidence shows that early intervention with these young people will have an important and lasting impact on improving their lives. In particular, there are 4 key outcomes which should be considered for successful transition:

- Employment
- Community inclusion;
- Independent living; and
- Being healthy

The key to successful transition is joint working between services (especially adults and children's services) and involving the young person in plans for their future from an early stage.

Young people with physical or learning disabilities may or may not be eligible for support from adults' services. For those who are eligible for adults service support, there is a need to ensure that this transition is smooth and easy for the young person to navigate. In addition, it is important to ensure that there are sufficient resources and services available to manage these young people. For example, in Tower Hamlets there is a particular area of unmet need with regards to appropriate accommodation within the borough.

There is a large area of currently unmet need among those young people who are not eligible for support from adults' services since currently available universal services may not be well equipped to manage the needs of these young people. In addition, there is likely to be a level of unexpressed need in Tower Hamlets since the estimated numbers of young people with physical or learning disabilities are lower than those that might be expected given the prevalence of known risk factors within the local population.

There are a number of services available for young people with physical and learning disabilities who are preparing for adulthood. However, given the uncertainties surrounding the estimated number of young people in the transition period it is difficult to assess to what extent these services are meeting the needs of young people. The predicted population growth in the young population of Tower Hamlets over the next 5-10 years may lead to an increased number of young people in transition who require support. Therefore it is particularly important that services work together to monitor demand for support and ascertain where areas of need remain.

## **Recommendations**

### **Monitoring and assessing need**

1. Develop and implement a database for integrated use by adults and children's services which records the needs of all young people, aged 14-25 with physical or learning disabilities. The database must include person identifiers, age and particular needs (with detail beyond those categories currently used by Children's services). The dataset should also include current services being received, referral for assessment by adults service, date of assessment by adults services, result of assessment by adults services, specialist adults services to which young person is referred, universal services to which the young person is referred. This database must be updated in real-time as changes in individual's circumstances occur.
2. Conduct analysis of the new integrated dataset to identify the proportions of young people who have been assessed as eligible for adults' services, those who are assessed as eligible and those who are assessed as ineligible and the characteristics of each of these groups.
3. Ensure that all children's and adults services (both specialist and universal) use the Council equality monitoring template. This should be reported in a timely manner with prompt analysis of the disability section for those young people aged 14-25.
4. Compare the results of equality monitoring analysis with the analysis of the transition dataset to identify areas of unmet need. In particular, this comparison should focus on the 4 areas identified as being critical for successful transition (employment, community inclusion, independent living and health)
5. Analysis of data from the Clinical Effectiveness Group (CEG) to assess the coverage and outcomes of annual health checks for those young people with physical or learning disabilities who are preparing for adulthood.
6. Once implemented, the Special Educational Needs and Disabilities Inspection Framework should be used to evaluate services.

### **Transition Planning**

7. Ensure clear monitoring by children's and adults social care of the Council's policy of transition planning beginning at age 14 at the year 9 review
8. Develop and implement a clear Preparing for Adulthood Strategy which joins up the existing PFA action plan, with all other strategies relevant to young people with physical or learning disabilities across the Borough.
9. Ensure that the Preparing For Adulthood strategy includes defined transition pathways appropriate for all young people preparing for adulthood; those who will go on to receive support from adults services

and those who will not be eligible to receive support from adults service including signposting to other possible targeted or universal services.

10. Focus on the importance of joint working between specialist children's and adults services and universal services to ensure successful transition for all young people irrespective of their needs.
11. Ensure that transition planning starts at the year 9 review, is person centred, focuses on the young person's aspirations and includes contributions from all the key stakeholders: the service user, family or carer, careers, education, children & families services
12. Include the needs of those young people preparing for adulthood in all wider council strategies which cover services relating to employment, independent living, community inclusion and health.
13. Deliver training, specific to transition planning, to a variety of groups working with young people across the Borough, such as teachers, youth workers, social workers and careers advisors.
14. Develop leaflets and information resources for individuals / parents / carers explaining how they will be supported through the transition period. This should include information available through the Council's local offer.

#### **Meeting the needs of young people eligible for adults services**

15. **Independent living:** Ensure adequate provision of appropriate accommodation to guarantee that independent living within the borough is available to all young people who need it as they move into adulthood. This should include clear pathways for housing options for young people not eligible for adult social care but who have additional needs. In addition, ensure that young people have the knowledge and skills to look after themselves and manage their own lives. These skills must be built from a young age (before the transition process begins).
16. **Employment:** Develop a supported internship model and roll out that model in all special and mainstream secondary schools and colleges with young people with disabilities and additional needs. Ensure there is a named staff member in each school or further education establishment with lead in area who is responsible for assessing employment of training needs of young people with SEN. Develop models of work-awareness and supported work experience to be rolled out in all special schools and mainstream schools with young people with additional needs.
17. **Community inclusion:** Build on Children's Services work with universal providers, to extend service provision and include all young people with physical or learning disabilities up to the age of 25 years old.
18. **Being healthy:** Work with public health to ensure that all annual health checks are completed for the full cohort of those with SEN and/or disabilities and additional needs
19. Develop methods for assessing the extent to which each of these outcomes is achieved for young people with physical or learning disabilities in the Borough.
20. Explore further opportunities for joint commissioning of services for young people preparing for adulthood between the CCG and the Local Authority
21. Ensure there is no gap in support for children transitioning to adult NHS Continuing Health care.

#### **Meeting the needs of young people who are not eligible for adults services**

22. Establish clear pathways from children's services and schools to Adult Social Care services for people who will not be eligible for support from the community learning disability service, but may be eligible for support from other services

23. Conduct wider advertising of the informal networks / information hubs which may be able to signpost to other forms of support
24. Conduct a full assessment of accessibility of all universal services to ensure that they meet the needs of those people with physical or learning disabilities who are assessed as ineligible to receive support from adults' services.
25. Carry out further community engagement with this group of young people to ascertain what their priorities are with regards to support
26. Work with local education and training providers (in particular with post 16 education providers) to ensure that support is available for those who need it to plan their future careers and achieve their aspirations.

## **1. What is Preparing for Adulthood?**

A young person who has disabilities and/or learning difficulties, which were identified in childhood, has changing needs as they grow older. At the same time, the support that they receive will change as responsibility for providing their support services moves from children's services to adults' services.

Transition into adulthood is a very important period of time where a young person with physical disabilities and/or learning difficulties is helped to prepare for adult life. The transition phase starts from age 14 (Year 9) and continues for several years sometimes up to age 25. During this time, children's services practitioners with their colleagues in adults' services will need to work together with the family to understand the young person's needs and how those needs can be met.

### **Who does this factsheet cover?**

This factsheet covers young people in Tower Hamlets with physical disability, learning difficulty or other special educational needs (SEN) between the ages of 14 and 25. Due to differences in service provision for children and adults, not all young people who are receiving support from Children's Services will be eligible to receive support as adults. However, both groups of young people, those who will go on to receive support from adult services and those who will not receive support from adult services have needs relating to transition. For those who go on to receive support there is a need to ensure a smooth transition of care to services which can best meet their needs. For those who will not receive support from adult services, there is a need to ensure that young people are sufficiently prepared for independent living as an adult. This fact sheet covers both these groups of young people.

There are separate factsheets on Children with Disabilities, Learning Disability (all ages), Diabetes (all ages), Asthma (all ages), Autism, and Consanguinity.

### **Key terms used throughout this factsheet**

#### ***Disabilities***

This is a broad term which, according to The UN Convention on the Rights of Persons with Disabilities, is defined

as the presence of “a long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder [a person's] full and effective participation in society on an equal basis with others.”<sup>1</sup> Article 7 draws attention to the rising profile of childhood disability and the need “to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other Children.”

### ***Learning Disability***

*Valuing People*, a 2001 government strategy for learning disabilities<sup>2</sup>, defines a learning disability as 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 (before the age of 18), with a lasting effect on development.

This definition is consistent with both the International Classification of Diseases (ICD-10) and the Statistical Manual of Mental Health Disorders.

### ***Physical Disability***

There are many physical disabilities that can affect children, such as delayed walking, deafness or visual impairment. Cerebral palsy (CP) is the most common physical disability in childhood.<sup>3</sup> Approximately 2 per 1,000 infants in developed countries are born with the condition, which provides an umbrella term for a broad group of non-progressive motor impairment conditions secondary to lesions or anomalies of the brain arising in the early stages of development. There are other conditions that may not usually be considered as disabilities but are chronic in nature and therefore can have an impact on the child's development indirectly (e.g. through days lost at school, inability to partake fully in physical activities, need to take medication regularly). These include asthma or diabetes, for example. In addition, disability may be the result of accidents, deliberate injury or physical trauma in childhood. In high income European countries falls and road traffic accidents are the ranked 10 and 11 as causes of disability adjusted life years among children<sup>4</sup>.

### ***Special educational needs (SEN)***

This is a legal term which refers to those children to have any learning disability or physical disability which affects their ability to learn. They can include:

- behaviour or ability to socialise (for example, not being able to make friends);
- reading and writing (for example, dyslexia);
- ability to understand things;
- concentration levels (for example, Attention Deficit Hyperactivity Disorder);
- physical needs or impairments.

### ***Short Breaks***

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<sup>1</sup> UN enable. Frequently asked questions regarding the Convention on the Rights of Persons with Disabilities. <http://www.un.org/disabilities/default.asp?id=151>

<sup>2</sup> Department of Health 2001. *Valuing People. A New Strategy for Learning Disabilities for the 21<sup>st</sup> Century. A White Paper*

<sup>3</sup> Rosenbaum P; Cerebral palsy: what parents and doctors want to know. *BMJ*. 2003 May 3;326(7396):970-4.

<sup>4</sup> World Health Organisation 2008, *World report on Child Injury Prevention*.

In Tower Hamlets short breaks are services which enable disabled children and young people to access the kind of activities that are open to non-disabled children. The aim of these services is to help children to have fun, try new activities, gain independence and make new friends at the same time as providing a break for carers. Types of short breaks which are provided include:

- holiday schemes;
- weekend day services;
- befriending (including group befriending);
- overnight short breaks;
- after school clubs.

In Tower Hamlets all disabled children have access to one short break of their choice from available services. In order to manage finite resources access to more than one specialist short break requires an assessment for eligibility.

### **Adult Services**

The Care Act 2014 introduced a national eligibility threshold, which consists of three criteria, all of which must be met for a person's needs to be eligible for care and support services. The eligibility threshold is based on identifying:

- whether a person's needs are due to a physical or mental impairment or illness;
- to what extent a person's needs affect their ability to achieve two or more specified outcomes; and
- whether and to what extent this impacts on their wellbeing.

Firstly, in considering whether a person's needs are eligible for care and support, local authorities must consider whether the person's needs are due to a physical or mental impairment or illness. This includes conditions such as physical, mental, sensory, learning or cognitive disabilities or illnesses, brain injuries and substance misuse.

This means that a significant number of young people who may have SEN statements and other needs which are not classed as being a 'physical' or 'mental' impairment may not be eligible for support within Adult Social Care and may need to be signposted to other forms of support.

If the person does have needs caused by physical or mental impairment or illness, the local authority must consider whether as a result of the impairment or illness they are unable to manage two or more of the following specified outcomes:

- Nutrition
- Personal hygiene
- Toilet needs
- Clothed
- Safe use of home
- Habitable home environment
- Family or other personal relationships
- Access work / education or volunteering
- Using facilities or services

- Parenting responsibilities

The practitioner will then work with the individual to identify how significant the impact of this need is on their wellbeing.

If the need is identified as having a significant impact on the wellbeing of the individual, the local authority will have a legal 'duty' to provide support to meet those needs. Alternatively, the local authority may have the 'power' to meet a need which has been assessed as having a lesser impact on wellbeing.

### **Why is preparing for adulthood a public health issue?**

The period of transition to adult life can be a very unsettling time with young people and their families facing the challenge of understanding, navigating and working with the education, social care and health systems. At the same time they are making choices about the future which will have a profound effect on their lives. It is important to ensure that systems and services are in place which support young people in the transition period to make choices that will allow them to fulfill their potential with regard to living and live healthy, safe and satisfying lives. Poorly planned transition from young people's to adult-oriented health services can be associated with increased risk of non-adherence to treatment and loss to follow-up, which can have serious measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes. There are a number of public health concerns that specifically apply to young people with physical or learning disabilities and should be considered in ensuring that their needs are met.

### **Health inequalities**

People with disabilities report seeking more healthcare than people without disabilities, have greater unmet needs and experience poorer health than the non-disabled population. These differences are to a large extent avoidable and, thus, represent health inequalities. Five key determinants of health inequalities for people with disabilities have been identified<sup>5</sup>:

1. Greater risk of exposure to social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness
2. Increased risk of health problems associated with specific genetic and biological causes of learning disabilities.
3. Increased risk of communication difficulties and reduced health literacy.
4. Higher likelihood of displaying personal health risks and behaviours such as poor diet and lack of exercise.
5. Deficiencies relating to access to healthcare provision. It is to be expected that young people with learning disabilities would have poorer health, not because of their learning disability per se but because they are more likely than their non-disabled peers to be exposed to a range of 'social determinants' of poorer health.

It has been estimated that increased exposure to low socio-economic position/poverty may account for:

- 20–50% of the increased risk for poorer physical and mental health among British children and

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<sup>5</sup> Emerson, E., Baines, S., Allerton, & Welsh, V. (2011). Health Inequalities and People with Learning Disabilities in the UK:2011. Durham: Improving Health & Lives: Learning Disability Observatory.

adolescents with learning disabilities; and

- a significant proportion of increased rates of self-reported antisocial behaviour among adolescents with learning disabilities<sup>6</sup>

Health promotion and prevention activities often do not target or account for specific needs of people with disabilities<sup>78</sup> and people with disabilities are particularly vulnerable to deficiencies in health care services<sup>9</sup>. Depending on the group and setting, people with disabilities may experience greater vulnerability to secondary conditions, co-morbidities, age-related conditions, engaging in unhealthy behaviours (such as smoking, substance misuse, poor diet, poorer sexual health and physical inactivity) and have higher rates of premature death.

### ***Co-morbidities***

A number of other health conditions are associated with learning disabilities and represent additional risks to an individual's health. For example, mental health problems and challenging behaviours are more prevalent among people with autistic spectrum disorders, and obesity and sleep problems are more prevalent among people with Down's Syndrome. The prevalence of epilepsy rises from 0.5% - 1% in the general population to up to 35% among those with moderate learning disability and 30% among those with severe and profound disability. Studies suggest that the prevalence of depression is higher in adolescents with learning disability than in typically developing adolescents,<sup>10</sup> and children and young people with learning disabilities are 6 times more likely to have mental health conditions than other young people.<sup>11</sup>

### ***Multiple impairments***

Many people experience multiple types of impairment, for example:

- People with learning disabilities are 8-200 times more likely to have a visual impairment compared with the general population
- Approximately 40% of people with learning disabilities are reported as having a hearing impairment
- People with Down's Syndrome are at particularly high risk of developing vision and hearing loss
- It has been estimated that between 20 and 33% of people with learning disabilities also have an autistic spectrum disorder (ASD)<sup>12</sup>

### ***Increased risk of harm***

Children with disabilities are three to four times more likely to be victims of violence: 3.7 times more likely for combined measures of violence, 3.6 times for physical violence and 2.9 times for sexual violence. Children with

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<sup>6</sup> Ibid

<sup>7</sup> Department of Health (2005) Vaccination services: reducing inequalities in uptake. London: Department of Health

<sup>8</sup> Peckham C, Bedford H, Seturia Y et al. (1989) The Peckham report – national immunization study: factors influencing immunisation uptake in childhood. London: Action Research for the Crippled Child

<sup>9</sup> Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Russ L. Confidential inquiry into premature deaths of people with learning disabilities (CIPOLD): final report. Mar 2013. [www.bris.ac.uk/cipold/fullfinalreport.pdf](http://www.bris.ac.uk/cipold/fullfinalreport.pdf)

<sup>10</sup> Ibid

<sup>11</sup> The Mental Health of Children and Adolescents with Learning Disabilities in Britain (2007), Institute for Health Research, Lancaster University

<sup>12</sup> Emerson et al (2011)ibid



mental or intellectual disabilities were found to be 4.6 times more likely to be victims of sexual violence than peers without disabilities.<sup>13</sup>

Parenting a child with additional needs is associated with increased stress levels in parents, and local research suggests that this is the case in Tower Hamlets also.<sup>14</sup>

### **Quality of life**

A disabled person's quality of life is determined not solely by their impairments (and subsequent health and social care needs), but access to appropriate services, attitudes, and the environment in which they live. An environment which enables good quality of life for all those with physical and learning disabilities includes engagement in a meaningful activity and having satisfying social relationships, equal access to education, healthcare, leisure activities, transport and housing services. In addition it is important that young people with disabilities are included in family and community activities.

## **2. What is the Policy Context?**

### **International Framework**

#### ***UN Convention on the Rights of the Child***

This convention was adopted by governments around the world in 1989 and aimed to change the way in which children were viewed and treated from being passive objects of care and charity to human beings with a distinct set of rights. The convention covers all aspects of a child's life from the right to education, health, protection from abuse, freedom of expression and access to information. There are 4 over-arching principles: (i) Non-discrimination - the convention covers all children irrespective of ethnicity, gender, religion language or abilities; (ii) Best interests of the child – this should be top priority in all decision and actions which affect children and determining what is in a child's best interest should include taking into consideration that child's own views and feelings; (iii) Right to life, survival and development – governments must do all they can to ensure that children survive and reach their full potential, including ensuring basic needs such as nutrition, shelter and access to healthcare; and (iv) Right to be heard – every child has the right to express their views feelings and wishes in all matters affecting them and these views should be considered and taken seriously.

### **National policy**

A number of UK statutes influence services for children and young people with disabilities, setting out the broad legal framework and establishing the rights of young people with learning difficulties and disabilities.

#### ***The Children and Young Persons Act 2005***

Section 25 requires local authorities to provide Short Breaks for Disabled Children. From April 2011, a new legal duty came into force on local authorities to provide a range of Short Break services including:

<sup>13</sup> Jones L, Bellis MA, Wood S, Hughes K et al. (2012) Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies. The Lancet - 8 September 2012 ( Vol. 380, Issue 9845, Pages899-907

<sup>14</sup> Shedden S, Taylora V, Pajaka R, Corredor-Lopez P 2013. Parenting children with disabilities is hard. Does parenting style contribute to experience of parental stress in parents of children with additional needs? LBTH Disabled Children's Outreach Service

- Overnight care in the homes of disabled children or elsewhere
- Day time care in the homes of disabled children or elsewhere
- Educational or leisure activities for disabled children outside their homes
- Services available to assist carers in the evenings, at weekends and during the schools holidays.

### ***Equality Act 2010, Mental Health Capacity Act 2005 and Health and Social Care Act 2012***

Under these legislative Acts health commissioners and NHS Trusts have statutory responsibilities to ensure the health and wellbeing of people with disabilities. These Acts are in addition to the UN Convention on the Rights of Persons with Disabilities. The Mandate from the Government to the NHS Commissioning Board (NHS CB) (2012), requests that the NHS CB “support children and young people with special educational needs or disabilities, to ensure that these children and young people have access to the services identified in their agreed care plan and that, from April 2014, their parents are able to ask for a personal budget based on a single assessment across health, social care and education” as part of its objectives.

### ***Special Educational Needs and Disability (SEND) Act 2001***

Many, but not all, children with disabilities will be assessed as having SEN. The provision for these children falls within Part IV of the Education Act 1996 as amended by the more specific SEND Act. Until 2014, provision for these pupils was guided by the SEN Code of Practice (2001). This has since been replaced by the SEND Code of Practice 2014 (see below). The UK Government published *Support and aspiration: A new approach to special educational needs and disability* Green Paper in 2011 in order to address weaknesses that it perceived as being inherent in the current system of education provision for children with special needs. Namely, that children did not have a voice, teachers were given insufficient training and support, too many assessments were involved, appropriate support could be too difficult to access and that the appeals process was costly. Draft legislation was presented to Parliament in September 2012.

### ***The Children and Families Act (2014)***

This Act and the accompanying SEND Code of Practice (2015) set out to reform the systems for adoption looked after children, family justice and SEND. It took forward the reform programme set out in *Support and aspiration: A new approach to special educational needs and disability*.

Key measures relating to transition are:

- Replacing SEN statements and Learning Difficulty Assessments (for 16 to 25 year-olds) with a single, simpler 0 to 25 assessment process that might result in an Education, Health and Care (EHC) Plan (see below);
- Extending statutory protections comparable to the SEN statements to age 25 as long as an individual is in further education;
- Revised Code of Practice;
- Requiring local authorities to publish a local offer showing the support available to disabled children and young people and those with SEN, and their families. This must include information on the education, health and care services available locally;
- Giving parents or young people with EHC Plans the right to request a personal budget for their support;
- Requiring Local Authorities and Clinical Commissioning Groups to make arrangements for joint commissioning.

EHC plans are for children and young people who require more support than that which is usually available through special education needs support within schools. These plans identify educational, health and social needs and set out the support which is required to meet those needs. A parent or carer/guardian, or school with the agreement of parents/guardians, can request that the local authority conducts an assessment for an EHC plan. A young person between the age of 16 and 25 can request an assessment themselves. EHC assessments can also be requested by doctors, health visitors, social workers, teachers or family friends.

The local authority should notify the person who requested the assessment within 16 weeks as to whether an EHC plan will be made. Parents/ carers and guardians have the opportunity to comment on the draft EHC plan before a final decision is made. The local authority should provide a final EHC plan within 20 weeks of initiating the assessment.

Those children and young people who have an EHC may get a personal budget in order to help them and their carers to be more thoroughly involved in how money is spend on the required support. These personal budgets can be used in three different ways:

- Direct payments made to the young person/ their carer to buy and manage their support personally
- An arrangement with the local authority whereby they hold the money but the young person/their carer decides how it is spent (these are sometimes referred to as notional arrangements)
- The young person / their carer chooses someone else to manage the money on their behalf.

All children who were receiving support prior to September 2014 who have a statement of SEN or a learning disability assessment will transfer to EHC plans over a three year period <sup>15</sup>.

The Children and Families Act puts new duties on further education (FE) colleges extending the definition of SEN to include YP up to the age of 25. FE colleges are required to use their best endeavours to support students with SEN, and the SEN Code of Practice<sup>16</sup> outlines what this might entail. FE colleges have a duty to admit students if that institution is named on a young person's EHC plan. FE colleges are also under a duty to identify and meet needs, with a focus on ensuring young people achieve personal outcomes linked to employment, independent living and community participation. FE colleges, therefore, need to: build links with LAs, commissioners and funders of high needs students; contribute to the development of the local offer and tailor packages of support, which may include work experience, supported internships, traineeships and apprenticeships in partnership with local employers.

### ***SEND Code of Practice, 2015***

The Code of Practice provides statutory guidance on the duties, policies and procedures relating to those sections of the Children's and Families Act which cover provision for young people with SEN. The Code of Practice is for use by local authorities, schools, further education colleges and pupil referral units, early years providers, the NHS Commissioning Board, Clinical Commissioning groups, NHS Trusts, Local Health Boards, Youth Offending Teams and First Tier Tribunals dealing with SEN appeals. The main changes from the 2001 code of practice, which are relevant to transition to adulthood are:

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<sup>15</sup> Children with Special Educational needs and disabilities (SEND): <https://www.gov.uk/children-with-special-educational-needs/overview>

<sup>16</sup> SEN Code of Practice, 2014: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

- The age range covered is extended from 0 to 25 years
- The guidance covers all disabled children as well as those with SEN
- There is a focus on the participation of children, young people and their parents in decision making
- There is a stronger focus on high aspirations and on improving outcomes for children and young people
- There is guidance on joint commissioning of services to ensure close co-operation between education, health and social care providers
- It includes guidance on publishing the Local Offer
- There is new guidance for education and training settings on taking a graduated approach to identifying and supporting students with SEN
- The introduction of EHC plans
- There is an increased focus on support that enables those with SEN to succeed in their education and make a successful transition into adulthood.

The guidance includes a full chapter dedicated to preparing for adulthood. In particular, this chapter focuses on the importance of young people having high aspirations around employment, independent living and community participation. In practice this means that discussion about longer term goals should start early (in year 9) and should focus on the young person's strengths and the particular outcomes they could like to achieve.

#### ***The Care Act 2014***

This Act gives young people and carers a legal right to request an assessment before they turn 18. This is to help them to plan for the adult care and support services they may need. The Act says that if a child, young carer or an adult caring for a disabled child are likely to have needs when they, or the child they care for, turns 18, the local authority can assess them if it considers there is 'significant benefit' in doing so. This is regardless of whether the person currently receives children's services. The Act states that information should be given at the point of assessment about whether the young person or child's carer is likely to be eligible for support. The person should receive advice and information about what can be done to meet their needs, as well as what they can do to stay well, and prevent or delay the development of needs. If the local authority does not accept a person's request for an assessment, it must explain why in writing. It must also provide information and advice about what the person can do to prevent or delay the development of care and support needs.

The Care Act and the Special Educational Needs provisions in the Children and Families Act require that there is cooperation within and between local authorities to ensure that the necessary people cooperate, that the right information and advice are available and that assessments can be carried out jointly.

#### ***Other national policy context***

Current national policy developments, including changes to social housing provision, the welfare reform programme, changes to education funding and reform of the health service, pose challenges and opportunities for the borough and are likely to impact in particular upon families and young people with disabilities.

#### **Local policy**

##### ***Tower Hamlets Health and Well-Being Strategy***

The strategic vision is "to improve health and wellbeing through all stages of life to reduce health inequalities

and promote choice, control and independence". Within the 4th priority area, long term conditions and cancer, the strategy identifies 'ensuring robust and integrated care and support, including a focus on improved housing options and support for young people' and 'improving engagement and understanding of carers by primary care services including improved recognition of specific needs of carers, increased use of carers registers, and greater provision of health checks' as priorities. The Tower Hamlets Health and Wellbeing Strategy is currently being refreshed with an updated strategy due to be published in autumn 2016.

#### ***The Tower Hamlets Children and Families Plan 2012-2015***

The plan was developed using the UN Convention on the Rights of a Child. The Tower Hamlets plan sets out the vision that all young people are safe and healthy, achieve their full potential, are active and responsible citizens and emotionally and economically resilient for their future. To help achieve this vision for children with disabilities, the London Borough of Tower Hamlets and Tower Hamlets NHS promote inclusion by ensuring services in universal settings can be accessed by young people with disabilities and additional needs. Additional services are targeted to the needs of those with more complex needs and there is a commitment to services being timely, accessible, coordinated and responsive to the needs of young people and their carers. The plan is being refreshed for 2016-19.

#### ***Tower Hamlets CCG Priorities***

The 2013/16 strategic vision from the CCG includes the aim to provide integrated health and social care for the population of Tower Hamlets. This includes commissioning services which use a holistic approach and consider people's wider needs, such as social care and employment. A consultation is currently underway to determine the priorities for 2016 onwards.

### **3. What are the effective interventions?**

#### **General Principles of Transition Planning**

It is recognised that commissioning services for people with learning and physical disabilities is complex as the young people involved have a wide range of needs that can be the responsibility of a number of services.<sup>17</sup>

As such, commissioning services for people with learning and physical disabilities requires organisations to work together in effective partnerships in order to secure better outcomes for this population. The Children and Families Act requires that for more complex needs, an integrated assessment and a single Education, Health and Care Plan are in place from birth to 25. Disabled young people must have the chance to live a fulfilled life with the same opportunities offered to them as their non-disabled peers. To do this young people need to be aware of and have access to services such as leisure, housing and transport.

#### ***The National Getting a Life programme***<sup>18</sup>

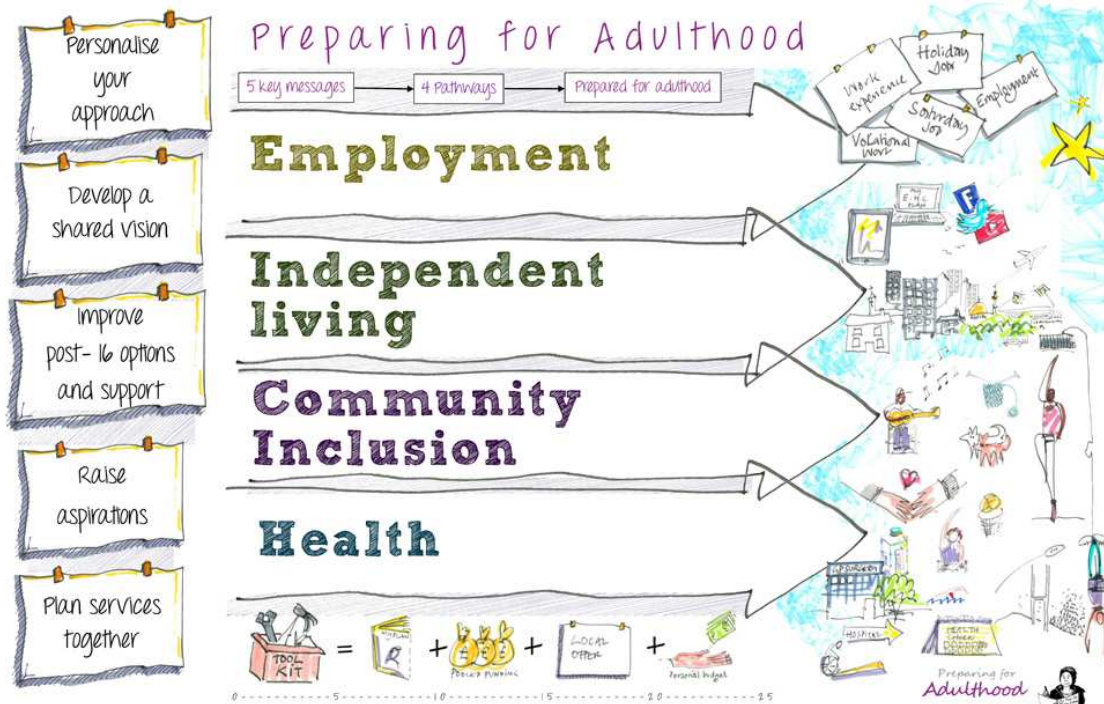
This programme which ran from April 2008 to the end of March 2011, as part of Valuing People Now, set out 5 key areas and 4 outcome areas which should be considered for a successful transition **Figure 1**. The programme

<sup>17</sup> Royal College of General Practitioners (2012) Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs). <http://www.rcgp.org.uk/>

<sup>18</sup> <http://www.gettingalife.org.uk/>

emphasised that the transition process should be service-centred, transparent and accessible, beginning as early as possible in order to maximize a young person and their family's involvement with planning and decision-making.

**Figure 1: Getting a Life Programme structure**



**Transition: getting it right for young people (DH 2006)<sup>19</sup>**

The following points are key to achieving a successful transition and one which ensures that the 4 key outcomes outlined above are effectively addressed. These points are considered good practice in transition planning.

- Staff working with young people should balance the needs of the young person for privacy and confidentiality, and their wish to take increasing responsibility for their own health care, with the need for their parents to have sufficient information to provide the support that these young people often require.
- There are several models for good transition and there is no clear evidence that one is superior. Therefore a range of approaches should be utilised. Different approaches may be needed for different types of conditions according to their prevalence and the ways in which specialist health care is organised.
- Implementing improved transition involves: recognition of the importance of the process; adequate consultation with professionals and users; flexibility in the timing of transition; a period of preparation for the young person and family; information transfer; monitoring of attendance until the young person

<sup>19</sup> Department of Health and Department for Education and Skills, 2006. Transition: Getting it Right for Young People. [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4132149.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4132149.pdf)

is established in the appropriate adult oriented service.

- Professionals may need to consider further development of their knowledge and skills in working with young people, including: the biology and psychology of adolescence; communication and consultation strategies; multi-disciplinary and multi-agency teamwork; and an understanding of the relevant individual conditions and disorders and their evolution and consequences in adult life.
- Young people with complex disability present particular problems because often there is no equivalent adult service able or willing to take on their long term health care and medical supervision. The need to develop a holistic approach for these young people is emphasised but it is also important for individual specialties to ensure access to quality health care for people with complex disability

***The Care Act (2014)*** set out a range of specific requirements to ensure successful transition planning:

- Timing: Transition assessments should take place at points that provide sufficient time to plan support, education, training, employment and independent living that the young person will need just before and after 18. Assessments should not be done at a set age across the board or just before 18, as each young person will have specific needs and some will need more time for necessary support to be put in place.
- Clearly defined referral routes for young people not already known to children's services but who may have care and support needs
- Carers and Young carers: Carers of young people with care and support needs should be offered an assessment, particularly to check whether they can continue to care for the young person beyond 18 and if so, what support they might need.
- A transition assessment should include:
  - Current care and support needs and impact on wellbeing
  - Likelihood of needs when they turn 18
  - Outcomes that the young person wishes to achieve
- Partnership working: This includes working with other teams within the local authority, health, schools, voluntary sector etc. when developing transition plans. Ideally this should involve a 'key worker' who coordinates assessment and support planning for the young person. This gives the young person a single point of contact and helps minimise duplication of assessment and repetition for the young person.
- Information: There is a duty to provide up to date information and advice to help the young person and their family to access universal or specialist support, and to prepare themselves for the move into adulthood, where some or all of the support received from Children's may cease. Young people and their families should also have an indication as to what needs are likely to be eligible for support after 18, and how this support could be provided. They should also have information on how to meet needs that the council will not support after 18
- After the young person turns 18: A decision needs to be made whether a young person or their carer's needs will be met under the Care Act when the young person turns 18 and create a care and support plan. EHC plans will be with care and support plans, and care and support aspects of EHC plans will be provided under the Care Act.

### **Evidence for improving specified outcomes**

#### ***Employment***

The benefits of work, especially that paying at least the London Living Wage, are wide ranging including

promoting independence, choice, confidence, financial stability and giving people a role in the community as well as improving mental wellbeing and access to wider social networks<sup>20, 21</sup>. 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.

Valuing Employment now<sup>22</sup> 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.

Evidence of best practice and what works in terms of enabling the transition to work has highlighted the following key themes<sup>23, 24, 25, 26</sup>:

- 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.

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

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<sup>20</sup> Department of Health and Department for Children, Schools and Families, 2007. A Transition Guide for All Services: Key Information for Professionals about the Transition Process for Disabled Young People

<sup>21</sup> Mencap, 2002. A Life in the Day: The Modernisation of Day Service for People with a Learning Disability

<sup>22</sup> Department of Health, 2009. Valuing Employment now.

<sup>23</sup> Department of Health, 2009. Valuing Employment now.

<sup>24</sup> Prime Ministers Strategy Unit, 2005. Improving the life chances of disabled people.

<sup>25</sup> Department of Health, 2010. Person Centred Planning: Advice for Using person centred thinking, planning and reviews in schools. .

<sup>26</sup> DH and DCSF, 2007. A Transition Guide for All Services: Key Information for Professionals about the Transition Process for Disabled Young People



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 <sup>27</sup>

While statutory education finishes at the end of the school year in which the young person turns 16, pupils may stay in mainstream or special educational until the school year after they turn 19. Post 16 education is diverse and includes schools, sixth form colleges, general further education colleges or vocational training providers. It is important that schools and colleges are ambitious for all their young people, including those who have learning or physical disabilities. Support should be available to ensure that young people progress well achieve positive outcomes such as continuing education or employment. This should include providing access to independent careers planning.

## **Independent Living**

### **a) Housing**

Housing options form an important element in promoting choice, control and independence for people with disabilities and complex health problems. Accommodation is a key issue for transition planning. At the time of transition some young people will be living at home and attending day school provision, either in Tower Hamlets or other local boroughs. A small number attend residential schools.

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 most appropriate option will depend on many factors 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.<sup>28</sup>

Housing has been identified as an area which is often neglected in transition planning <sup>29</sup>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 that these choices are regularly reviewed.

Housing may be a particular concern for those young people who are not eligible for adult's services. Therefore transition planning should ensure that these young people are supported to find the most appropriate accommodation for their needs and that they have the life skills necessary to be housed within that environment.

### **b) 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

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<sup>27</sup> Department of Health 2010. Valuing People Now.

<sup>28</sup> Wright, K (2010) JSNA: Transition for 14-25 year olds in Westminster

<sup>29</sup> Heslop et al, 2003. Transition Planning: how well does it work for young people with learning disabilities? British Journal of Special Education, 30 (3) 132-137.

and information for transport, not having someone to travel with, attitudes of staff and the fact that people may feel vulnerable to abuse<sup>30</sup>. 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.

### **c) Finance**

The Government's 'personalisation' agenda introduced in *Our Health, Our Care, Our Say*<sup>31</sup> centres on giving people more choice and control in the health and social care services they receive, including how their care is financed and delivered. A key component of this agenda has been the introduction of direct payments<sup>32</sup> and personal budgets.<sup>33</sup>

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<sup>34</sup>.

### **Community Inclusion**

Young people consulted as part of the Independent Living Review<sup>35</sup> 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 get 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<sup>36</sup>. 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

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<sup>30</sup> Westminster City Partnership, 2010. *Transition from Children's to Adult's Services for Young People Aged 14-25 in Westminster*. Literature Review.

<sup>31</sup> Department of Health, 2006. *Our Health, Our care, Our Say*

<sup>32</sup> 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).

<sup>33</sup> 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.

<sup>34</sup> Department of Health 2010. *Person Centred Planning: Advice for Using Person-Centred Thinking, Planning and Reviews in Schools and Transition*.

<sup>35</sup> Prime Minister's Strategy Unit, 2005 *Improving the Life Chances of Disabled Young People*

<sup>36</sup> Department of Health, 2001. *Valuing People Now*.

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<sup>37</sup>

Research has shown 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<sup>38</sup>.

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<sup>39</sup>.

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;
- Young people taking 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

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<sup>37</sup> Department of Health and Department for Children, School and Families, 2007. A transition Guide for All Services: Key Information for Professionals about the Transition Process for Disabled Young People.

<sup>38</sup> Department of Health and Department for Children, School and Families, 2007. A transition Guide for All Services: Key Information for Professionals about the Transition Process for Disabled Young People.

<sup>39</sup> Department of Health and Department for Children, School and Families, 2007. A transition Guide for All Services: Key Information for Professionals about the Transition Process for Disabled Young People.

## Health

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 whom 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<sup>40, 41</sup>.

Transition will involve transfer from children's to adult NHS Continuing Health Care (CHC). As for educational and social services, some young people will not be eligible for NHS CHC when they turn 18. Moreover, 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<sup>42</sup>. Similarly, whereas speech and language therapy (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. 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<sup>43, 44</sup>.

### **a). Health Action Plans**

These were first developed for adults with learning disabilities as part of recommendations in Valuing People<sup>45</sup> but have since been recommended for young people in transition. Guidance in Valuing People 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

<sup>40</sup> Prime Minister's Strategy Unit, 2005. Improving the Life Chances of Disabled People.

<sup>41</sup> Office FOR Disability Issues, 2008. Independent Living: a cross-government strategy about independent living for disabled people

<sup>42</sup> Department of Health and Department for Education and Skills, 2006. Transition: Getting it right for Young People.

<sup>43</sup> Department of Health and Department for Education and Skills, 2006. Transition: Getting it right for Young People.

<sup>44</sup> Vinner et al, 1999. Transition from Paediatric to adult care. Bridging the gap or passing the buck. Archives of Disease in Childhood, 81, 271-5.

<sup>45</sup> Department of Health, 2001. Valuing People.

- Details of medication taken and side effects
- Records of screening tests

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 on 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?

***b). Annual Health Check:***

Health checks are the basis for contractual payment for GPs to manage the physical health needs of, and provide health promotion advice to, people with learning disabilities. Locally, eligibility for the register is defined by being in contact with the community learning disability service. The annual health check 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.

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

***c). 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 who 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. 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.

## 4. What is the local picture?

### Tower Hamlets Population

Tower Hamlets has a younger population than England as a whole. There are 35,228 young people aged 14-25 (the transition age group) living in the borough<sup>46</sup>. This is equivalent to 18.5% of the total population of Tower Hamlets compared to 15.11% of the London population and 15.1% of the England population in the same age group<sup>47</sup>. Over the next 5- 10 years the population of Tower Hamlets is predicted to increase. In the 14-25 year old age group, the population is expected to increase by 10.9% by 2020 and 16.9% by 2025<sup>48</sup>. This population growth will have an impact on scale of need and demand for all health and social care services including those concerned with transition. In Tower Hamlets in 2014, 3.8% of all pupils in schools had an either a statement SEN or an EHC plan. This is higher than London (2.8% of all pupils) and higher than England (2.8% of all pupils)<sup>49</sup>.

### The wider determinants of health

There is a well-established link between socioeconomic deprivation, reflected in lower income, poorer housing, higher unemployment and a greater reliance on welfare benefits, and the prevalence of mild or moderate learning difficulties.<sup>50</sup> Some evidence of a link between severe learning difficulties and poverty has been reported.<sup>51</sup> High levels of material and social deprivation have been found amongst South Asian people with learning disabilities and their families. It has been suggested that such deprivation may combine with other factors – such as inequalities in access to maternal health care, misclassification and higher rates of environmental or genetic risk factors – to produce the much higher prevalence rates than in more affluent groups<sup>52 53</sup>. Tower Hamlets has high levels of poverty and deprivation with 37.9% of children under the age of defined as living in poverty (compared to 19.2% in England) in 2012. Therefore it could be expected that Tower Hamlets may have higher rates of learning disabilities than are seen in more affluent parts of the country.

One report found that nationally SEN associated with learning disabilities is more common among boys, children from poorer families and among some minority ethnic groups. Moderate and severe learning difficulties are more common among Traveler and Gypsy/Romany children. This report also found that profound multiple learning difficulties are more common among Pakistani and Bangladeshi children (who account for 62.5% of the 0-17 year old population in Tower Hamlets)<sup>54</sup>. However, nationally the proportion of children who have statements of SEN are: 2.5% for Asian children (2.7% for Bangladeshi children) compared to 3.1% White (3.2% White British)<sup>55</sup>. Therefore the impact of ethnicity on SEN remains unclear.

### Young people in transition in Tower Hamlets

Young people who are receiving support from Children's services are a diverse group with a variety of needs.

<sup>46</sup> ONS 2014 Mid-year population estimates

<sup>47</sup> ONS 2014 Mid-year population estimates

<sup>48</sup> GLA, Population projections, 2014.

<sup>49</sup> Special Education Needs in England 2015, Local Authority Tables, SFR25/2015, Table 11A

<sup>50</sup> Emerson E (1997) 'Is there an increased prevalence of severe learning disabilities among British Asians?' *Ethnicity and Health*, 2:317–321.

<sup>51</sup> Mir, G., Nocon, A., Ahmad, W., et al (2001) *Learning Difficulties and Ethnicity*. London: Department of Health.

<sup>52</sup> Baxter C (1998) 'Learning difficulties', pp. 231–242 in: Rawaf S and Bahl V, (eds.) *Assessing Health Needs of People from Minority Ethnic Groups*, London: Royal College of Physicians/Faculty of Public Health Medicine.

<sup>53</sup> Emerson E (1997) *ibid*.

<sup>54</sup> Emerson E, Hatton C, Robertson J, Roberts H et al (2010) *People with Learning Disabilities in England 2014*

<sup>55</sup> Department for Education, *Special Educational Needs in England 2013*

Therefore, there is a range of different support services coordinated by a number of different teams. The multifaceted nature of this social care means that estimating the number of young people who are receiving services is not straightforward.

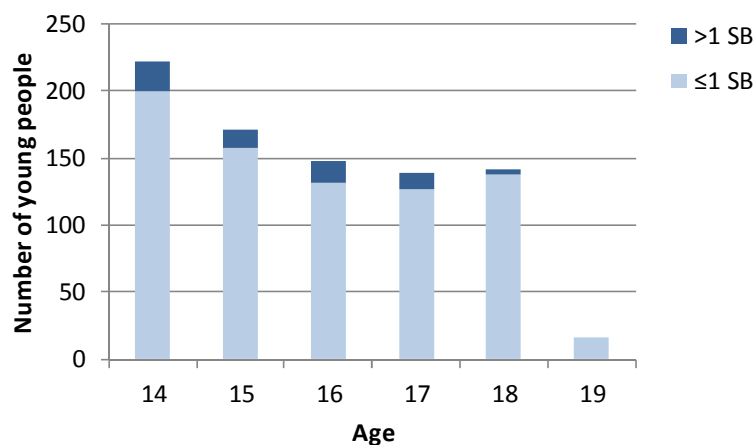
A combined dataset, including information on all young people with SEN, children with disabilities and those young people receiving any short breaks was used to estimate the total number of young people supported by Children's Services in the transition age group. Data was only available up to the age of 19. No data was available for those aged 20-25. Therefore the numbers presented represent an underestimate of all those young people Preparing for Adulthood.

Those young people who are eligible to receive more than one short break are those with the highest needs and as such could be predicted to be eligible for adult services. For this reason, receipt of more than one short break (>1SB) was used as a proxy measure for identifying those young people who will be eligible for adult services. As such, it has been possible to provide the following estimates for the number of young people in Tower Hamlets with physical or learning disabilities who are in the transition age group and to predict those who will be eligible for adult services and those who will not. However, it is important to note that not all young people who are eligible for short breaks may take up the opportunity and therefore these numbers may represent an underestimate of the true numbers who will be eligible for adult services.

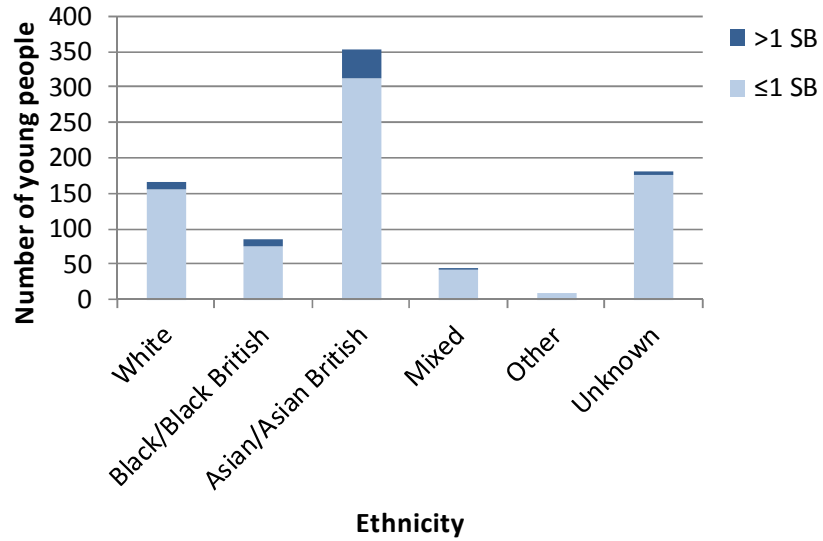
Overall there are 838 young people in the transition age group. Using the proxy of having received more than 1 short break it is estimated that 67 (8%) of these young people will be eligible for adult services. Overall, more than 1 in 4 young people in the transition age group are aged 14 (**Figure 2**) and 42% of young people in the transition age group are of Asian or Asian British ethnicity (**Figure 3**). Of all those young people preparing for adulthood a higher proportion of young people who are from Asian ethnic groups (11.8%) and black ethnic groups(11.6%) are predicted to be eligible for adult service compared to young people of white ethnic background (5.4%).

The highest rates of young people with learning disabilities in the transition age group are in Poplar and Bow West wards (**Figure 4**). The same wards have the highest rate of young people who are not predicted to be eligible for adult services. However, the wards with the highest rates of young people who are predicted to be eligible for adult services are Stepney Green and Bow West (**Figure 5**).

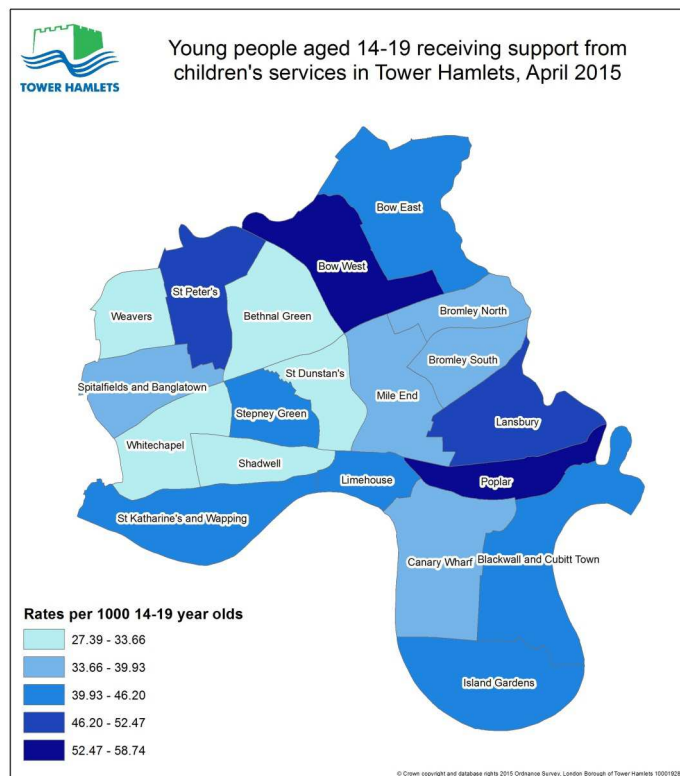
**Figure 2: Age distribution of young people preparing for adulthood, Tower Hamlets, 2015**



**Figure 3: Ethnic distribution of young people preparing for adulthood, Tower Hamlets, 2015**

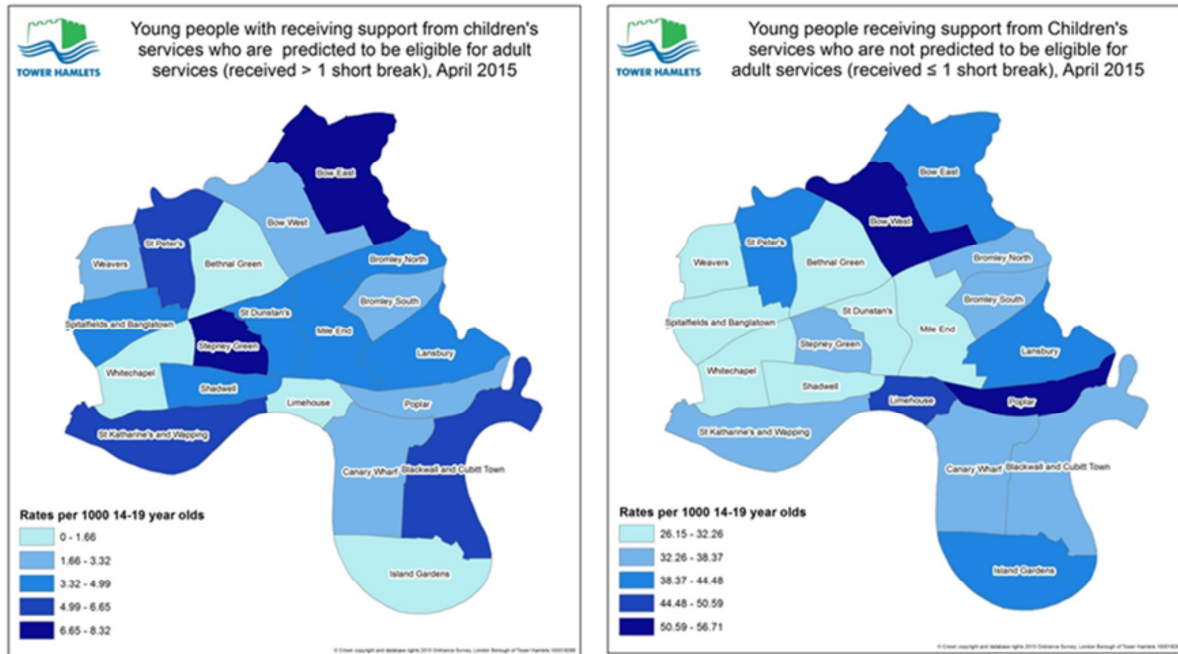


**Figure 4: Geographic distribution of young people preparing for adulthood in Tower Hamlets, 2015**





**Figure 5: Young people preparing for adulthood and their predicted eligibility for adult services**



There are 21 young people preparing for adulthood who are currently living outside of the borough. These young people may be living out of borough as they are attending a specialist facility outside of the borough or because they are currently looked-after young people. There are specific service needs associated with transition for these young people. They still require assessment for eligibility and their transition into adulthood may necessitate greater upheaval which includes a move in where they live.

The SEN code of practice defines 4 broad areas of need:

- **Communication and interaction (C&I)**  
This includes all those children and young people with speech, language and communication needs. Needs may be due to the young person having difficulty saying what they want to or not understanding or using the social rules of communication. Children with autism spectrum disorder may have particular needs with regard to social interaction
- **Cognition and learning (C&L)**  
This includes all children and young people who learn at a slower pace than their peers, even with appropriate differentiation. A wide range of needs are covered from moderate learning disabilities to severe learning disabilities where the young person requires support in all areas of the curriculum and profound and multiple learning difficulties where the learning disability is likely to be accompanied by a physical disability or sensory impairment
- **Social, emotional and mental health difficulties (SE&M).**  
These difficulties are wide ranging and may manifest in a variety of ways including becoming withdrawn or isolated as well as displaying challenging or disruptive behavior. These difficulties may reflect an underlying mental health condition. Other children have disorders such as attention deficit disorder or

attention deficit hyperactivity.

- Sensory and or/physical needs (SP)

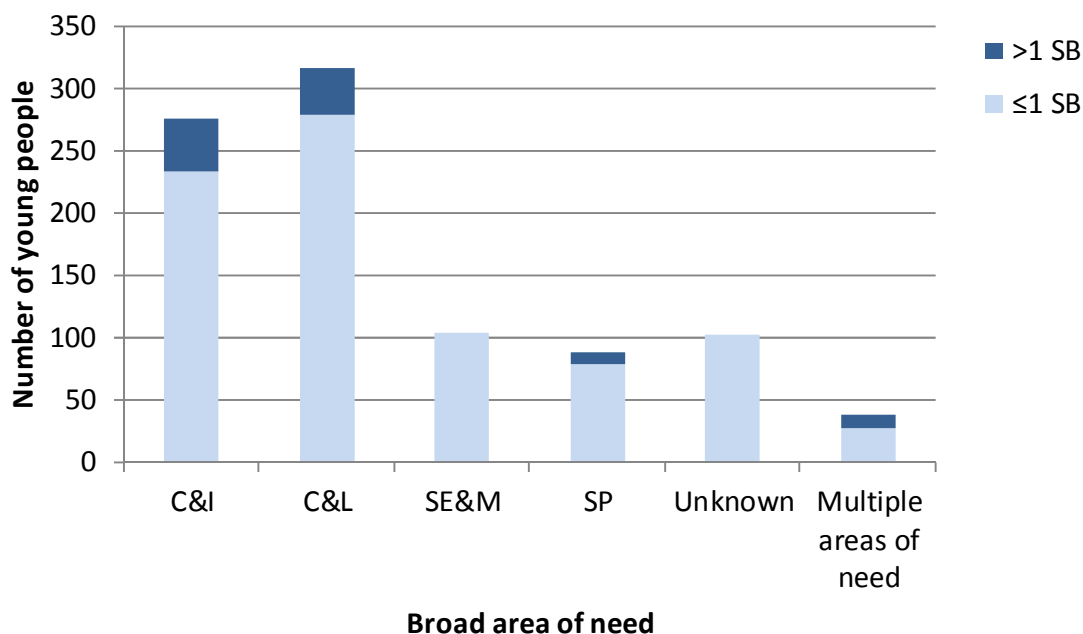
This includes all disabilities which prevent or hinder a young person from making use of educational facilities which are generally provided. This includes visual and hearing impairments which require specialist support or equipment to access learning and physical disabilities which require support or equipment to access all the opportunities available to their peers.

These areas of need are not mutually exclusive. Children and young people may have a combination of different types of need and their level of their need may fluctuate over time. In Tower Hamlets 1 in 20 young people preparing for adulthood has multiple areas of need. The most common type of needs are those related to cognition and learning – more than 2 in 5 young people in transition have cognition and learning needs and almost than 1 in 3 young people in transition have communication and interaction needs (**Figure 6**).

Among those individuals who are predicted to be eligible for adults services, a higher proportion have cognitive and learning needs (more than half) and/or communication and interaction needs (almost two thirds). None of the young people with social, emotional and mental needs were predicted to be eligible for adults' services and 13% had physical or sensory needs.

It is important to note that all areas of need are represented among those young people who are not predicted to be eligible for adult's services: 30% have communication and interaction needs; 36% had cognitive and learning needs ; 13% had social emotional mental health needs and 10% had sensory or physical needs. In particular, 3.5% of young people who are not predicted to be eligible for adult's services have multiple areas of need

**Figure 6: Number of young people in the transition age group in Tower Hamlets, April 2015, by broad areas of need**



The annual number of young people transitioning from Children to Adults services can be estimated using service data from the Children With Disabilities team and the Community Learning Disability Service (CLDS) and the Children with Disabilities team. The table below gives an indication of the number of young people identified by children's services as having needs which may be met by Adults services and the number of young people who are assessed and accepted by and the adults CLDS service. The table includes the number of young people supported by Children with Disabilities Team in Children's Social Care, and the number of young people eligible for the Community Learning Disability Service in Adult's Social Care (**Table 1**).

The transition period lasts for more than one year and therefore the actual numbers of young people preparing for adulthood who are currently receiving support from the CLDS transition team is greater than the numbers shown in the table. As of December 2015, there were 127 active cases assigned to a social worker and 76 assigned to a healthcare team within the CLDS transition team. In addition, there are around 40 young people waiting to be assessed and around 5 new referrals every 2 weeks. The transition team estimates that on average 3 out of 4 young people who they assess will be eligible to receive services.

**Table 1: Annual numbers of young people transitioning from children's to adults services 2011-2014**

Year	Young people identified by Children's Services a likely to need support as adults		Young people in assessed by adults services
	Young people (aged 14 and above) with an allocated social worker in the Children With Disabilities Team	Looked after young people (aged 14 and above) in the Children with Disabilities Team	Young people aged 16-18 assessed eligible for Community Learning Disability Service (CLDS)
2014	79	13	43 eligible and 16 awaiting assessment
2013	86	9	30 assessed 24 eligible
2012	97	10	33 assessed 24 eligible
2011	93	7	46 assessed 41 eligible

**Unmet and unexpressed needs**

Whatever method is used to estimate the number of young who will be eligible for adult care it is clear that there are two key points at which young people who have been receiving support from Children's services may enter the group who do not receive support as adults. Firstly it may be that their needs are not deemed great enough to require referral for assessment by adults services. Secondly, it may be that they are referred for assessment by adult services but they are not deemed eligible once the assessment has taken place. As a result, there are many more young people who are currently receiving support who will not continue to do so once they turn 18. Those young people who will not be eligible for adult services represent an area of unmet need as sufficient planning will be required to ensure that they are ready to live independently once their current support ends.

In addition to this unmet need, Tower Hamlets is likely to also have a level of unexpressed need. That is, those young people who have physical or learning disabilities, but who are not accessing those services which they would be entitled to. For example, of all 14-19 year olds in Tower Hamlets, 49% are of Bangladeshi ethnicity. However, in the transition group only 42% of 14-19 year olds preparing for adulthood are of Bangladeshi ethnicity. This may indicate that among this population there is group of young people who have particular physical or learning disabilities who are not currently in touch with either children's or adults services.

**Future trends**

The 14-25 year old age group is predicted to increase over the next 5-10 years. The proportion of young people

with a statement of SEN remained relatively constant with a very small increase over the last 8 years (3.3% in 2008, 3.5% in 2012 and 3.8% in 2015), although absolute numbers of children with SEN statements have increased as the population of the borough has grown. Therefore assuming that the prevalence of learning disability and physical disability remains the same the population of young people in transition could also be predicted to increase by the same proportions (a 10.9% increase by 2020 and a 16.9% increase by 2025). This would mean an estimated 930 young people (aged 14-19) preparing for adulthood by 2020 and 980 young people preparing for adulthood by 2025 (aged 14-19). However, there are a number of other factors which may impact on the number of young people in transition. For example, the population increase among 14-25 year olds over the next 5 years is predicted to be greatest among the white and Indian ethnic groups. Since national estimates indicate a higher prevalence of need among ethnic minorities this may affect the number of young people in transition in Tower Hamlets.

## **5. What is being done locally to address this issue?**

### **Strategic input**

A local preparing for adulthood action plan has identified areas for improvement in line with the four preparing for adulthood outcomes specified in Getting a Life (employment, independent living community inclusion and health) (Appendix 1). The full action plan is currently being jointly governed and implemented by the 'Young People Preparing for Adulthood Group' which reports to the Children's and Families Board and the 'Children and Young people with Disabilities Strategic Group'.

Following new requirements under the Children's and Families Act 2014 and the Care Act 2014 the young people in scope under 'Preparing for Adulthood' action plan has broadened to include:

- Children with disabilities, 14-18, currently under Children with Disabilities team
- Young people 18 to 25 currently receiving services with the Community Learning Disability Service
- Looked after and former looked after children and young people
- Young carers
- Young People with Mental Health conditions
- Young people with special educational needs and disabilities under the Young Offending Team
- Young people aged 14-25 young people who are not eligible for services under Social Care (requirement to provide information, advice and signposting)

Tower Hamlets has produced a guidance document for practitioners which outlines the available information, services and provides advice on best practice for professionals involved in the care of young people in this age group<sup>56</sup>. This guidance focuses on a person-centered approach to transition meaning that a young person's wishes, needs and aspirations form the basis of planning. The document also highlights that there are a large number of parties who should be involved in transition planning including the young person and their family, the school, children's social services, health professionals, voluntary agencies involved in providing any care and support to the young person and any other professional or organisation who has a current role in the young person's care. With so many people involved it is vital that the young person has a lead practitioner who is responsible for overall co-ordination of the process.

<sup>56</sup> Preparing for Adulthood for young people with disabilities and/or learning disabilities. Guidance for practitioners in social health, health and educational services.

The Community Learning Disability Service is being further developed to ensure that all young people with learning difficulties are included in preparing for adulthood from the age of 14. This will ensure that the needs of both those young people who are eligible for adult services and, importantly, those who are not can be addressed. For those who are not eligible for adult services, this will allow early referral or signposting to other support services which may be available to them, for example universal services. The community learning disability service is developing a document for families with information on services that are available for young people who do not meet the eligibility criteria for Adult Social Care to be provided when families are informed that the young person is not eligible.

The Tower Hamlets Autism Strategy is currently being reviewed and updated taking into account new legislation (namely the Care Act and the Children and Families Act). Adults' services continue to commission the Diagnostic Intervention Service, a service for adults with autism who don't have a learning disability. The service will be reviewed as part of the autism strategy. At the same time the Autism JSNA is currently being updated.

The Care Act places the individual at the centre of the process. To support practitioners in implementing the Care Act Tower Hamlets has introduced a practice framework, designed to guide all elements of the work of the practitioner. The framework aims to ensure that the individual is fully engaged in assessments, clearly identifying issues from their perspective, describing how these impact on their lives and what they see as the key outcomes from the assessment. The practitioner will work with the individual to help them formulate a clear picture of their needs. The local authority will work with the individual to look at ways of meeting needs which may involve family, friends, informal networks and the community. This aims to maintain independence wherever possible, empowering the individual to manage their own care and support, as well as reducing pressure on the local authority to provide services in a climate of diminishing resources. If the individual has difficulties engaging in the process, weighing up options or retaining information, the practitioner will discuss whether support would be appropriate to enable them to contribute fully. This could be informal support provided by a family member, college lecturer or potentially the local authority may appoint an independent advocate.

### **Education and Health Care Plans**

Tower Hamlets is working towards transferring children and young people who have a statement of SEN or a learning disability assessment onto EHC plans. At Sept 2014 there were 2180 potential statements/learning disability assessments that needed to be considered for converting to an EHC plan. Since then, of the original 2180, 71 are no longer required as the pupil has moved or left education. 1679 conversions were targeted for 14/15 and 15/16 academic years. As of the start of February 2016, 745 SEN statements were in the process of being converted to EHC plans which is 35% of the target we aim to achieve by the end of August 2016.

### **Services available**

#### ***The Local Offer***

The Children's and Families Act requires all local authorities to publish their offer with regard to the support available. In Tower Hamlets, the Local Offer is an online resource<sup>57</sup>, supplemented by a telephone service, which gives children and young people with SEND and their families' information about what services are

<sup>57</sup> [http://www.towerhamlets.gov.uk/ignl/education\\_and\\_learning/local\\_offer/local\\_offer.aspx](http://www.towerhamlets.gov.uk/ignl/education_and_learning/local_offer/local_offer.aspx)

available for them in the area and how to access them. This in turn supports transparency and accountability as people know what support they can expect in their local area.

The Local Offer was developed in consultation with children, young people and their families who have directly informed its content. We have included information on a wide range of provision which includes some information on post 16 provision, including video content to inspire young people in their decisions about post 16 education. There are also useful links to a range of external information sources, and information about adult social care services.

The local offer is being developed in response to feedback, in line with statutory guidance. Priorities for development include making the directory search easier as well as including more video content. We are also putting in place a communications and marketing strategy to increase usage of the local offer.

### ***Young person's inclusion services***

These are services which are provided for all young people. They are open to all young people in the Borough but may be accessed to a lesser or greater extent by young people with physical or learning disabilities or SEN depending on how accessible they are and what facilities are in place to manage the needs of these young people. Those services which come into contact with young people in transition need to be fully informed of adults' services which are available so that they can advise young people who are preparing for adulthood of where they can access support. At present there are 40 commissioned services which include youth clubs, drop in support sessions, outdoor education, arts and information and support services for young people. However, only 2 of these services specifically work with young people who have particular needs due to physical or learning disabilities.

### ***SEND Advice and information service (SENDIAS)***

This service aims to provide information advice and support for young people aged 16-25 with SEND. This includes providing advice on EHC plans, ensuring the views of young people are heard and providing advice on employment as well as providing sessions and groups which will develop young person's skills and interests (for example creative skills, life skills and strategies for dealing with bullying). From June to November 2015 the service worked with total of 78 young people of whom the majority were male, and 1 in three were not in education or employment. Only 7 of these young people were eligible for support from adult's services.

### ***Adult's universal services***

These are services provided within the borough which can be accessed by all adults irrespective of whether they are receiving social care from adult's services. In the context of transition, these services may be of particular importance to those young people who have been receiving support from children's services but who are not deemed to be eligible for adult's services. These services will often be targeted at specific groups, for example people with mental ill-health, people with particular physical disabilities or people of particular community groups. A summary of currently available services and those services which are will be newly available in the forthcoming year are shown in **Table 2**. It is important to note that those services with more general target groups may provide additional support to some people with physical or learning disabilities. However, they may also not have appropriate or accessible facilities for individuals with more complex needs. In addition, staff providing less targeted services may not feel they have the skills necessary to deal with more complex issues arising from physical or learning disabilities or the particular problems encountered by young people preparing for adulthood.

**Table 2: Adults universal services which may be accessed by young people preparing for adulthood**

Target group <sup>1</sup>	Number of services available		Type of services available
	Currently available	Available in the forthcoming year	
Individuals with physical disabilities	1	2	Fitness sessions Self-management support
Individuals with mental ill-health	5	3	Advocacy 1:1 intensive support Self-help courses Peer support Inclusion General support services
Individuals with sensory impairment	3	2	Peer support to increase independence Nutrition and cooking courses Health workshops Awareness raising Physical activity Inclusion
Individuals from BME groups and migrants	2	4	Drop-in sessions Health workshops and walks Advocacy Peer support English language support
Lesbian, gay, bisexual and transgendered residents	1		Outreach and case work
Informal carers	1		General support
General	1	6	Information, advice and advocacy for anyone who needs it Health and wellbeing Advice and advocacy Physical activity Advice for vulnerable adults

<sup>1</sup>Services targeted at older adults have been omitted from this list as they are less relevant to young people preparing for adulthood.



### ***Education, employment and day services for young people with SEN***

There are currently 11 different services within the borough which are providing employment and day services to young people with SEN. There are a range of different types for service available and each service is currently serving between 3 and 60 young people with SEN. The largest of these services, serving around 60 young people (The Tower Project), provides information, advice and guidance on finding work, keeping a job, developing skills and making adjustments for work. They also provide specialist training advice, coaching and work placement opportunities. Other services serving smaller number of clients offer day services, short breaks away from London and group sessions. All of these services are available only to those who are eligible for adult social care. In addition, young people with autism who are not eligible for adult social care may access the services provided by the Tower Project through the Autism Diagnostic service.

In the academic year 2014/15 the careers service had information on 716 young people aged 14-25 with SEND. Of these the majority (496 young people, 69%) were entering further or higher education. In particular colleges and sixth form colleges were popular destinations for young people in school years 11-13 (222 young people). Thirty seven young people were not in education training or employment and the destination of 119 young people was unknown. Of all the young people with SEND the careers service had provided significant support to 238 young people aged 14-25. This would involve some in depth work such as a careers guidance interview and jointly agreed progression action plan. Among these young people 10 were not in education training or employment; the majority (200) were entering further or higher education and 20 were entering traineeships, apprenticeships or employment.

### ***Housing***

For people with physical or learning disabilities who require supported housing there are 8 facilities across the Borough. However, a 2013 report on Housing for people with Learning Disabilities within the Borough reported that people with any sort of complex learning disability - however moderate - are highly unlikely to find suitable accommodation and support within Tower Hamlets and will be placed outside the borough, often against their own and their family's wishes. In other words, demand is clearly out-stripping supply. The same report also concluded that the needs of young people coming through transition are not being met - all of those young people 19+ leaving school in the year of the report who needed an accommodation based service would receive that service outside of Tower Hamlets. This is not only a solution which may cause upheaval for the young person and their family but is also expensive compared to using facilities within the Borough. The majority of accommodation within the Borough is allocated to those over the age of 50.

## **6. What evidence is there that we are making a difference?**

There are no national indicators which relate specifically to transition. However, there are some indicators which are relevant:

### **Public Health Outcomes Framework**

- 1.06i Adults with a learning disability who live in appropriate accommodation
- 1.08i Gap in employment rate between those with a long term condition and the overall employment rate

- 1.08ii Gap in employment rate between those with a learning disability and the overall employment rate

Overall, 63.6% of adults with a learning disability in Tower Hamlets are living in appropriate accommodation. This is lower than the figure for London (68.6%) and the figure for England (74.9%). There is a 58% gap between the proportion of people with learning disabilities who are in employment and employment in the total population in Tower Hamlets. While this figure is similar to that for London (60.9%) and slightly lower than for England as a whole (65%), it illustrates the challenges involved in ensuring that people with learning disabilities are supported to enter into employment. The gap in employment between the total population and those with all long term conditions is smaller. In Tower Hamlets there is a 15.4% gap between those with long term conditions who are in employment and the total population employment rate. This gap is higher than that in London as a whole (10.7% gap) and higher than the gap in England as a whole (8.7% gap).

These findings indicate that in terms of housing and employment, Tower Hamlets is performing worse than London and England for adults with learning disabilities and long term conditions. Transition is the gateway to appropriate accommodation and employment for young people, therefore performance in these indicators will require concerted effort to improve accommodation and employment opportunities for young people who are preparing for adulthood.

#### **Clinical Commissioning Group Outcomes Indicator Set**

- 2.1 Health-related quality of life for people with long term conditions
- 2.2 Proportion of people who are feeling supported to manage their condition

These indicators encompass more than just those people with physical or learning disabilities. However, they still provide some insight. Individuals in Tower Hamlets have an average health-related quality of life score similar to that for England. The proportion of people in Tower Hamlets who feel supported to manage their condition is 61.5% compared to 64.4% in England.

#### **Adults Social Care Outcomes Framework**

- 1A Social care related quality of life
- 1B Proportion of people who use services who have control over their daily life
- 1I Proportion of people who use services and carers who reported that they had as much social contact as they would like.

These indicators include all social services users not only those preparing for adulthood. In Tower Hamlets social care users have a similar average score for quality of life as those in London (18.2/24 compared to 18.5/24), but this is lower than the average score for England (19.1/24). Similarly, the proportion of service users who have control over their lives in Tower Hamlets is similar to the proportion in London (71.3% and 71.6% respectively). However, this is lower than the proportion for England as a whole. Compared to England Tower Hamlets performs poorly with regard to the proportion of service users who have as much social contact as they would like: 39.8% in Tower Hamlets, 41.8% in London and 44.8% in England.

From May 2016 all local authorities will have to demonstrate their implementation of the SEND reforms to Ofsted and the Care Quality Commission (CQC). In response to this requirement, local authorities are developing a SEND inspection framework which will be of use in future monitoring.

## 7. What is the perspective of the public?

The UN convention on the Rights of the Child explicitly states that all Children have a right to be heard on all issues which concern them and that their views should be taken into consideration when plans are made for them. As such, it is important that we have robust and in depth knowledge on the opinions of young people in Tower Hamlets who are preparing for adulthood.

In 2014 Tower Hamlets SEND Information, Advice and Support Service (SENDIAS) initiated a project which aimed to train young people with SEN and disabilities to interview their peers. The interviews focused on young people's experiences of services and what they want and need from services with regard to preparing for adulthood. Particular concerns of young people about entering adulthood included feeling nervous or anxious, having more responsibility, worries about bills and budgeting, cooking and cleaning, having less time to do fun things and the lack of school/college. Both verbal and non-verbal young people were involved in the research. Young people who were involved cited a desire for work, training, leisure time and relationships in their adult lives. In one session young people were asked to identify some things that could help them in the future. The young people cited doing courses, learning new skills having someone help with a CV, getting work experience having good teachers and having support from family as key elements what would be helpful to them in achieving their goals for the future<sup>58</sup>.

At a Parents' Workshop on Transitions (PACSEN) in 2015 and a fair of transition services held in October 2015 parents and carers voiced concerns about:

- The stage at which the 'front door' into Adults Services is opened. Parents' and carers' experience is that this is not until the young person is aged 18, and it needs to be earlier;
- Young people in receipt of Children's Services not meeting the eligibility for Adults Services, particularly young people with ASD not being eligible for services if they don't have also have a learning disability;
- Service decisions being made without a professional who knows the child being present and occasionally poor communication of decisions;
- Insufficient mental health support for young people during the transition period;
- Access to appropriate housing and further education options.

At national level Generate UK and Voice 1 worked with the Council for Disabled Children and Participation Works to assess what young disabled people want from their services as part of the "Making Ourselves Heard" project<sup>59</sup>. Ten key themes were identified. In the YPs own words, these were:

- Respect us
- Involve us from the start
- Listen to us
- Be open and honest with us
- Make it fun
- Prove you're listening to us
- Involve all of us
- Make sure we get something out of it
- Give us time

<sup>58</sup> Tower Hamlets Peer Research Project Process Report

<sup>59</sup> <http://www.participationworks.org.uk/topics/disability>

- Support us to make our own decisions

Tower Hamlets Healthwatch has set up a Young People's Health Project which aims to engage young people on their experiences of health services and to involve them in decision making. This could represent an opportunity in the future for consulting young people with disabilities in their needs.

The challenges faced by young people with special needs in the transition period are best illustrated by case studies. The following is a fictional case study based on a number of real-life situations which have been observed by the SENDIAS team.

*"A 16 year old with communication difficulties was referred to SEND Young People's Service by a CAMHS worker.*

*The young person was at an alternative educational provision but not making any progress. Staff at the provision had not seen the young person's assessment of learning disability and his Special Educational Needs Statement had lapsed. It was felt by staff at the provision that the young person was not on an appropriate course.*

*The SEND Young People's Development Officer worked with the young person to find out what their interests were and identify some courses and extracurricular activities that might be appropriate.*

*The officer also helped the young person to put in a request for an EHC plan.*

*The officer arranged placement visits for the young person and went with them to look at the different placements.*

*Once the young person had identified which course they would like to do the officer worked with the SENCO at that placement and staff at SEN to help put an EHC plan in place.*

*The officer helped the young person to find an extracurricular activity they could attend and the young person also joined the SEND Youth Forum and participated in several projects.*

*At a recent parents' evening, staff said the young person was doing extremely well on their course."*

## **8. What more do we need to know?**

- Further clarity is needed on the current total numbers of young people preparing for adulthood, the proportion who have been assessed for eligibility for adults' services and the proportion who are eligible or not for support as adults. This report has presented estimates based on the proxy measure of receipt of more than one short break. This provides an estimate only and excludes those young people who are age 20 or older. It is also necessary to understand the characteristics of the entire group with regards to age, ethnicity, area of residence and specific needs identified.
- A more thorough understanding of future need is required in order to ensure that there are sufficient

resources available in the event of an increase in numbers of young people preparing for adulthood. In order to gain this it will be important to have robust estimates of the total population of young people in transition as described above. This information could be used to model the potential increase in numbers over time.

- Future forecasting of the number of young people preparing for adulthood is also required to predict the likely impact of future limitations in resources. These future limitations need to be considered in the context of a likely increase in the number of young people who are preparing for adulthood.
- Trends in annual numbers of young people who are assessed by adults services and the proportion eligible is needed to ensure that there are no changes service provision which may impact the needs of young people preparing for adulthood.
- Knowledge on the specific needs of those young people who are assessed as ineligible for adult services is required in order to ensure that universal adults' services are meeting their needs. In particular, this includes:
  - Nature of needs i.e. sensory impairment, learning disability or particular physical disability
  - Accessibility needs
  - Required support i.e. what are the most pressing issues for these young people (housing, employment support, social networks?).
- Information on uptake and outcome of universal services among people with learning and physical disabilities. All services are required to report on service use by protected characteristics and this information could be used to assess uptake and coverage of services.
- Knowledge on accessibility of currently provided universal services. While these services are intended to be open for all, there may be access issues for some people with physical disabilities or staff within the services may not feel that they have appropriate knowledge or skills to manage needs of people with learning disabilities.
- Information on the extent to which adults' services are meeting the specific needs of those young people who are eligible for support during the transition period. For example:
  - How well do these young people understand how transition will impact them?
  - What proportion of these young people are in appropriate employment or training?
  - What proportion of these young people are living in appropriate accommodation?
- Since the Children and Families Act is recent legislation, it is unclear whether young people and their families are aware of their entitlement to and EHC plan beyond the age of 18. This should be investigated in order to plan appropriate work which could raise awareness amongst those who could benefit from post-19 EHC plans.
- Work is required to further understand the challenges which are faced by young people in ensuring that their voices are heard throughout the transition period.

## **9. What are the priorities for improvement?**

- Development of clear pathways of transition for all young people with physical or learning disabilities including those who are assessed as eligible for adults services and those who are not considered eligible for adults services.
- Development of an integrated recording system for young people in the transition age group. This system must be accessible and editable both by adults' and children's services and kept updated in real time. Information to be recorded in the system includes: person identifiers, age, particular needs (with

detail beyond those categories currently used in children's services), current services being received, referral for assessment by adults service, date of assessment by adults services, result of assessment by adults services, specialist adults services to which young person is referred, universal services to which the young person is referred.

- Creating robust and measurable methods for referral of those young people who are not eligible for adults' services into universal services and monitor the outcomes of these referrals. Monitoring the uptake of services could be achieved through universal use of the Council Equality Monitoring Template.
- Ensuring that all universal services (for adults and children) are fully accessible and free from barriers which would prevent their use by people with any physical or learning disabilities this includes ensuring accessible facilities and training of staff so that they are confident managing the needs of these young people .
- Increasing the volume of appropriate housing/accommodation available for young people with physical or learning disabilities within the borough in order to minimise the disruption caused by moving young people far from their friends, family and support network.
- Increasing the number of young people who are preparing for adulthood who are in appropriate education employment or training.
- Development of methods to identify and address unexpressed need, i.e. those young people in the transition period who would be eligible for children's and/or adults services but are not currently accessing any support.

## 10. Contacts / Stakeholder Involvement

### **Authors:**

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### **Stakeholders:**

Representatives from the Children with Disabilities Strategic Group and the Young People's and Preparing for Adulthood Programme Board, have been consulted during production of this JSNA. Their expertise and insights have been invaluable and are much appreciated.

*If you have any questions relating to content in this document please do not hesitate to contact:*

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## Appendix I: Tower Hamlets Preparing for Adulthood Action Plan

ACTIVITY	MILESTONE	HOW WILL WE MEASURE SUCCESS?
Promote improved understanding and appropriate support about sex and relationships for young people with special education needs and disabilities	<ul style="list-style-type: none"> <li>- Develop a sex and relationships pathway for children with disabilities</li> <li>- Hold a forum with parents and residential care providers</li> </ul>	<ul style="list-style-type: none"> <li>- Equity with peers re: access to service</li> <li>- Evidenced based practice in place</li> <li>- Confident parents and carers</li> </ul>
Promote wider understanding of long term consequences of brain injury with pathway	<ul style="list-style-type: none"> <li>- Develop pathway</li> <li>- Work with Health colleagues</li> </ul>	<ul style="list-style-type: none"> <li>- Assessment and intervention of trauma reflects greater process understanding</li> </ul>
Promote improved understanding of need for young people with Tracheostomy	<ul style="list-style-type: none"> <li>- Review support for young people with Tracheostomy out of school hours when parents are unable to meet this need</li> </ul>	
Provide effective support to meet the emotional needs of young people with special education needs and disabilities and additional needs, as they face the challenges of approaching adulthood	<ul style="list-style-type: none"> <li>- Increase the use of advocacy services for young people at transition from age 14, through the new Adult's service for information, advice and advocacy (provided through a consortium, led by Real).</li> </ul>	<ul style="list-style-type: none"> <li>- A year on year increase in the number of young people aged 14 to 18 accessing advocacy via the Adult's service for information, advice and advocacy.</li> <li>- Advocacy support to all young people with SEND placed out of borough approaching adulthood</li> </ul>
Provide effective support to meet the emotional needs of young people with special education needs and disabilities and additional needs, as they face the challenges of approaching adulthood	<ul style="list-style-type: none"> <li>- To ensure smooth transition between children's and adults Mental Health services for vulnerable young people ; inclusive of those with special education needs and disabilities, Looked After, those out of borough, additional needs and young carers.</li> </ul>	<ul style="list-style-type: none"> <li>- Child and adults mental health services to refresh transitions policy ensuring Children and Families and Care Act requirements are met</li> <li>- Child and adults mental health services audit recommendations to be implemented</li> <li>- Increase brokerage activity and continue interim arrangements from Tower Hamlets Child and adults mental health services pending resolution to Child and adults mental health services in Surrey/ out of borough needs</li> </ul>



ACTIVITY	MILESTONE	HOW WILL WE MEASURE SUCCESS?
Promote healthy choices and healthy behaviour through sport	<ul style="list-style-type: none"> <li>- Increase access to sports for young people aged 19 to 25, via Health Action Days and improved signposting and information on sports by the Community Learning Disability Team.</li> </ul>	<ul style="list-style-type: none"> <li>- Increased number young people with special educational needs and disabilities and additional needs aged 19 to 25 accessing universal sport programmes and specialist gyms (SBUG Mile End &amp; Roman Road)</li> </ul>
Develop pathways to supported internships/ further education/ training and paid employment for young people with SEND and additional needs	<ul style="list-style-type: none"> <li>- Improve access to further education, paid employment, supported internships and training.</li> <li>- Monitor progress in order to inform future commissioning and service development decisions.</li> </ul>	<ul style="list-style-type: none"> <li>- Employment and performance data tabled to YPPA/ C&amp;YPB</li> <li>- Review learning disability employment strategy</li> <li>- Indicator to be developed on children with disabilities and young people's access, retention and progress in further education, training, supported internships and paid employment</li> <li>- Wider choices for young people with disabilities and an enriched curriculum.</li> <li>- Helping young people looked after (including those placed out of borough) have more direct advice and practical help re: further education options</li> </ul>
Ensure young people with SEND have access to safe, appropriate accommodation	<ul style="list-style-type: none"> <li>- Explore options for increasing the availability of appropriate Supported Housing for young people with special educational needs and disabilities 2018 LBTH Accommodation Plan.</li> </ul>	<ul style="list-style-type: none"> <li>- Reduction in out of borough housing placements for young adults with special educational needs and disabilities through an increased number of housing placements in-borough.</li> </ul>
Ensure young people with SEND have access to safe, appropriate accommodation	<ul style="list-style-type: none"> <li>- Improve access to appropriate housing provision and access to appropriate housing support for young people with SEND</li> <li>- Extend overnight respite options for young people who do not meet the threshold for Adults Social Care</li> </ul>	<ul style="list-style-type: none"> <li>- Appropriate housing advice and actions are included in young people's transition action plan</li> </ul>
Promote independence and build resilience for	<ul style="list-style-type: none"> <li>- Use Signs of Safety approach and book</li> </ul>	<ul style="list-style-type: none"> <li>- Feedback from young people shows an improvement</li> </ul>

ACTIVITY	MILESTONE	HOW WILL WE MEASURE SUCCESS?
young people and young adults	<ul style="list-style-type: none"> <li>- Explore options for undertaking group reviews and group planning for young people in friendship groups, to support them to maintain their friendships as they transition into adulthood.</li> </ul>	<p>in the number who report they are able to spend time with their friends and maintain friendships during and beyond the transition into Adults Services.</p>
Promote independence and build resilience for young people and young adults	<ul style="list-style-type: none"> <li>- Increase access to universal and preventative services for young people with disabilities aged 19 to 25, including those young people who are not eligible, and improve access to Day Opportunities for young people aged 19 to 25 who are eligible.</li> </ul>	<ul style="list-style-type: none"> <li>- In line with the Care Act and whole family approach.</li> <li>- Ensure adults social care assessments ask if there is a child in the family.</li> <li>- Monitoring reports from Universal and Preventative and Day Services service providers to Adults Commissioning Team show an increase in uptake of services for young people from age 18 to 25</li> </ul>