Northumberland, Tyne and Wear NHS
NHS Foundation Trust

Learning Disability – Health Transition Team - Sunderland		
Health Transition Learning Disability Team Practice Guidance Note **Health Transition Nurse Team - Learning Disabilities – V03**		
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1 Introduction

1.1 In recent years there has been increasing recognition that the process of transition from childhood into adulthood for children with disabilities needed to be improved with better planning and support. The Transition Support Programme supported by targeted policy and guidance aimed to ensure that all local authorities had in place strategic arrangements to enable them to meet their statutory duties governing transition.

1.2 Sunderland City Council, Northumberland Tyne and Wear NHS Foundation Trust (the Trust/NTW) and their partner agencies have worked together to develop a Multi – Agency Transition into Adulthood Protocol and Pathway for Disabled Young People (2009) document to plan and coordinate the process of transition.

1.3 The Single Heath Education Care Plan, from 2014 a single plan which is an integrated education health and care plan will be in place from birth to 25 years old. This will replace the special needs education statements.

1.4 Children with a learning disability aged 14 plus are now included in the Direct Enhanced Services Annual health check scheme within their GP practice.

1.5 For all young people and their families/carers the transition from childhood to adulthood can be a stressful and challenging time. This can be further compounded if the young person has multiple diagnosis, additional complex health care needs, disabilities and or challenging behavior and autism.

1.6 For the young people above the journey through transition can be made smoother through the formulation and implementation of a coordinated Health Transition Plan as part of their overall person centred transition plan. In turn this can support the handover of information and future engagement of the young person in the process of negotiating the transition to adult health care services.

2 Purpose and Scope

2.1 There are two elements within the scope and purpose of the transitions teams, when working with children and young adults 14 to 19 years

- Health and wellbeing
- Transitions planning

2.2 Legislation and guidance requires health service involvement in the transition process and single education plan. In Sunderland a Learning Disability Transition Nurse Team has been established, to offer health needs assessments and support to young people with a learning disability / complex healthcare needs / recognition of an individual with multiple diagnoses needs, challenging behaviour or mental health issues, in order to improve the transition from child to adult services. The role includes ensuring that health is part of the Single Education Plan and supporting access to the DES annual health check with the GP practices in Sunderland.

2.3 This policy sets out the roles and responsibilities of the Health Transition Nurse Team and describes the way in which the Team will contribute to the multi-agency approach to transition planning in Sunderland. The associated pathways and practice guidelines offer further detail.

3 Service Principles

The following principles underpin service provision;

- The young person's needs and aspirations are placed at the centre of the health transition process
- Young people and their families are fully involved in and recognised as partners in the process
- Planning is person centred
- Work collaboratively with other agencies to ensure services are seamless with clear pathways between child and adult services
- A range of appropriate and accessible information is provided to the young person and their families/carers by all partner agencies including acute health services
- Be integral to the development of the Single Education Plan

4 Roles and Responsibilities

4.1 The Transition Nurse Team consists of 2 x Band 6 Registered Nurses and 1 x Band 3 Support Worker. The Registered Nurses will share responsibility for developing, managing and maintaining the pathways. The Support Worker will undertake specific duties assigned to them by the Registered Nurse.

4.2 **The Transition Nurse Team will:**

- Support the young person to become more aware of their health condition. Supporting access to GP for annual health check or other mainstream health services as required
- Coordinate completion of the young persons 'My Health Record' and 'Health Transition Plan'
- Contribute to the identification of health care needs of the young person, identify strategies to meet these needs and formulate and implement a Health Transition Plan
- Be involved in the development of a single health education care plan, within the school yearly review systems from 14+ which will include my health record or health transition plan and health action plan an integral part of the integrated health education and care plan
- Where appropriate support the young person in the development of their Health Transition Plan

- Oversee and evaluate the Health Transition Plan as part of the transition process
- Provide accessible information, advice and support to the young person, their families/carers and other agencies
- Signpost the young person, their families/carers and other agencies to the health care services that are available
- Work closely with and other partner agencies involved in the transition process
- Coordinate/facilitate a phased transfer from child health services into adult health services
- Provide health care transition summaries
- Proactively raise awareness of health care transition in child/adult services
- Correlate information from individual Health Transition Plans, highlight and report gaps in service provision, to the Health Sub Group of the Sunderland Learning Disability Partnership Board and act upon recommendations
- Health Transition Team will undertake advanced partnership work alongside CYPS Care Coordinator

5 Criteria for Referral to Health Transition Team

5.1 The Health Transition Team will work with young people from the age of 14 years old who have a learning disability:-

- Been diagnosed with **learning disabilities**, (sometimes classified as having an IQ of 70 delay or below and/ or diagnosis of a developmental /cognitive impairment, noted via a Statement of Special Educational Need/ single education plan or notification by consultant or General Practitioner)
- The child / young person is between the ages of 14 to 19 year and registered with a general practitioner in Sunderland
- If the child / young person is nearing 17 ½ years of age or older and is moving from a children health service into an adult health service. They will be supported to access the most appropriate adult health service, which is appropriate to their primary and associated needs. For example e.g. Attention Hyperactivity Disorder, Autistic Spectrum Disorder, learning difficulties with no classified diagnosis of Learning Disabilities or mild Learning Disability. These cases can be discussed at the Adult Learning Disabilities Interstream Meeting, for further clarification, and to support access to mainstream mental health services where more appropriate

5.2 **Entry routes to Health Transition Team:-**

- Accept/Assess referrals from the local authority children's/adults team to develop Health Action Plans (Health Transition Plans) as part of the Person Centred Transition Plan for young people with a learning disability and complex health care needs

- Accept/Assess referrals from the Consultant Paediatricians Neurodisability at City Hospital Sunderland for young people with PMLD (Profound Multiple Learning Disability) from 14 to 19 years of age towards the development of a health action plan and transition plan

- Accept/Assess referrals for young people with a learning disability 'and challenging behavior/autism in the later stages of transition aged 17-25 where they are moving back into the locality or where has been a gap in service or they suddenly come into contact with services for the first time' Referrals sources may include, local authority, special schools and children moving back to Sunderland from out of area school placements

- Referrals can be accepted from the CYPS (children and young person's team) from the age of 14 for planning however don't become actively involved until 17-17.5 as responsibility remains with CYPS. This will involve clarification of the child having been diagnosed with a learning disability towards the development of a health action plan and health transition plan. In conjunction with the care coordinator, this will include supporting the facilitation of a transitions plan and a MDT decision will be agreed on the child's primary need and which adult pathway maybe appropriate.: mainstream mental health e.g. psychosis /non psychosis or learning disability service e.g. physical health, mental health or challenging behavior pathway.

5.3 Ordinarily Transition Nurses will engage with the young person and their families/carers from Year 9 (Age 14) to age 19-25 as part of the yearly review and support the development of the integrated education health and care plan, along with access to DES annual health check.

6 Key Functions/Service Model

6.1 Referral do not go through NTW Initial Response service, as they are primarily a children services, commissioned via CCG and LD pool budget. On receipt of a referral the Team will review and allocate the referral to an appropriate pathway (**Appendix 1 or Appendix 2**) and named member of the Team.

6.2 The allocated nurse will then make contact with the young person, their families/carers and other agencies involved with the young person.

6.3 Where appropriate Transition Nurses will work the young person through the following 3 stages of transition:

- **Early Stage - Age 14,** the aim will be to introduce the young person and their families/carers to the concept of transition to adult health care as part of the transition process. A person centered approach will be key to highlighting the child's health needs and personalisation of services required. Supporting access to annual health checks and 'My Health Record' concept as part of the Single education plan

- **Middle Stage - Age 14 – 16**, the emphasis will be on further developing the young persons and families understanding of the transition process and introducing them to adult services, supporting annual reviews at school and annual health checks with the GP

- **Later Stage - Age 16 – 19**, continues with transition process towards developing planning for young person to access appropriate adult service/provision including facilitation of transition plans, and offering care coordination. For families this incudes supporting /offering a range of information and supporting decisions. This will include liaising with a range of multiagency multi-disciplinary professionals from both child and adult services

6.4 The above will be achieved by the Transition Nurse through provision of the following service:

- Screening using My Health Record and associated tools
- Assessment, the level of assessment will depend on complexity of need
- Signposting and/or referral to appropriate agencies
- Facilitation and coordination
- Monitoring and tracking children and young people journeys
- Consultation/Advisory role
- Support/Guidance to families
- Attendance at Inter - stream Meetings

7 Health Action Plan (Health Transition Plan)

7.1 As part of the transition process assessment of the child's/ young people's health needs will be undertaken using the Health Action Plan template. This process will offer a person centered approach, towards the development of an individualised action plan. The plan is to highlight health needs, if any assistance is required in relation to social, educational needs, then the action plan will highlight the appropriate service to offer assistance, this will be part of the Single education plan where ever possible.

7.2 Ordinarily development of the Health Transition Plan will commence at the Year 9 review (age 14 years) and the process will begin with an initial assessment using the My Health Action Plan assessment tool, carried out by the Transition Nurse, who will ensure this information is used within the integrated education single plan.

7.3 From this assessment the young persons health needs will be identified and the appropriate health transition pathway followed. With objectives and targets agreed with the young person and their families/carers, a plan is developed towards the move to adult services. This will be part of the integrated education single plan and reviewed as part of the annual review in school process.

7.4 Young people referred and accepted into the service at an older age will enter the pathway at the appropriate age point but follow the same process as above.

7.5 The Health Transition Plan might contain the following:

- Actions to enable the young person to maintain and manage good health
- Information and guidance on the medical management of the young person's long term condition
- Access to generic services and the journey into adult health care services
- Identification of specialist equipment and environmental adaptations
- Identified behavioural and mental health needs and services required to meet them
- Development of social skills and strategies to enable self care and independent living

8 Review of Health Action Plan

8.1 The Health Action Plan will be reviewed at least annually, by the following routes:

8.2 Review will take place in either of the following forums;

- Attendance at Educational Reviews
- Attendance /or updates from families following DES annual health checks
- Review at Consultant transition clinics at Portland Academy
- Review by the consultant Paediatrician Neurodisability from City Hospital Sunderland clinics
- Attendance by a member of the Transition Nurse Team at a multi disciplinary meeting facilitating the transfer back to Sunderland of a young person from an out of area school or of a young person diagnosed with learning disabilities coming into contact with services for the first time during the later stage of transition

- Review at Social Services Section 17 review meetings
- Case progress reviewed every 3 months from transition team member as required

9 Care Coordinator Status

9.1 The children and young people that the Transition Nurse comes into contact with will not ordinarily be subject to the requirements of the Care Programme Approach as described in the Trust's NTW(C)48 Care Coordination (including CPA) within Children and Young Peoples Services Policy. However, the underpinning standards and principles, modified to meet the needs of this specialist service, will influence the way in which the Transition Nurses work with regard to their planning and co-ordinating roles with the child or young person.

9.2 By adopting a Person Centred approach and through the use of specialist recording tools (see attach appendices) the Transition Nurse will work within the principles of CPA, however, they will not act as CPA Care Coordinator.

10 Consent to share information

10.1 Consent to share information will be agreed at the point of referral by the organisation making the referral.

11 Record keeping and use of information

11.1 The transition team is a separate team on Rio and referrals will be opened to this team on RIO.

11.2 Original copies of the My Health Action Plan (Health Transition Plan) will be retained by the individual child/young person, either sent by email or a paper copy. The plan will also become part of the integrated single education plan.

11.3 Records will be completed by the Transition Nurse in accordance with the Trust's NTW(O)09 - Management of Records Policy, practice guidance note, MR-PGN-02 - Record Keeping PGN and NMC professional standards.

11.4 Recordings on RIO. The transition team will record on RIO information relevant to the child/young person within progress notes. They will complete a narrative risk as appropriate. They will not complete core documentation, care planning or FACE risk or contingency planning unless the young person is becoming a patient within the adult services (17+) within NTW.

11.5 When undertaking advanced partnership work with CYPS – transitions nurses will only complete expected recording listed in 11.6. CYPS maintains responsibility for mental health/learning disabilities care planning, risk management and contingency planning

11.6 The main documentation will remain the within the education system, within the integrated single plan however the transitions nurses will be required to main professional recordings.

- These will include:
  - Progress notes
  - Transition team involvement plan
  - Narrative risk
  - Consent to share
  - This does not include core documents and risk management plan

11.7 Scanned images will include my health plan, transition care plan, information received from other agencies

11.8 Information on the child/young person will be gathered from a variety of sources and will be entered on NTW Rio and may be held electronically dependent within the Single plan in schools or local authority.

12 Interface/Multi Agency Working

12.1 The Transition Nurse Team will work collaboratively with a range of health professionals and other agencies in order to coordinate person centred healthcare as young people move from one service to another. This may include:

- Schools / Colleges
- Care and Support Sunderland
- Connexions
- General Practitioners
- Children's team
- City Hospitals Sunderland
- Acute Services Learning Disability Liaison Nurse
- Carer's Centre's
- Respite Services; child/adult
- Children and Young Peoples Team

13 Management and Supervision

13.1 The Transition Nurse Team are managed as part of the Community Treatment Team, Learning Disabilities in Sunderland. The Team are located at Monkwearmouth Hospital and report directly to the Clinical lead.

13.2 Arrangements are in place to ensure that the Health Transition Team is able to meet the requirements of the Trust's policy on clinical supervision.

13.3 Health Transition Nurse is to organise monthly supervisions with the Support Worker, following trust supervision policy documentation.

13.4 All attend Monthly Business Meetings

14 Service Outcomes and evaluation-performance management

14.1 Health outcomes that apply to transition are maximized, for example reduction in Obesity, cancers, smoking, etc, along with reduction of health inequalities associated with people with a learning disability. This will be demonstrated via good news stories and case studies presented in the health sub group/client questionnaire/feedback.

14.2 Greater coordination of health care during the transition period 14 – 19 (up to 25) years as appropriate.

14.3 Better access to mainstream services- Numbers of 14+ accessing DES annual health checks. Health care needs integral part of Person Centered Transition Plan (Integrated Education, Health and Care Plan)

14.4 Facilitate smoother transitions and provide a seamless transfer to adult health services

14.5 Compliance with NTW and Local Authority policies and Safeguarding procedures for children and vulnerable adults

14.6 Performance data will be collected in relation to number of referrals, caseload, health needs identified (including reporting of unmet health needs) including how many children /young people have been given information about an annual health check and how many have attended an annual health check.

14.7 The transitions team will not be included in NTW performance data, in relation to recording of core documentation, FACE risk, CPA, Clustering, as these in the main are not applicable to the service.

15 References/Bibliography

- Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) March 2013. www.bris.ac.uk/**cipold**

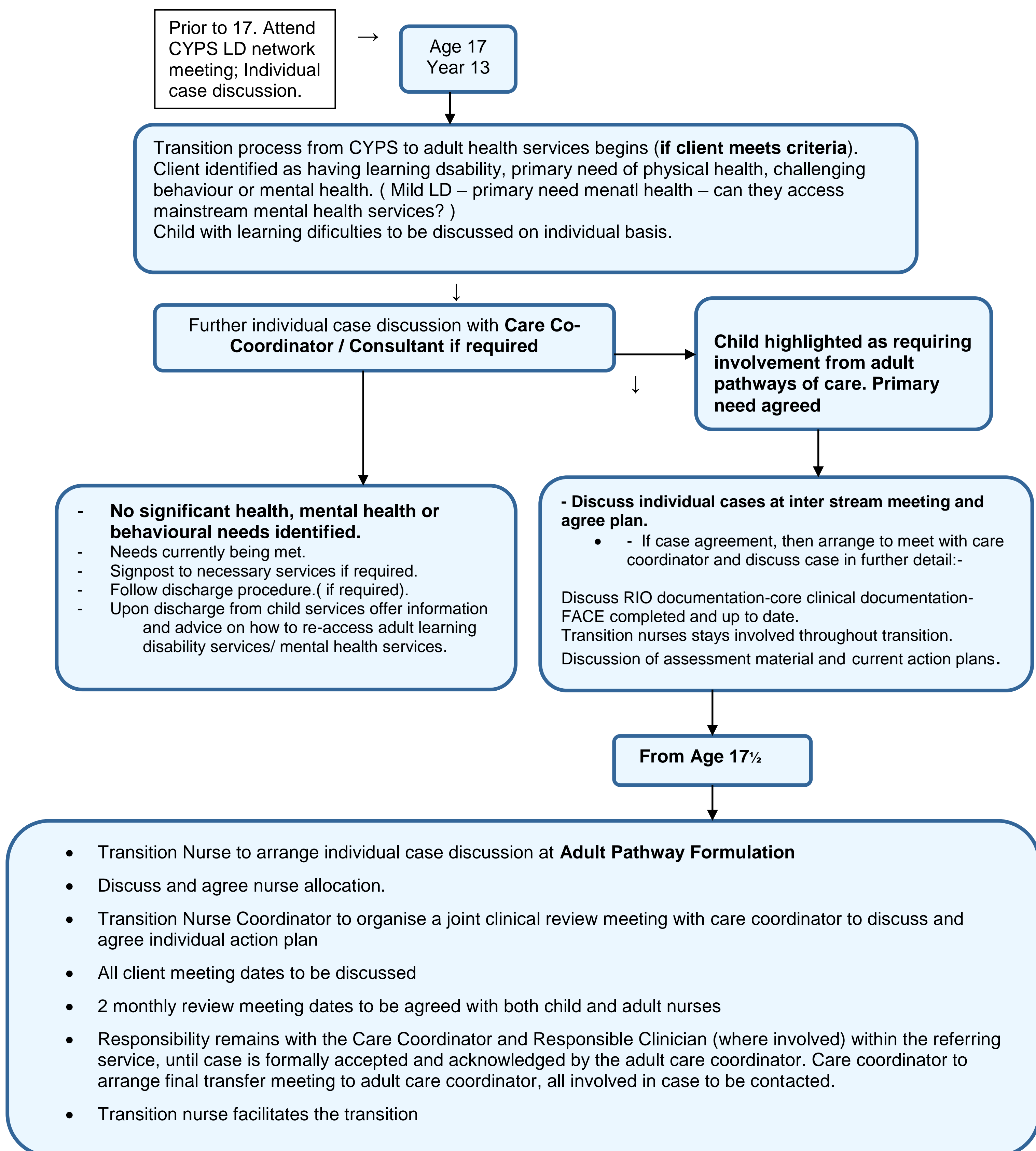
- Department of Health (2006) *Transitions: getting it right for young people* [Online]
  Available at:
  http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132145

- Department of Health (2007) *A Transition Guide For All Services* [Online] Available at: http://www.transitioninfonetwork.org.uk/publications.aspx (Accessed: 28 December 2012)

- Department of Health (2008) Transition: Moving On Well [Online] Available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592 (Accessed: 28 December 2012

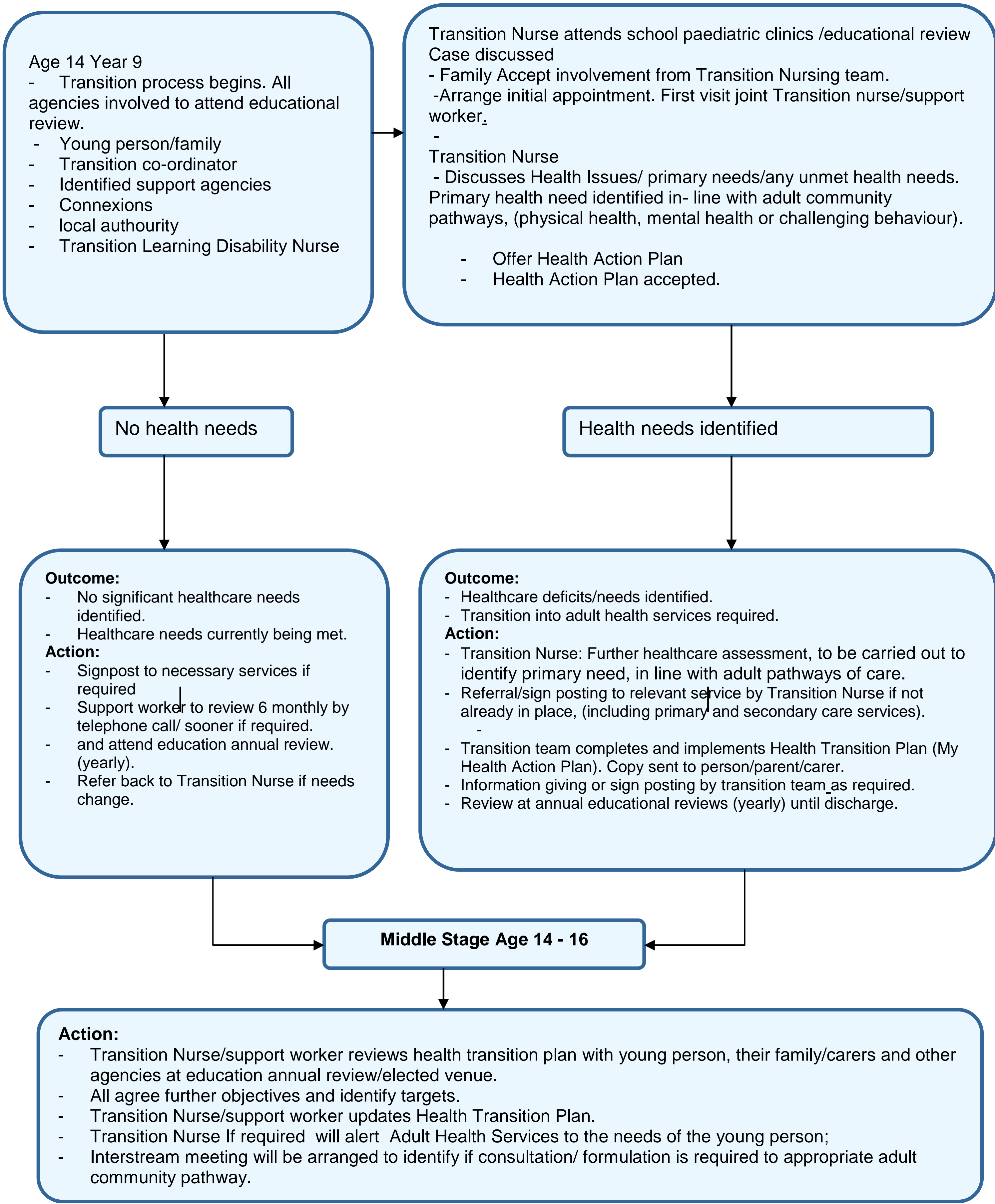
Appendix 1

Health Transition Pathway from CYPS to Adult Pathways of Care



Appendix 2

Sunderland Royal Hospital-Health Transition Pathway



Later Stage Age 16 - 17 -18

Action:

- Care co-ordinator/ Lead professional Transition Nurse/Support worker reviews/ updates Health Transition Plan with young person, their family/carers and other agencies.
- At 17 and a half. - Health Transition Nurse will complete RIO core clinical documentation if the need if adult Community Pathways has been identified.
- Organise handover meeting to identified pathway into adult health services at 18years of age to establish reason for referral, any historical assessment/intervention. To identify the most appropriate pathway i.e. access to mainstream, specialist service provision and facilitate transition into service.