Transition process for Young People with Learning Disability and health needs to adult Community Learning Disability Teams in Gateshead

'Adult and children's services should work together and information must be shared routinely so that young people and their parents don't waste precious time repeating information about their health. Young people must not fall in the gap between children's and adult services'.

[Professor Field, CQC, *from the pond into the sea: Children's transition to adult health services*, 2014]

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Introduction:

The transition from childhood into adulthood involves consolidating identity, achieving independence, establishing adult relationships and finding meaningful employment or activities. For many young people having access to timely information, guidance and advice can help them to meet their goals, whilst others might need support from a range of services.

Transition: getting it right for young people, published by the Department of Health and Department of Education and Skills in 2006 highlighted that those with neurological disorders and disabilities are the least well served. Their transition is made more difficult by concerns about whether, how and where their health and social care needs will be met. Transition services need to support young people with a range of conditions, varying from those who will attain independence despite having a long term condition, to those who have a progressive life-limiting disease.

This Transitions Protocol and Pathway provides the framework for how services in Gateshead will work together to ensure the best outcomes for all young people with disabilities as they move into adult life. It sits alongside Gateshead Council's SEND Multi Agency Transitions Protocol.

In addition, the aim of this document is to describe a person-centred process whereby young people with learning disabilities can transition smoothly from children's to adult health services. We have endeavoured to provide clear guidance on time frames, appropriate referrals, information provision and referral processes, to make the transition process smoother for professionals and therefore hopefully less anxiety-provoking for young people and their carers. We have also provided contact details for the relevant adult teams who can answer any queries.

Whilst this protocol describes a process that brings together professionals from different agencies to meet the needs of those young people who have the most complex needs, this would be too intensive for some young people and for them, a more appropriate, simplified process will be used.

Throughout these documents the term 'learning disability' is used in line with the definition in the Department of Health document *Valuing People*. This states that a learning disability includes the presence of:

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

The World Health Organisation (ICD 10) demarcates the severity of learning disability as below:

- **Mild** - Approximate IQ range of 50 to 69. Likely to result in some learning difficulties in school. Many adults will be able to work and maintain good social relationships.

- **Moderate** - Approximate IQ range of 35 to 49. Likely to result in marked developmental delays in childhood but most can learn to develop some degree of independence in self-care and acquire adequate communication and academic skills. Adults will need varying degrees of support to live and work in the community.

- **Severe** - Approximate IQ range of 20 to 34. Likely to result in continuous need of support.

- **Profound** - IQ under 20. Results in severe limitation in self-care, continence, communication and mobility.

What does good transition look like?

The Department of Health document Transition: moving on well provides guidance built upon a wealth of good practice and aims to:

- Place the young person's needs and aspirations at the centre of the transition process
- Reinforce the need for a clear inter-agency planning structure, which is based on good communication, education and training of staff, have agreed local protocols and evaluates outcomes to improve experiences of transition for these young people
- Acknowledge that transition is not an event and continues into adult services
- Highlight practical approaches through which both children's and adult health services can contribute to improving the transition process for young people with complex needs and disabilities (both those and without Education, Health and Care Plans)
- Support the Commissioning process by clarifying the driving principles of person centred planning, partnership working, clarifying roles and responsibilities of the professionals/main agencies involved in the transition process
- Good information available at the right time in an understandable format.

Some young people with a Learning Disability do not have sufficient understanding and communication skills to make their views known. In this situation it is essential that those working with them have the necessary skills to facilitate the involvement of the young person. Referral for independent advocacy may be appropriate, particularly when there is a conflict between the young person's views and others involved.

Adult Community Learning Disability Team (CLDT):

The Adult CLDT work with people with learning disability as defined by the Department of Health as noted above. The Adult CLDT support those people with a learning disability in the mild range as well as those with more severe difficulties.

The Adult CLDT perform direct work and liaise with other services to provide support and training regarding reasonable adjustments for people with a learning disability. Within the teams there are community learning disability nurses of mixed specialities, psychologists, speech and language therapists, occupational therapists, physiotherapists, psychiatrists and Liaison nurses.

The services are set up to work in episodes of care rather than a care co-ordination system. When people are referred to the service for the first time, an eligibility process is completed to establish whether the person has a learning disability as described above. This process is not repeated for each episode of care.

Professionals from the CLDTs work with people with learning disabilities and carers to establish which service(s) would be most appropriate for them. For some people it may be more appropriate for them to access 'mainstream' mental or physical health services, and the Equality Act 2010 requires reasonable adjustments to be made to enable this. The CLDT staff may be able to advise on how best to support individual people with learning disability in mainstream settings.

The adult CLDT are not joint services with social care (though work closely with them). If the person needs social care input they will need to be referred to the relevant social care team.

The adult CLDTs are not commissioned to work with people with Autism, ADHD or dyslexia without a global learning disability, or people whose difficulties are due to a brain injury that occurred after their 18th birthday.

The adult CLDT have catchment areas based on the service users' GP practices (not home address). They accept self-referrals, and referrals from professionals or carers with the consent of the person being referred, or in his/her best interests if he/she lacks capacity to consent to the referral. Contact details for individual teams are provided (see appendix 4).

There is a useful booklet about the Mental Capacity Act called 'Making decisions, a guide for family, friends and other unpaid carers' available from the Office of the Public Guardian on http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/opg-602-0409.pdf .

Health/Transitions Referral Group

Group Members:

Adult Community Learning Disability Team
Other nominated representatives from Community Learning Disability Team
Representatives from:
Transitions Team
Disabled Children's Team
Looked After Children and Young People'sTeam
Designated Nurse Looked After Children, Gateshead and Newcastle CCG
Named Nurse/Specialist Nurse Looked After Children, Gateshead NHS Health Foundation Trust
Children's Paediatrics
Children and Young People's Services (CYPS)
Designated Clinical Officer (SEND) GP

Transitions Timetable

Year 11 (aged 15)
The young person's name will be recorded on the 'Health/Transitions Referral list' (See Appendix 2) and any health or social care issues noted. These individuals will be identified in the meeting and an agreement reached as to who will inform them and their carers of their introduction to the list and the purpose.

Year 11 and 12 (16 and 17)
At 16 the young person will be discussed at each bi-monthly meeting (with their consent) to raise awareness of their needs, are they stable/changing. They will be discussed at each meeting thereafter until the referral is activated.

Year 13 (age 17/18)
At 17 ½ the young person will be referred to the Adult Community learning Disability Team, if they meet the referral criteria with their consent. (See appendix 3 **'**Transition meeting pathway for Young People with Learning Disability and health needs to the Adult Community Learning Disability Team in Borough of Gateshead'). If they do not have capacity to consent the carer can agree to the referral as a Best Interest decision.

Next Steps

The Community Learning Disability Team will then complete an assessment:

Assessment – When a referral is received for a health assessment by the Gateshead Adult Learning Disability Service an assessment contact will be made within 10-15 working days and an appointment will be made within 30 working days.

This assessment will be carried out by a qualified Learning Disability Nurse. The nurse may also be accompanied by a Health Care Support Worker.

At assessment the following will be considered:

- Consent to share/store information
- Brief medical history.
- Physical health needs
- Behavioural needs
- Mental health needs
- Smoking cessation
- Alcohol intake
- Schooling.
- Epilepsy risk
- Social Activities /Interests.
- Significant Life Events and screening questions.

What next?

After assessment has been completed the Nurse will agree with you and your primary carer what the next steps will be. This may include referrals to other services such as Occupational Therapy, Psychology, Physiotherapy, Psychiatry, other.

What if they are discharged?

If no health needs are identified at assessment then the Learning Disability Nurse will explain that you will be discharged at this point. The Nurse will give you contact number of the Gateshead Adult Learning Disability Service and the Gateshead Crisis Response Team numbers, in case you need further support in the future. The Learning Disability Nurse will also talk to you about being flagged and how to refer to the Gateshead Adult Learning Disability Service should you need further support from the service in the future, however this must be support for a health need.

What are the benefits for family/young person?
Integrated holistic care
Smooth transition from young people's to adult services
Time to form and build new relationships with other professionals
The person and family will know who is coordinating the person care
Help to alleviate anxieties around transition for the person and their family

Also provided:

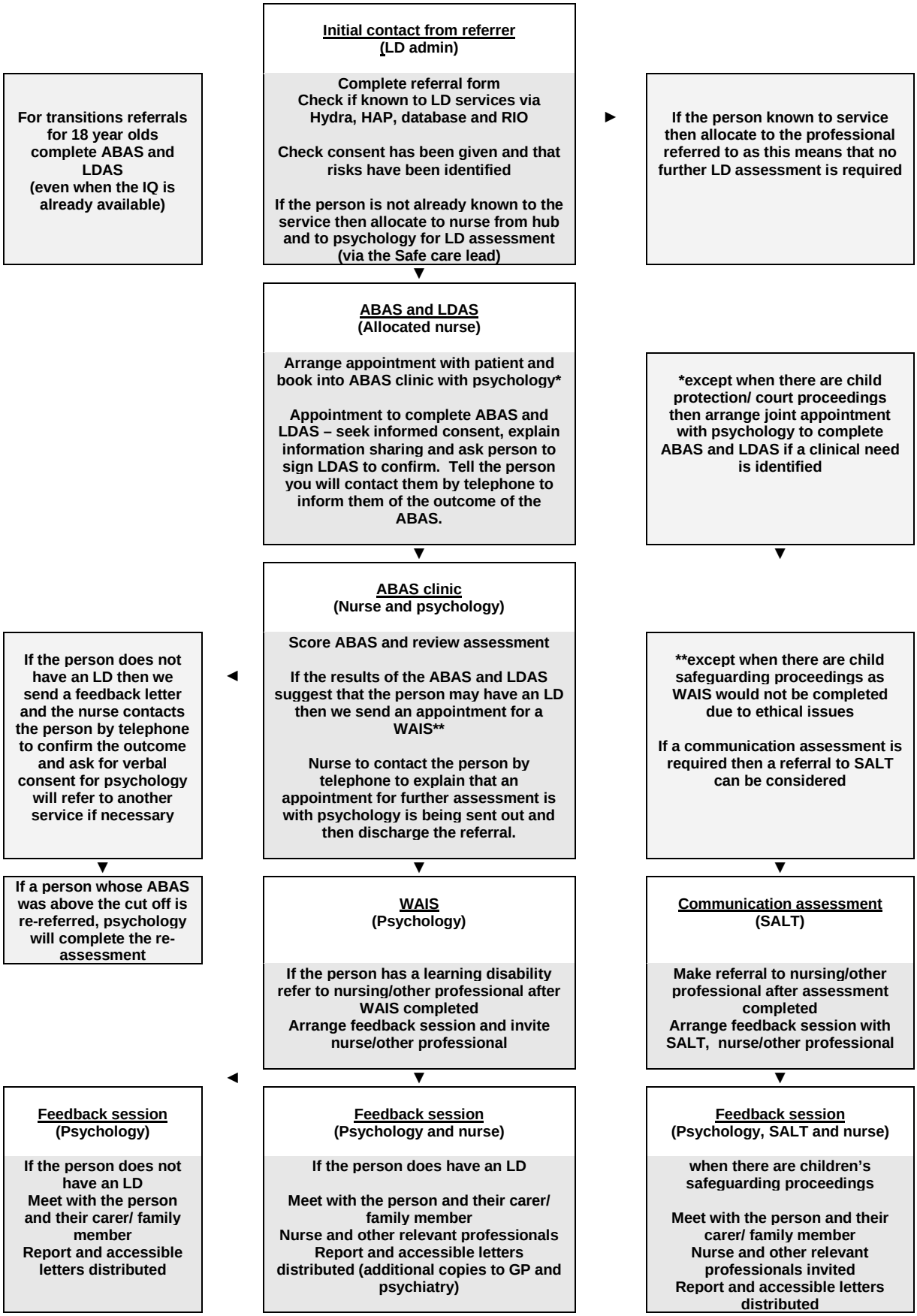
- Health Action Plan
- Health Passport
- Annual GP health check
- Flagging at local hospital (and reasonable adjustments)
- Access to learning disability Occupational Therapy, Speech Language Therapy, Psychology, Psychiatry, Nursing, Physiotherapy and Nurse Liaison

Learning Disability Screening

For many young people with an Education, Health and Care Plan it refers to their 'learning difficulties', this is terminology generally used by Schools and Educational Psychologists who use a different screening and assessment tool from health colleagues WAIS-IV^{UK}
For those whom it is unclear whether they have a Learning Disability, and uncertainty whether they can access Adult Learning Disability Services, the team can offer a screening. At 17 ½ they can be added to the Referral list through the group meetings.

What does this look like?

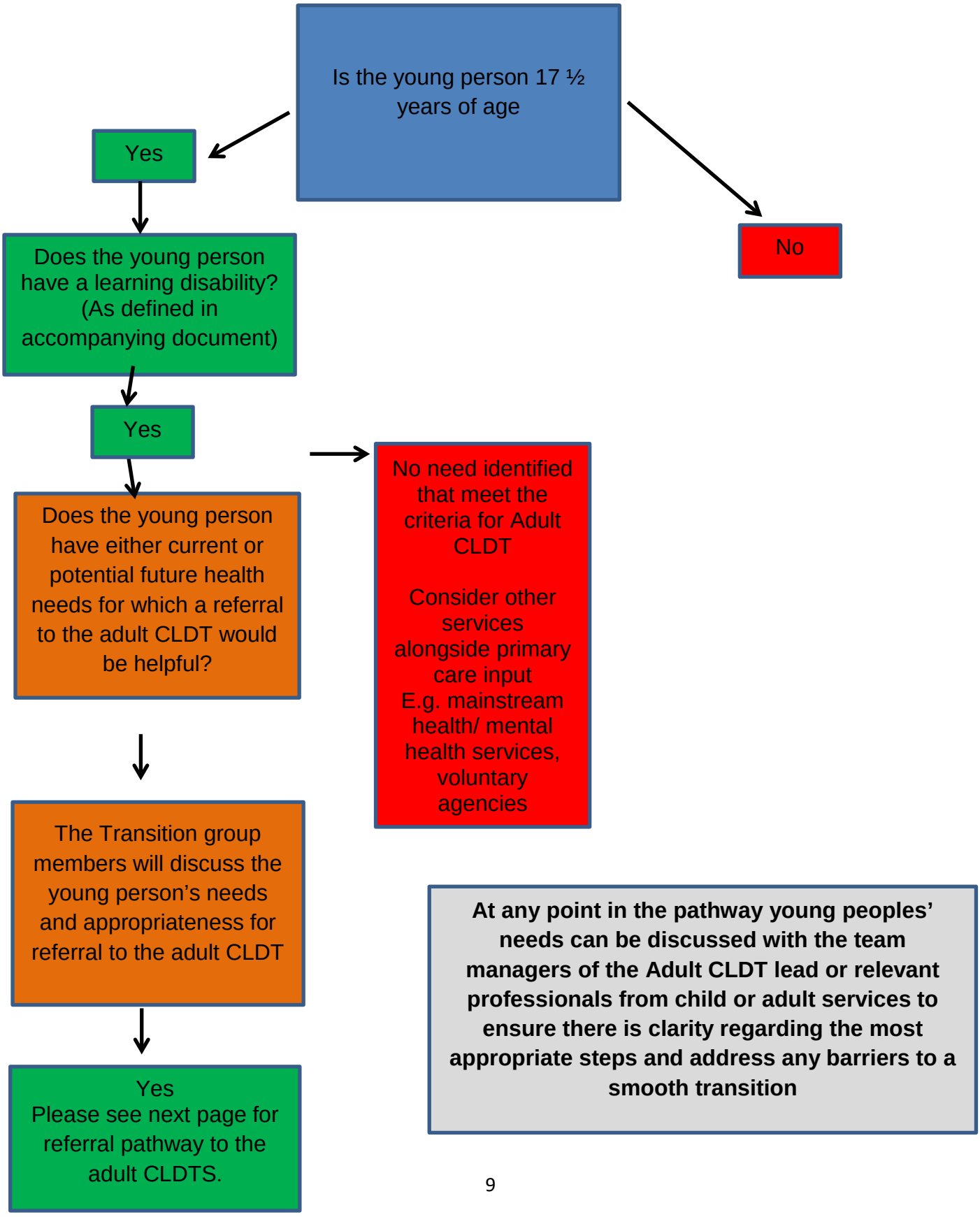
Learning Disability Assessment Pathway
Gateshead Community Learning Disability Teams



What next?
If a learning disability is identified following screening, then the Community Learning Disability Nurse will undertake a health assessment to identify if there is any further need/s.

Appendix 3

Transition meeting pathway for Young People with Learning Disability and health needs to the adult Community Learning Disability Team in Borough of Gateshead



Referral pathway to adult CLDTs

At Bi-monthly meeting the young person when 17 1/2 on transition list, is to be discussed

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Consider consent issues. Can the young person consent to this referral or is it to be made in their best interests? Discuss with family and carers.

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Those who meet eligibility criteria (set out above) and consent is in place to be referred to the adult CLDT which notes the young person's GP and address

Those where evidence suggest the presence of a learning disability though no formal assessment found, to be referred to the Adult CLDT for Learning Disability screening

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Referral received by CLDT, processed and allocated within 24 hrs.

Face to face contact made within 10 working days with young person and parent/carer unless either or both prefer a later date .

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More Complex situations - Both the professionals working with the young person and the adult CLDT staff should consider whether some or all of the following would be helpful: Joint assessment/handover meeting between services with young person and carer. - Professional to professional telephone handover - Professionals handover meeting

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CLDT staff complete
Core clinical documents
Health Action Plan
Young person flagged onto GP Direct Enhanced Service List so can qualify for annual health check
Young person flagged at General Hospital as having a learning disability for reasonable adjustments

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Outcome of eligibility process is communicated to young person, family/carer, referrer and GP

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If the young person is eligible to receive services from the adult CLDT, and he/she has current needs which the adult CLDT can address:

The adult CLDT staff will explain what services they can offer to the young person and his/her family/carers.
If they are taking over any aspect of care from children's services, the adult CLDT will inform the referrer, children's health care professionals and GP.

Please note that the adult CLDTs cannot provide clinical input until a patient's 18th birthday.

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If the young person is eligible to receive services from the adult CLDT, but there are NO current needs that the adult CLDT can address:
The young person, family and carers will be given information by the adult CLDT about how to access input when needs arise.
The CLDT will signpost to other relevant services if appropriate, e.g. social care, voluntary agencies.

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If the young person is not eligible to receive services from the adult CLDT:
The adult CLDT staff will endeavour to signpost the young person and carer to appropriate services.

Transition Group Forum	
Time	
Venue	
Next Meeting	

Present:

~~Apologies:~~

~~New Referrals~~										
Surname	**First name**	**RIO No.**	**DOB**	**Age (This column will automatically change when DOB is entered in column D)**	**Involvement**	**Comments**	**Risks/Hazards**	**ADMIN ONLY Database** □	**PAS Flag** □	**DES** □
				116 Years, 3 Months, 1 Days						
Case Discussions (16-18 yrs. only)										
Surname	**First name**	**RIO No.**	**DOB**	**Age (This column will automatically change when DOB is entered in column D)**	**Involvement**	**Comments**	**Risks/Hazards**	**ADMIN ONLY Database** □	**PAS Flag** □	**DES** □
				116 Years, 3 Months, 1 Days						
14-15 yrs only (add to case discussions at 16 yrs.)										
Surname	**First name**	**RIO No.**	**DOB**	**Age (This column will automatically change when DOB is entered in column D)**	**Involvement**	**Comments**	**Risks/Hazards**	**ADMIN ONLY Database** □	**PAS Flag** □	**DES** □
				116 Years, 3 Months, 1 Days						

Any Other Business:

Transition care plan 171/2 -18yrs

Transition Plan for: [Name of child]

Documented diagnosis -

Name of Keyworker/social worker:

Name of secondary school contact:

Address

D.OB

Main carer/s name

Dates of transition meeting:

People attended transition meeting:

Discussion:

Communication support needs:

Social understanding support needs:

Any other support needs / agreed modifications or arrangements:

Responsibilities allocated

Referred to Adult learning disability CLDT for HAP/ Assessment of need YES / NO

If NO…. why?

Date of next meeting / discussion

Outcomes achieved since last discussion

Further actions required

Sign Designation Date

Transition checklist

When assessing the service user in transition period from child to adult services please ensure below is completed and action's before the user is 18yrs of age

Name NHS No: Date of referral

To do	Completed	Completed Y/N/ Date
First visit	To organise visit so all action below can be completed by the time the user is 18yrs	
Information given	Team leaflet Safeguarding leaflet Data protection sheet	
Initial common assessment completed	Commence Multi-Disciplinary Risk Assessment and complete Lone Worker Risk Assessment Take copy of Data Protection Form bring back signed section for file Start or complete Common Assessment : Part A.B.C as appropriate Complete Complexity Rating Tool on return to base (Not part of client assessment)	
Referrals made	Note referral made for starting when 18yrs If the user's needs are such that they would benefit from being referred into the community learning disability team then generate a referral so can start support at 18yrs Referrals for psychology – psychiatry must be done within one month before 18yrs	
Intervention plan created	If the user's needs are such that they would benefit from being referred into the community learning disability team then generate an intervention plan so ready to support when turns 18	
HAP/My Health Record completed	Complete	
ABAS Completed	Where there is ambiguity about the diagnosis of a learning disability please complete an ABAS and take to ABAS clinic for scoring	
liaison	Persons details forwarded to Liaison for flagging at hospital and for DES list for GPs	