

## **Warrington**

### **Joint Strategic Needs Assessment (JSNA)**

**Children and young people (CYP) transition  
from children's to adult services in relation to  
CYP with disabilities, complex health needs  
and statement of special educational needs  
(SEN) – 2013/14**

### Version control

Version	Description of amendments	Date of amendment
5.0	Final Draft, alteration made from final proof read	13/02/2015

The Joint Strategic Needs Assessment (JSNA) considers a wide range of factors that affect the health and wellbeing of the people of Warrington. The objective of the JSNA is to involve partner organisations, such as the local NHS, local authorities, Police, Fire and third sector organisations in order to provide a top level, holistic view of current and future need within the borough. The JSNA is used to agree key priorities to improve the health and wellbeing of all our communities at the same time as reducing health inequalities

## **EXECUTIVE SUMMARY**

### **Introduction**

The aim of this JSNA chapter is to describe the existing landscape of services currently in place to address the often difficult process of transition from children's to adult services for children with disabilities, Special Educational Needs (SEN) and complex health needs. The process of transition from a child to an adult can often be a difficult journey for any individual; however, for those children with disabilities or chronic illness, the process of transition can be incredibly complex with the added pressures of the young person transferring from children's to adult services. The landscape of transition is also changing nationally with the introduction of Education, Health and Care Plans (EHCPs) in September 2014. The introduction of the EHCPs will ensure that agencies (education, health and social care) involved in the process of transition will have a legal responsibility to work together to create transition plans.

For the purposes of this chapter, the following definitions have been used to describe children with disabilities, Special Educational Needs (SEN) and complex health needs. Disability is defined as "...a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities." (Disability Discrimination Act, 2005). Some children have needs or disabilities that affect their ability to learn and there are stages of support to try and help children with special educational needs, one of which is a Statement of Special Educational Needs (SEN), which describes a child's needs and how these should be met, including what school they should go to ([www.gov.co.uk](http://www.gov.co.uk), 2013). If a child has an illness, disability or sensory impairment that needs a lot of additional support to live day to day, they might be described as having "complex needs". A child might have complex needs from birth, or following an illness or injury (NHS Choices, 2012).

This chapter will focus on the transitional processes of children and young people who have a transition plan in place. Transition plans are written for children and young people who have a Statement of SEN or are in receipt of Care, Learning, Access and Support Planning (CLASP) funding and children with complex health needs. CLASP is time-limited funding for learning or medical support for schools where there are children who do not meet the criteria for a Statement of SEN but have significant special educational needs or where the child does not have special educational needs, but have very significant physical or medical needs which may prevent them from attending mainstream school (Warrington Borough Council, 2012). CLASP funding ceased in April 2013, this funding stream has been transferred to schools. The schools will have responsibility to allocate funding to students who will require this specific type of support.

A number of agencies can be involved in the creation of transition plans, depending on the needs and aspirations of the young person. This chapter will examine three transitional processes, the transfer from compulsory education to higher and/or

further education or employment; transition from child to adult health services, and the transition from child to adult social services for children and young people aged 13 to 25 years.

Young people who are engaged with education, health and social services may go through a number of transitions that are unique to a service or shared between all three agencies, which may or may not result in a transition plan.

### **Social Care Transition**

There are a number of transitional processes within the social care pathway, depending on the requirements of the young person. Support needs to be determined if a young person is a child in need; their support needs should be assessed whilst they are in Year 9 (aged 13/14 years) and Year 11 (aged 15/16 years). Children in care require the transition planning process to begin whilst they are in Year 8 (12/13 years), with a pathway plan to be developed when they are in Year 11 (15/16 years) and continued when they are 17 and 18 years of age. Young people who are in need of social care support should have their needs assessed at 17 years of age (Parker, Honigmann & Clements, 2013).

### **Health Transition**

#### **Health Care Plan (HCP)**

Health Care Plans (HCP) are created for children and young people with complex health needs. The HCP should include information about the specific health needs of the young person and the details of the support they will require from health care staff and their carers (LeMesurier et al., 2005). The HCP process should be started when the young person is in Year 9 (aged 13/14 years) and then updated annually between the ages of 16 and 18 years to take into account any changing needs of the young person.

#### **Care Programme Approach (CPA)**

The Care Programme Approach is conducted for young people transitioning from Child and Adolescent Mental Health Services (CAMHS) to either adult mental health services or primary care. The transitional process should take place by the time the young person has reached 18 years of age (Parker, Honigmann, Clements, 2013).

### **Education Transition**

#### **Learning Difficulty Assessment (LDA)**

Learning Difficulty Assessments (LDA) are arranged for all young people who have a Statement, are in their final year of school, and are expected to go onto post-16 education, training or higher education. An LDA can also be used for young people who do not have a Statement, but appear to have a learning difficulty and are receiving or likely to receive post-16 education. The assessment is used to identify

the needs of the young person and identify what provision is needed. Once a Local Authority have decided an LDA is needed, they must support the young person if they stay in further education or training, up to the age of 25, if they continue to have a learning disability (Parker, Honigmann & Clements, 2013).

### **Transition Plan**

A transition plan is written for young people with a Statement of Special Educational Needs (SEN) or in receipt of CLASP funding. It is a document that draws together a young person's needs (which includes what the young person would like to achieve and what support they would need to receive) in the medium term. Historically, transition plans led by education only included information about the young person's educational aspirations, more recently transition plans normally include information about education, employment, health, housing, transport and leisure activities (Ambitious about Autism, 2013).

The transition plan is led by the head teacher of the school that the young person attends. It is expected that transition plans should be started when the young person is aged 13 or 14 years (Year 9). The transition plan meetings must include the Careers Service, Social Care must be invited, and other agencies must be informed about the transition plan meeting, for example, health services (Parker, Honigmann & Clements, 2013). Education, health and social care should be involved in the annual review of the transition plan when the young person is in Year 11 (aged 15 and 16 years). If the young person enters further education, the agencies should be involved in annual reviews when the young person is in Year 12 and Year 13 (aged 16 to 18 years). By ensuring multi-agency input into the transition plan, subsequent reviews can be informed by any other assessments the young person has been part of (Parker, Honigmann & Clements, 2013). Transition plans which have multi-agency input are also known as person centred reviews.

The government has acknowledged the strong evidence base for multi-agency working through the Green Paper, Support and Aspiration (2011). The Green Paper announced that Statements of SEN and LDAs were to be replaced by an Education, Health and Care Plan in September 2014. This will ensure that education, health and social care services will have a legal responsibility to work together to create the plan (Department of Education, 2012).

It is acknowledged that this chapter does not address all transitional process a young person with disabilities, Special Educational Needs (SEN) and complex health needs may encounter. It also acknowledges that transition affects a wider group of young people than those described above. However, for the purposes of this chapter it has not been possible to examine each and every transition process.

### **Key Findings, Issues and Gaps**

- The process of transition has improved slightly in Warrington in recent years through the implementation of national transition programmes.
- Locally, many issues around transition have been addressed and developed through dedicated transition staff, transition strategic and operational groups, development of business plans and multi-agency protocols.
- Remaining issues and gaps include:
  - There is an issue around the centrally held data on children transitioning: data is incomplete and there are issues relating to quality of recording
  - As a result of the incomplete data, it is not possible to accurately predict the size of the future transitioning population (this is especially important for young people with complex needs).
  - This work has highlighted that the quality of the content of transition plans can vary quite widely.
  - Person centred reviews (gold standard transitioning document) are only performed at a small number of schools.
  - This work has highlighted that post-16 opportunities in education and employment have been identified as lacking by transition staff and have also been identified as an area of weakness during the National Transition Support Programme in 2009.
  - A gap in health monitoring/provision has been identified for young people who leave education at 16 years.

### **Recommendations for Commissioning**

- It is suggested that the monitoring system which lists all young people who require a transition plan in Warrington is continued and further improved and developed:
  - The system should be updated on a regular basis and data quality checks routinely conducted.
  - The monitoring system should be held by the Transition Operational Group (TOG).
- To work to ensure that transition plans are of a consistent quality.
- It is recommended that person centred reviews are conducted at all schools in Warrington.
- It is suggested that a monitoring framework is developed to monitor the number of new post-16 education and employment opportunities developed in Warrington.
- A process needs to be developed to maintain relationships between young people who leave education at 16 years and health professionals involved in writing Health Action Plans at 18 years of age.

## **1) WHO IS AT RISK AND WHY?**

This section will detail the groups who are at risk and why, due to the lack of transition planning. Research has shown that 'poor transition' could lead to reduced support and unmet needs which may have far reaching consequences for the young person's educational attainment, health and welfare. Other factors have been linked to poor transition for young people, these include: poor staff attendance at meetings; lack of clarity among services about responsibility for service provision; untimely addressing of key issues; poor coordination between agencies; lack of information about planning; limited capacity of transition workers and high staff turnover; young people who are supposed to have a transition plan not actually received one; and uncertainty and stress for families caused by lack of planning (Beresford et al., 2013).

### **1.1) Transition from education to employment**

Research has shown that for young people with learning difficulties, there are low expectations and aspirations about work, as work is often seen as a low priority and not defined as an outcome as part of the transition process (Department of Health, 2011; Beresford et al., 2013).

Disabled populations have not been encouraged to see themselves as valuable contributors to society (Burchardt, 2005). For example, a study showed that of people born in 1958, the proportion of disabled people who aspired to be in semi-skilled and unskilled jobs was six times higher than amongst non-disabled people. The study also showed that there was a gap between aspiration and outcomes for disabled young people. A fifth of disabled young people age 18 had achieved the occupational group they had desired at age 16, for non-disabled young people it was a third (Burchardt, 2005).

It has been identified that there are a lack of appropriate employment opportunities, including supported employment, for disabled young people to transition into (Sloper et al., 2010; Beresford et al., 2013). In response to this, the Government will introduce supported internships in England for students aged 16 to 25 with a Statement of SEN, LDA or an Education, Health and Care Plan from September 2013.

### **1.2) Transition from child to adult health services**

Poorly planned transition to adult orientated health services can be associated with increased risk of non-adherence to treatment and loss to follow up, which can have serious consequences (Department of Health, 2006). Young people with a complex disability face particular problems because often there is no equivalent adult service able or willing to take on their long-term health care and medical supervision (Department of Health, 2006).

Research has shown that few children with learning difficulties have a Health Action Plan in place (Department of Health, 2011). Of the children with learning difficulties who have contact with health professionals, they tend to be with specialist child health services. There is little contact with their GP, who will need to ensure a health check is conducted annually once the young person is an adult (Department of Health, 2011). Research has also shown that the advice some young people and their families receive about health is often poor, uncoordinated and sometimes wrong (Department of Health, 2011).

### **1.3) Transition from child to adult social care**

It has been found that a major area of concern for parents, carers and practitioners is trying to find out what support could be available for a young person if they are ineligible for adult social care (Beresford et al., 2013).

### **1.4) Transition: moving out of the family home**

Research has shown that there is a fear about young disabled people moving out of the family home. Young people and their families are not aware of the possibilities available to them for housing and related support. It is assumed that young people with disabilities wish to live at home for longer than non-disabled young people and therefore addressing housing within the transition plan at school is seen to be too early (Department of Health, 2011).

It has been identified that there is an unmet need in housing that is suitable for disabled populations and there is a shortage of accessible housing (Sloper et al., 2010; Beresford et al., 2013).

### **1.5) Transition: Friends, relationship and community**

Often, young people with learning difficulties find it very difficult to start to develop independent lives, making friends through school and communities, and parents fear their children will become socially isolated (Department of Health, 2011). Research has shown that young people with life limiting and life threatening conditions are consistently concerned about relationships, friendships, sex, fitting in, being different and being independent (National Transition Support Team, 2009).

### **1.6) Transition: Parents and Carers**

Parents and carers play a key role in the outcome of transition, yet evidence with regard to good practice in support of parents and carers is very limited (Sloper et al., 2010). Research has found that the children of parents who can provide an exceptional level of material, social and emotional resources during the transitional period had better experiences of transition (they were described as 'exceptional parents'). These parents tend to be highly educated and from higher social class backgrounds. This research suggested that parents and their children from lower

social classes/lower levels of educational achievement will need extra support during the transition period to attain similar levels of outcomes (Burchardt, 2005).

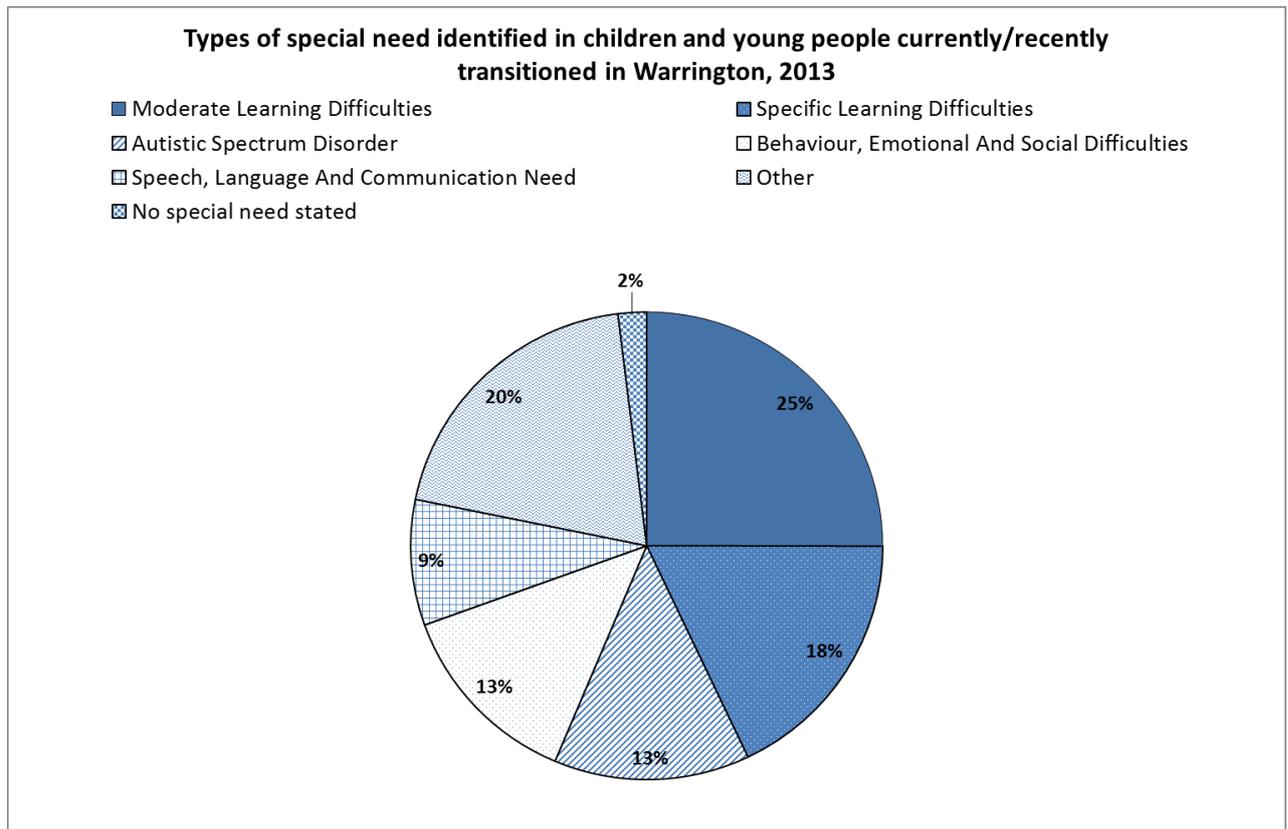
## **2) THE LEVEL OF NEED IN THE LOCAL POPULATION**

The Transition Operational Group (TOG) (Within Warrington Borough Council) maintain a list of young people who have a Statement of SEN or are in receipt of CLASP funding, are known to education, health or social care and have either recently transitioned or are in the process of transitioning. The TOG working spreadsheet was first created in September 2012 and required input from all agencies involved in the transition process to complete all data fields. However, data recorded on the spreadsheet is incomplete, and there are gaps, in particular, relating to when transition plans and annual reviews were conducted, and thus it is not possible to accurately quantify the number or proportion of young people who have a transition plan or annual review. As at June 2013, 715 young people in were identified as either recently transitioned or in the process of transitioning. The following section contains analysis performed on this data set.

715 young people were identified within the TOG working spreadsheet, with ages ranging from 12 to 20 years. The most common ages of young people who appeared on the list were 13 years (n=133) and 17 years (n=133), followed by 16 years (n=132).

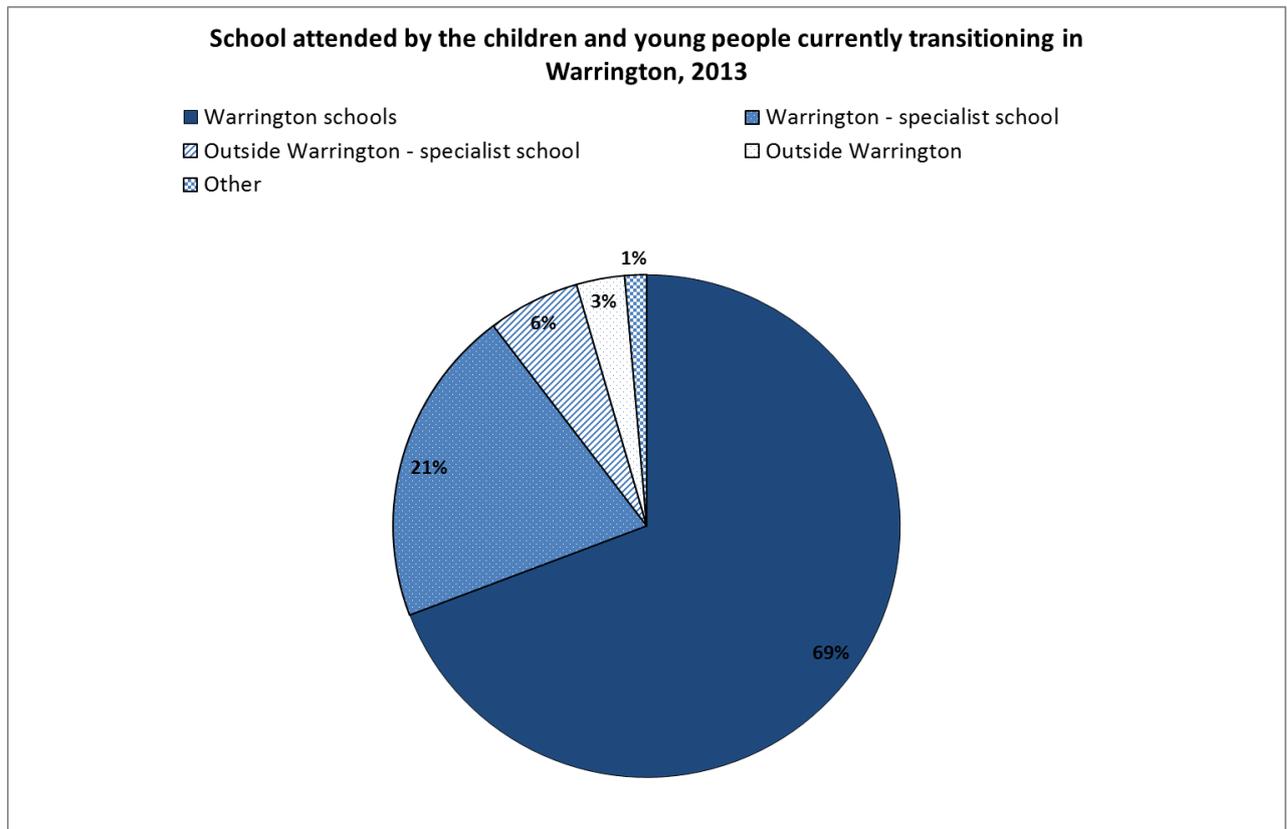
The TOG working spreadsheet provides information about the main special need of the young person. Analysis has shown that children who are currently transitioning have a broad range of needs. As chart 1 shows one-quarter of the young people who are listed on the TOG working spreadsheet had moderate learning difficulties, whilst just under a fifth had specific learning difficulties. 2% of the records on the TOG working spreadsheet did not state the type of special need the young person was defined as having. The 'other' category includes, physical difficulties, severe learning disabilities, social communication difficulties, hearing impaired, visually impaired, profound multiple learning difficulties and mental health issues. These specific types of special need were grouped together due to the small numbers involved.

**Chart 1: Types of special need identified in children and young people currently/recently transitioned in Warrington, 2013**



The TOG working spreadsheet also provides details of the school attended by the young person. Over two thirds of the young people listed on the TOG working spreadsheet attended a Warrington mainstream school (69%) whilst 21% of young people attended a special school in Warrington. 9% of young people attended a school that was outside of Warrington as illustrated in the chart 2.

**Chart 2: School attended by the children and young people currently transitioning in Warrington, 2013**



86% of the young people on the TOG working spreadsheet had a Statement of SEN, of these, 65% attended a Warrington mainstream school. 13% of young people included on the TOG spreadsheet received CLASP funding, of these all attended a Warrington mainstream school.

Information supplied by the Partnerships and Performance Team within Warrington Borough Council provides the number of children with disabilities aged 14 years and above who were expected to have a transition plan to support their move from Children’s Services to Adult Services. The data provided by the Partnerships and Performance Team is extracted on a monthly basis, during March 2013 it was identified that 73 children required a transition plan, all of whom received a plan (100% of the identified population). The target in place within Warrington is 90% of children identified to be in need of a Transition Plan to have received it.

The figures provided by the Partnerships and Performance Team, however, are substantially lower than those provided within the TOG working spreadsheet (73 young people aged 14+ with a disability identified as requiring a transition plan in March 2013 whilst the list provided by the TOG stated that there were 561 young people aged 14+ going through transition).

There may be two possible reasons for this discrepancy. It is possible that the Partnership and Performance team do not hold details about all young disabled people aged 14 and above requiring a transition plan. An alternative possibility is that the TOG working spreadsheet includes individuals who have gone through transition and now need to be removed from the spreadsheet. This discrepancy requires further investigation and it is suggested that the TOG and Partnership and Performance team meet to compare data, conduct data quality checks to ensure that the data both teams hold is accurate.

It is also suggested that data quality checks are carried out on the TOG working spreadsheet to ensure that, if a transition plan or annual review has been conducted, it is recorded in a timely fashion. Regular audits should be conducted to ensure that all data fields are completed.

### **3) CURRENT SERVICES IN RELATION TO NEED**

Transition services for children and young people with disabilities, SEN and complex health needs has improved over recent years in Warrington. The improvements have been fuelled by an increasing evidence base which showed that nationally, transition services were either not in place or were poorly co-ordinated. In response to the evidence, a National Transition Support Programme was developed and ran between October 2008 and March 2011. As part of the programme, National Transition Support Teams were created to support local areas to raise the standards of transition support and provision and achieve greater consistency in all local areas.

A local advisor was assigned to work with Warrington and a number of self-assessment questionnaires were completed to establish the local position at that time. The self-assessment completed in autumn 2009, identified a number of key areas requiring progress. The local advisor identified the following priorities:

- A multi-agency strategic group needed to be developed.
- A multi-agency protocol (strategy) to be developed and endorsed by the Children's Trust.
- The need to ensure good planning commences with quality person centred reviews for young people in Year 9.
- The development of clear pathways and good information, advice and guidance for young people and families.
- To increase the choice and options for young people at age 16 and to support them into appropriate education, employment and training opportunities.

Warrington has been successful in addressing the majority of the priorities identified from the self-assessment questionnaires. A multi-agency strategic group was developed (Strategic Transition Group) in the Spring of 2010 whose aim is to

oversee the establishment of a robust framework for the delivery of improved transition (14+) and ensure a seamless experience with effective communication, addressing all of the needs of the young person and family. The Strategic Transition Group developed a Business Plan for 2012-13; the plan addressed three main transition priorities:

- T1) Moving into adulthood with good health.
- T2) Developing post-16 options and the provider market so that young people have choice and control, paid jobs, independent living, and good health and community inclusion when they move to adult hood.
- T3) How to ensure that the experience of young people and their families inform commissioning, local services and community developments.

The priorities from this plan reflect the priorities of the two year programme 'Preparing for Adulthood' (<http://www.preparingforadulthood.org.uk>). Preparing for Adulthood programme is built on past and current transition programmes and initiatives which include: Transition Support Programme, Getting a Life, Valuing Employment Now, Aspirations for Life, Learning for Living and Work and Project Search (Preparing for Adulthood, 2011).

A multi-agency protocol was written in 2010 and then updated in 2012. The purpose of the protocol was to ensure that young people with complex needs have a positive experience of transition in which:

- Transition is planned throughout a young person's life so that they are aware of any future changes. To achieve this, there must be open and honest communication about any future provision.
- Young people are supported in a way that enables them to actively make the transition, rather than it being done 'to' them, so that they can take responsibility for their own social and emotional development, health and well-being. This requires a streamlined, integrated and straightforward process, across health, education and social care.
- Young people feel that services are provided in a sensitive way.
- Young people and their families report a positive experience of transition.
- Support provided for transition is consistent.

The protocol also promoted the use of person centred reviews in Warrington, it recognised their importance in supporting a successful transition as they can easily identify if input is required from other agencies which may not be present at the time of writing the plan. At present, person centred reviews are routinely conducted at Fox Wood Special School. However, person centred reviews are not conducted routinely at other schools within Warrington. It has been highlighted that the quality of the content of transition plans varies quite widely.

Warrington council have developed a section of their website that focuses on the transitional process to inform young people, parents and carers. The transitional process in Warrington has been branded as 'travelling to the future'. This branding has been based on young people's description of the transitional process: ([http://www.warrington.gov.uk/info/200463/travelling\\_to\\_the\\_future](http://www.warrington.gov.uk/info/200463/travelling_to_the_future) ). The information produced for the website has also been replicated in paper format for those with no internet access. Travelling to the future contains information about services currently available in Warrington to support young people and their families during transition and on into adulthood.

Post 16 education, employment and training opportunities have still been identified as a gap in Warrington by various staff involved in the transitional process. Concerns have been raised about the provision in local colleges, finding post-16 provision very difficult and concerns about post 19 provision for young people with very low abilities. It is envisaged that priority T2 from the Business Plan will help to address some of the concerns raised.

### **3.1) Agencies involved in the transitional process in Warrington**

Within Warrington, a number of agencies are involved in the transitional process. The agencies involved in transition are represented in the Transitional Operational Group (TOG). The TOG is a virtual group who meet regularly and is made up of professionals supporting the transition of disabled young people and focus on children with complex health needs. The following agencies are represented in the group: Children's Commissioning, Inclusion Team, Continuing Health Care Team, Children In Care Team, Learning Disability Team, 11-19 Learning and Achievement Division, Fox Wood School, Community Matron, CAMHs and Transition Social Workers.

### **3.2) Transition in Education**

Within Warrington the aim is to start the transition process whilst the young person is in Year 9 at school, as recommended by national policy. This process differs in Fox Wood Special School as the majority of students who attend this establishment remain there until 19 years of age; therefore transition formally begins in their final year of school. However, transition is discussed from year 9 as part of the annual review and all relevant paperwork is completed. Schools are supported through the transition process by a number of agencies within Warrington. The 11 to 19 Learning and Achievement Division will meet with schools, parents and young people to discuss future educational options when they leave school. The division mainly support young people who have a Statement of SEN, but will also support young people who are in receipt of CLASP funding. The Inclusion Team and Children with Disabilities Team will also work with the school once transition plans and annual reviews have been completed.

### **3.3) Transition in Health**

Within Warrington, transition plans relating to health (Health Action Plans, Health Care Plans, Nursing Assessment and Care Plans, Complex Needs Health Assessments) tend to be conducted in the young person's final year of school. The timing of these assessments are crucial, if they are conducted too early, their needs may have changed once transition takes place or if they take place too late changes in the health care received by young people may be halted or changed immediately causing distress to the young person and their family.

Once the young person has had a health transition plan completed and they have agreed for their information to be shared, the plan is then handed over the Access All Areas Team. The Access All Areas Team is led by the community matron for vulnerable adults, they will assist young people aged 18 years and above to receive the health care and support that is needed. A gap in services has been identified for those who leave school at age 16; a Health Action Plan will be written in their final year at school and then handed over to the Access All Areas Team, they will then write to the young person to let them know their plan has been handed over and will then be in contact when the young person is aged 18. This process results in the young person not receiving an assessment of their overall health for two years.

### **3.4) Transition in Social Care**

The transition process between children's to adult social care has improved over the last few years due to the introduction of transition social workers who are employed through adult social care. Previous to this, adult social care was not involved with transition until the young person was 18 years old. It was recognised that this process led to ineffective transition, and in August 2011 the first transition social worker was put into post followed by a second in September 2012.

A young person will only be assigned a transition social worker if they are already involved in the social care system, a transition social worker is not required for every young person who is currently transitioning. When the young person is 14 years old, their social care worker will contact the transition social workers to inform them that they are approaching transition. The transition social workers will then write to the family of the young person to let them know that a referral has been received and that the young person is starting the transition process. As with health transition, the timing of the transition assessment is crucial, as a young person's needs can change, the transition assessment will take place three months before the young person's 18<sup>th</sup> birthday.

## **4) PROJECTED SERVICE USE AND OUTCOMES**

At present it is not possible to predict projected service use and outcomes for Warrington as it is currently unknown how many young people have transitioned in previous years in Warrington. Once a comprehensive list has been developed

detailing all young people who require a transition plan, it will be possible to produce future trends. It is recommended that projected service use is conducted when baseline data has been gathered.

However, we do know that the number of young people aged 14 and above with a disability and required a transition plan increased when comparing figures for March 2013 (73) to March 2012 (65). What is known is that there are increasing numbers of children and young people with health and support needs are surviving into adulthood (Morris, 1999; Department of Health, 2006), therefore it is assumed that the number of young people with disabilities, Special Educational Needs (SEN) and complex health needs will increase in future years.

It is vital that the number of children and young people who are in transition is collected; the information will be required to help commission services in the future. In times of austerity it is very important to have this knowledge. Concerns have been raised within the transition groups in regard to predicting the number of young people with the most complex needs to ensure that there are services in place to meet the needs of this particular group.

## **5) EVIDENCE OF WHAT WORKS**

The Social Care Institute for Excellence (2011) provides guidance on the transition of young people from children's to adult's mental health services (Guide 44); however, the guidance can be applied to other transitional agencies. The ten main points identified are:

1. Fully involve the young person, family and carers where appropriate and with the young person's consent.
2. Begin planning as early as you can and at least six months before the discharge from Child and Adolescent Mental Health Services (CAMHS).
3. Refer young people to age-appropriate, accessible services where they exist. Do not assume that young people in CAMHS need transfer to Adult Mental Health Services (AMHS). Offer young people additional and alternative support to AMHS.
4. Take account of the wider context of young people's lives: helping young people with broader life issues leads to improvements in their mental health.
5. Work collaboratively with other professionals and agencies.
6. Make service transition a flexible, managed process, with planning and assessments, continuity of care and follow-up. A period of shared or parallel care is good practice.
7. Work at the young person's pace and acknowledge that change takes time

8. Follow up after the discharge from CAMHS, including those who don't transfer to AMHS.
9. Include young people, families and carers in the process of reviewing and evaluating your practice and service models.
10. Use processes and corresponding paperwork that are consistent across agencies, including formally agreed cross-sector transition protocols.

The Royal College of Nurses (2008) published 'Lost in Transition', highlighting similar issues. Ensuring that services are flexible and accessible to young people is essential to reduce missed appointment and promote engagement. Providing services that are acceptable to young people can increase adherence to treatment. Joint working between local services, parents and carers and the young person is also important, especially when the upper threshold for accessing children's services differs to the entry threshold for adult services. The voluntary sector can be a useful source of support during the transition period. The RCN also suggest that services have designated staff to handle transitions. Allowing the young person to visit new services can help to make the transition easier and allows for partnership working between children and adult services.

In a study describing the experiences of young people, parents and professionals in regards to transition from children's to adults mental health services, Hovish et al (2012) highlighted that transfers between AMHS, changes of key-worker and waiting lists were viewed negatively. Other life transitions, including changes in housing, pregnancy, physical illness, and the involvement of parents or other services were sometimes powerful extraneous influences on transition experiences. Hovish et al (2012) concluded that service user experiences are more likely to be positive if healthcare transition is a gradual process, tailored to the young person's needs and managed in the context of the other simultaneous practical, developmental and psychosocial transitions.

Forte et al (2011) examined the content and salience of worries experienced by young people with mild intellectual disabilities (IDs) during transition to adulthood, and whether disadvantages, such as being more socially marginalized, remaining more dependent upon their family, and having fewer options for future careers than their typically developing peers, are associated with the level of reported anxiety and their sense of self-efficacy. It was found that the ID group's most salient worries (being bullied, losing someone they are dependent upon, failing in life, making and keeping friends) were largely different from their non-disabled peers (getting a job, not having enough surplus money, failing, and having to make decisions about their future choices) at this stage of transition. Not only was there a difference in the nature of worries expressed, but the intellectually disabled group also reported ruminating significantly more about their worries and being more distressed by them.

Rutishauser et al (2011) assessed the expectations of adolescents with chronic health disorders with regard to transition from paediatric to adult health care and compared them with the expectations of their parents. The majority of adolescents and parents (64%/70%) perceived the ages of 18-19 years and older as the best time to transfer to adult health care. Chronological age and feeling too old to see a paediatrician were reported as the most important decision factors for the transfer while the severity of the disease was not considered important. The most relevant barriers were feeling at ease with the paediatrician (45%/38%), anxiety (20%/24%), and lack of information about the adult specialist and health care (18%/27%). Of the 51% of adolescents with whom the paediatric specialist had spoken about the transfer, 53% of adolescents and 69% of parents preferred a joint transfer meeting with the paediatric and adult specialist, and 24% of these adolescents declared that their health professional had offered this option. In summary, the age preference for adolescents with chronic disorders and their parents to transfer to adult health care was higher than the upper age limits for admission to paediatric health care in many European countries. Anxiety and a lack of information of both adolescents and their parents were among the most important barriers for a smooth and timely transfer according to adolescents and parents.

Kraus de Camargo (2011) argues that the transition process of vulnerable adolescents, including those with complex health conditions, occurs in all domains of their life. Systems of care are usually designed but also restricted within certain aspects of life, as addressed by health, education and social welfare. The need for a co-ordinated approach to support the transition process is usually focused on one system of care, such as the healthcare system or the education system. However, integrating these different systems may allow for a more cohesive transition process. In order to assist adolescents in transition of services, there is a consensus that the approach should be individualized. The overall goal of any intervention or service should be to achieve optimal functioning of the patients. This requires an exchange of information between the different systems or the integration of those systems involved with the patient.

Allen et al (2011) found that, when young people make the transition from child to adult diabetes services, it is assumed that they will also undergo a parallel transition away from dependence on parents to independent diabetes management. However, the parent-child relationship is often facilitative of their diabetes management, and this is not always reflected in healthcare policy and practice. Carer's indicated that they tend to stop receiving information and feel that their ability to continue to support their child into young adulthood is undermined. This was also found by Unwin et al (2008) using focus groups to identify parents' concerns surrounding the transition process from child to adult services for their adolescents with learning disabilities and mental health problems. Allen et al (2011) concluded that there is a clear need to develop service structures that recognize the continuing role played by carers in the care of young adults.

Personalised Transition is used in Sheffield and demonstrates how a collaborative approach to funding individual budgets for disabled school leavers with complex needs has led to more positive, individualised outcomes for the young people and their families. The approach allows young people and their families to be in control of support planning and organising their lives beyond school with a mix of funding from health, social care and education according to individual needs. The focus is on the young person as a citizen with a contribution to make, rather than as a service user. The model is already being used in five other local authority regions in Yorkshire and the Humber (Cowen et al, 2011).

The Northern Ireland Commissioner for Children and Young People (Lundy et al, 2012) proposed the following recommendations for transitions to adult services for young people with learning disabilities:

### **Education, Training and Employment**

There is a need for:

- Better and more consistent transitions planning and support.
- Statutory obligations to provide transition planning for all young people with learning disabilities and not just those with statements (or Co-ordinated Support Plans (CSPs)).
- A legal obligation to take young people's views into account in transitions planning.
- Involvement of parents in the transitions process.
- Consistency about the age at which a young person has to leave Moderate Learning Disability (MLD) schools.
- Information and support for young people and their families about the transitions process and choices on leaving school.
- Greater communication and co-operation between education and health and social services.
- Appropriate and accessible post-school educational opportunities with real options for progression and lifelong learning opportunities.
- Opportunities for work experience while in school.
- Personal support for young people when they are settling into Further Education (FE).
- A statutory obligation to make provision for young people with learning disabilities generally as well as on transition into FE and from FE to employment.
- Provide a way of challenging decisions about FE provision.

- Targeted employment interventions.

## **Health and Social Care**

There is a need for:

- Age appropriate and flexible day services and short break services.
- Opportunities to build up experience of attending day services while still at school.
- The need for continuity in the health and social care provision when the young person becomes 18 while still at school.
- Good quality, resourced, educational and lifelong opportunities in day services.
- Greater co-operation in planning and decision-making across Health and Social Care
- Greater transparency of information and support for parents about social care options available including on the range of accommodation, alternative sources of support and eligibility for services.
- Advocacy support for young people and their family carers.
- Support for children and young people making transitions into and out of acute hospital care.
- Support to facilitate transitions to adult residential care and/or independent living.
- Support and information on the transition to adult mental health services.
- Age appropriate, tailored sexuality and relationships education.
- Information and advice for parents and carers on the types of family support available.
- Equal access for support for families across Northern Ireland.

## **Social Security, Leisure and Transport**

There is a need for:

- Support networks for parents and opportunities for young people to socialise.
- Accessible information about entitlement to benefits.
- Support for the process of claiming benefits.
- Information and support to connect to the local community.
- Equal access to age appropriate leisure opportunities.

- Support on the use of online tools.
- Individualised support to take part in age appropriate leisure activities.
- Information and support for parents on supporting their son/daughter in accessing and participating in leisure opportunities.
- Opportunities for transport training and independent travel initiatives.
- Accessible information about public transport.
- Training on meeting the needs of young people with learning disabilities for staff in public transport and leisure services.

## **6) (TARGET) POPULATION/SERVICE USER VIEWS**

### **6.1) Feedback from Parents**

A locally facilitated feedback session in 2010 sought information from parents about issues related to transition. Parent's feedback is included in the themes below:

#### **6.1.1) Information:**

1. More information was required regarding the options and pathways, particularly for services out of area, taking into account that the age ranges vary for different services.
2. More comprehensive information is needed for children with mild/moderate disability, particularly regarding adult services provision after transfer.
3. A catalogue of third sector services would be useful for parents. Provision of case studies to give examples of when these services can provide support when young people do not/no longer meet the criteria for community services.
4. A comprehensive pack detailing what happens and when from 14 onwards to 25 and beyond.

#### **6.1.2) Designated case worker:**

5. A single point of contact is needed during the transition period.
6. A mentor champion would be helpful to support the child during this process.

#### **6.1.3) Parental involvement:**

7. Parents wish to be intrinsically involved in the transition plan from 14 years. Parents should be able to attend all meetings with child as an advocate if wished.

8. Flow of communication to parent must be timely before decisions are made at each stage to allow enough time to consider the options.

#### **6.1.4) Schools:**

9. More comprehensive information should be provided and more services should be involved when children are transferring from primary to secondary school.

10. Parents and children should receive more support at a more appropriate time when choosing a secondary school, particularly regarding the decision between mainstream or special secondary provision.

11. Children in mainstream schools should receive more support in accessing relevant services.

12. More contact and support is required after college.

#### **6.1.5) Gaps in provision:**

13. There is a gap in support from transition services between 16-18 years when children leave provisions such as Green Lane.

14. There is a lack of reviews in college, and there is no transition to the next step.

15. There is no follow up from children's services after transfer to monitor the transition.

16. There should be more consideration of the employability skills for young people with ASDs.

17. There should be third sector support for activities during school holidays.

### **6.2) Feedback from Children and Young People**

The Buzz Consultation (2008) highlighted a number of positive steps taken to help children transition from primary to secondary school. However, a number of children found that they had difficulties with access and appropriate equipment.

#### **6.2.1) Positive experiences:**

"My support teacher took me to visit the high school a few times before I started in September"

“I went for five transition days, had a moving to high school booklet to complete”

“I didn’t feel very nervous because I had induction days there. Also I visited the school with the OT to look at equipment and what adaptations needed making in the school”

“I have lots of friends outside of school. My best friend is going to high school with me so that will make it easier”

“It’s a bit scary and exciting moving to high school but we’ve had some trips to visit and that’s helped”

“In high school all the buildings and walls were very bright and really cheered me up. Everybody in the school was supportive, helpful, polite and lovely to be with”

### **6.2.2) Challenges:**

“Unfortunately when I started school the ramp wasn’t complete for almost a whole term. So I couldn’t play with my friends. This made me feel lonely and isolated”

“The lift is alright but sometimes it doesn’t work the first time you use it. This has made me late for lessons. Also I’m not allowed to use the ramp to get to some classrooms because it’s too steep so I have to go a long way round the car park to some lessons”

“(My school) not very good facilities, not good for disabled people. My mum told them it wasn’t very good”

## **7) UNMET NEEDS AND SERVICE GAPS**

- There is an issue around the centrally held data on children transitioning: data is incomplete and there are issues relating to quality of recording
- Currently it is not possible to predict future service needs of the transitioning population until the number of young people transitioning is established (this is especially important for young people with complex needs).
- It has been highlighted that the quality of the content of transition plans can vary quite widely.
- Person centred reviews (gold standard transitioning document) are only performed at a small number of schools.
- It has been highlighted that post-16 opportunities in education and employment have been identified as lacking by transition staff and have also been identified as an area of weakness during the National Transition Support Programme in 2009.
- A gap in health monitoring/provision has been identified for young people who leave education at 16 years.

## **8) RECOMMENDATIONS FOR COMMISSIONING**

- It is suggested that the monitoring system which lists all young people who require a transition plan in Warrington is continued and further improved and developed:
  - The system should be updated on a regular basis and data quality checks routinely conducted.
  - The monitoring system should be held by the Transition Operational Group (TOG).
- To work to ensure that transition plans are of a consistent quality.
- It is recommended that person centred reviews are conducted at all schools in Warrington.
- It is suggested that a monitoring framework is developed to monitor the number of new post-16 education and employment opportunities developed in Warrington.
- A process needs to be developed to maintain relationships between young people who leave education at 16 years and health professionals involved in writing Health Action Plans at 18 years of age.

## **9) RECOMMENDATIONS FOR NEEDS ASSESSMENT/INTELLIGENCE GATHERING**

It is recommended that once the comprehensive list of all young people transitioning in Warrington has been developed, a full needs assessment on this particular population is conducted.

### **Key Contacts**

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