1. Report Overview

The contents of this report include:

- A description of a CAMHS LD pathway mapped against the Thrive framework. This conceptual framework is supported as the foundation of how CAMHS LD services should be structured.

The following specific areas are then considered in more detail:

- Early help and prevention
- CAMHS LD – the core team
- The Autism pathway – assessment and support
- Support for Keeping our young people with behaviour that challenges in our communities.
- Links to Intensive Support Services and Respite linked to early warning signs from the Dynamic support database.
- Specialist LD/ASD beds in the NW region linked to NW community services.
- Transition from child to adult services.

Recommendations alongside use of Thrive framework include:

- The importance of Training of staff universal services in working with children and young people with Learning disability and/or Autism and reasonable adjustments
- Parents Carers and Young people to be able to access training to promote wellbeing and health and prevention.
- CAMHS LD to be sited with mainstream CAMHS but with strong multi-agency links
- Children and young people to be able to access mainstream mental health pathways when needed (Audited with Greenlight toolkit)
- An allocated Key worker using the DSD as an early warning system and CETR.
- An Autism assessment and support pathway
- Schools consultation model
- Specialist LD /ASD inpatient unit in NW
• Transition into adult services be supported by a transition worker, with all age ITSB and Crisis service supporting young people across the age range into adulthood
  o Intensive short breaks model to be piloted
• Specially commissioned respite beds to be linked to intensive support and crisis services which could be extended across adult and child services.
• Roll out of the Dynamic Support Database
• Model linked to rolling out good practice via an IT platform and a rolling programme of good practice events in NW England.

2. Background

The Children's model of care work stream was arranged to -

• Map the different service models in adults and children
• Map good practise for post diagnostic services
• Identify gold standards across the country for diagnosis and post diagnosis

At the workshop, on reviewing outcomes from group work and comments, further areas were identified for development. Further smaller sessions were facilitated to explore these themes in more depth:

• Guidelines on what a CAMHS LD service should look like.
• No good examples of joint working between different services.
• Some schools not identifying LD or Autism in school aged children due to lack of access to education psychology or the lack of funding for 1:1 support.
• Joint working with criminal justice system needs to improve.
• No crisis support and a lack of early intervention.
• No children's specialist LD/ASD beds available in North West region.
• Challenges around the specification.
• Out of Area placements – residential education.
• Ofsted SEND reviews – found issues with ASD pathways in some areas

3. The Thrive model

We propose that the CAMHS LD pathway should sit within the overall THRIVE model. (THRIVE elaborated Wolpert et al 2015) The Clinical Model proposed for the CAMHS LD pathway, has been developed based on the Thrive conceptual framework, and is fully in line with the requirements of the Five Year Forward View and other national guidance, and builds on new ways of working which will provide the best and most sustainable model of care for children, young people and families across the full spectrum of support – from ‘Getting Advice’ through to ‘Risk Support’ for the most vulnerable children and young people:

This is a framework for an approach which broadens the definition of mental health services beyond specialist NHS provision to include education, social care and others.

The model should be aimed at children and young people between 0 to 25 years, reflecting the SEND agenda (Children and Families Act 2014):

All children and young people with intellectual disability and/ or autism and no emotional and behavioural needs would access universal services. However, due to their developmental needs there would be an expectation that staff working with these people were trained, in making reasonable
adjustments and to recognise the early signs and risk factors for challenging behaviours, and mental health issues.

Where concerns arise, children and young people and families should be able to access support via a Single Point of Access. This should be multi-agency including staff from CAMHS, community health and local authority (educational psychology, SEND officer, social care for children with disabilities), staff relevant to transition should also be included in a needs assessment where needed (adult LD services, transition key workers).

The vision for delivery of the Thrive based model is to offer each child or young person access to a range of services which:

- Are needs led not diagnosis led.
- Are Person centred.
- Maximise a multi-agency approach which wraps around the child young people and family – the network should function as one service using a shared formulation and joint multi-agency plan. (The Team Around the Family /Common Assessment Framework approach is recommended by NICE guidance for challenging behaviour)
- All young people with Learning Disability or Autism to have annual Health checks at 14 years of age.
- Utilise the Dynamic Support Database within all services.
- Link into the SEND framework and use the Education Health and Care Plan as the multi-agency record whenever the child or young person has one.
- Ensure that when children and young people must be admitted or require an alternative placement that they remain close to their family and community using the least restrictive options.
- Are under pinned by a joint outcomes framework.
- Support the full range of needs in line with the principles of Thrive.
- Offers early support and intervention to prevent escalation of difficulties and to maximise the ability of generic services.
- Focus on building resilience to ensure capacity to facilitate capacity to manage life challenges.
- Offers access to all children and young people, and their families / carers, requiring a level of support.
- Enables all members of the community to seek support in the most suitable way.
- Provides an appropriate and reliable level of service 7 days per week.
- Aligns the care offer with CAMHS services to ensure a clear and coherent connection to other services (including the complimentary and 3rd sector) with consistency of language.
- Provides the best quality of care and embeds systems to continuously improve.
- Supports transition to other services in the best way possible, according to presenting need, with continued support.
It is proposed that increased access to advice and support at the earliest opportunity is critical to the improvement of our offer. The model proposes establishing or ideally working with any existing local single point of contact for CYP, families, schools to ensure children who have a learning disability do not miss out on access to local services. To supplement the offer we would be proposing a comprehensive Digital Offer (digital support, alongside signposting which should be predominantly kept in the Local Offer) and supported by the Complementary Offer within the locality.

Increasing the offer in communities will ensure that more CYP have access without delay but will also stabilise ‘flow’ through the model of care, allowing appropriate planned pathways to be offered in a consistent and sustainable way, without the generation of secondary waiting times. This element for children and young people who have a learning disability will be described in more detail related to the responsiveness of Intensive Support building to a Intensive Support Respite offer.

A Single Point of Access ‘hub’ in a defined locality to support an agreed population base should provide triage and assessment relevant to the level of need, which can be escalated/de-escalated as required, and which will link with all ‘Thrive’ activity offered within the locality. This would lead to a multi-agency triage assessment indicating what to signpost to next. An initial rag rating for the dynamic support database should also be obtained at this point. Workers should be skilled, or senior enough to make a timely decision.

Plans of Care, predominantly delivered as Education Health & Care Plan (EHCP) will be co-ordinated by the most appropriate person involved in the care of the CYP with digital enablers to support access to records for others involved in the delivery of care.
3.2 Elements of the CAMHS LD Thrive pathway

3.2.1 Thriving

Where children and young people are seen as thriving with no concerns about behaviours or emotional wellbeing, Services should be making reasonable adjustments, using clear communication, (communication standard) and aware of early signs for concern about behaviour or emotional health via:

- Training of universal staff
- Partnership working of paediatrician and mental health worker
- Having a lead professional for each child or young person.

Education would most often be the lead provider for this group.

All families with a child or young person with Learning disability and/or autism, should be able to access local authority resources such as Short Breaks or “Early Help “ for carers without an assessment. All local resources must be published in the Local Offer by local authorities. All young people with learning disability should receive an annual health check from their GP.

The quality of training provision is vital in supporting the wellbeing of children and young people and enables the prevention of emotional and behavioural difficulties developing. To achieve this we recommend that staff working in mainstream services in health education and social care, receive training in making reasonable adjustments, communication, sensory needs and spotting the early signs and risk factors for challenging behaviours, or mental health issues. This training should also be accessible to parents and carers.

I have a good and meaningful everyday life.

I get good care and support from mainstream health services.

From : Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition - Service model for commissioners of health and social care services : October 2015

Supplement : Developing support and services for children and young people with a learning disability and autism or both (October 2015)

Once concerns are raised by the young person, family or staff, and they have been assessed at the single point of access, including initial use of the dynamic support database rag rating, the pathway of interventions and advice offered fit into the following areas.

3.2.2 Getting advice

- Adapting environmental factors, e.g. providing a space to retreat to in school.
- Support for children young people and parents/carers.
- A key worker to guide the young person or family through systems to ensure they are accessing supports such as short breaks or early help (from the local authority).
- The key worker should be reviewing the dynamic support database regularly to identify barriers.
- Parent carer training including web based resources and training the trainers.
- Schools consultation (Pennine model)
- Delivering effective and effective education, health and care plans.
3.2.3 Getting Help

- Early identification and intervention for changes in behaviour should use the Common Assessment Framework (team around the child approach) to ensure a coordinated multi-agency intervention for behaviour.
- Behavioural intervention based on needs with or without a diagnosis.
- Intensive modelling of interactions, communications and behaviours
- Diagnostic assessments
- Enable self-help via further training such as evidence-based parents groups or signposting as required.
  - Examples: “Riding the Rapids” (Beresford et al, 2012)
  - Sleep workshops
  - “Signposts for building better behaviour” parenting group (Hudson et al 2003, 2008)
  - Early Bird / Early Bird Plus / Early Bird Healthy Minds (NAS)
  - Cygnet parent carers support programme (Barnardo’s)

I can access specialist health and social care support in the community.

Everyone should have access to integrated, community-based, specialist multidisciplinary health and social care support for people with a learning disability and/or autism in their community that is readily accessible, when needed, by children, young people.

Specialist support might be provided by a range of services, and often across services (e.g. children’s services, Child and Adult Mental Health Services (CAMHS), learning disability CAMHS teams).

From: Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition - Service model for commissioners of health and social care services: October 2015

3.2.4 Getting more help

If more specialist intervention is required there should be a clear pathway to specialist interventions which include:

- Neurodevelopmental assessment.
- Sleep interventions
- Positive behavioural support – Functional analysis leading to PBS plan
- Medication for anxiety / low mood etc
- CAMHS LD to ensure multi-agency package of support and care including primary care and education is coordinated.

3.2.5 Getting Risk support:

If risk concerns are raised, evaluation and contingency planning using Care Education and Treatment Review and DSD must be carried out. Social Care would often be the lead agency. Plans and provisions may include:

- Transition planning.
- Increased multi-agency package of support and interventions.
- Educational placements including residential.
- Intensive therapeutic short break service linked to a 24 hour crisis support service and local short breaks placements.
- Specialist inpatient beds accessible to the local area with effective continuing care to receiving services.
An example of a young person’s journey through different groupings of support in the THRIVE framework. They would not have to move through each area in turn, for example a young person could move from getting risk support, back into the “getting help” or “getting more help” grouping. Another young person could move from the getting more help stage after getting an autism diagnosis and move to receiving provision from the getting advice stage, receiving reasonable adjustments and an adapted curriculum at school.

**Getting advice: a good practice example**

**The Stockport School Consultation Process**

**CAMHS – Mini LD Team (moderate to severe LD) and the Children’s Community Learning Disability Team (CCLDT)**

School consultation – Half a day per half term per specialist school dedicated to implementing the PBS model – Staff and parent workshops (getting advice) – Individual staff and parent drop-in’s (getting help) – Greater collaboration on complex existing cases (getting more help) – Multi-disciplinary management of young people and families in crisis (getting risk support) – First part of wider Challenging Behaviour Pathway

Outcomes at 12/24 months – High levels of satisfaction and reported staff development – School reports of effective interventions offered • Identify the right support at the right time – Impact on referral rates – (interventions occurring earlier)
Getting advice: Good practice example

The Autism Support Coordinator: Trafford

This post provides both post diagnostic support for adults who have received a diagnosis of autism, and their families, training and awareness raising, coordination, awareness raising and training of the local multi-agency network including upskilling local mainstream services.

Carer Resilience workshops for parent carers have recently started in partnership with the National Autism Society to improve the wellbeing and self-care of parent carers. Part of this model includes training parent carers to jointly deliver the workshops themselves.

3.3 THRIVE Component: The CAMHS LD core team

CAMHS LD services should be providing a part of the support for our children and young people with emotional health difficulties or behavioural issues. As outlined in the Thrive model this should be provided alongside support from Education, health, social care and the third sector.

The level of this input will vary depending on which level of support our children and families are accessing. It would range from being part of the multi-agency staff providing training to universal services our children who are "Thriving", leading and advising on positive behavioural support for the network around children who are “getting more help” to being part of the multi-agency risk management plan or support in returning to the community from a placement, for children who are “getting Risk support”.

It should be one of the agencies which may provide the known contact/or key worker for our children and families at the getting help, more help or risk support levels. It would depend on the needs of the child which agency is best to provide this role.

The CAMHS LD service should have close links with other health and local authority services, but should sit within the mainstream CAMHS services as a distinct team.

This is in order to prevent the risk of dilution and loss of expertise that can happen when individual learning disability clinicians are spread through mainstream teams whilst still enabling access to mainstream mental health services both in and outside office hours and the full range of therapies they provide. Mainstream mental health services should use the Greenlight Toolkit to audit their progress in this. This should include Accident and Emergency departments where long waiting times and the environment can cause more distress for children and young people with learning disability or autism.

There should be clear pathways enabling our children and young people to have their needs met by LD or mainstream CAMHS. Where mainstream CAMHS are supporting a child, they should have access to advice and consultation by their colleagues in CAMHS LD.

Everyone should expect mainstream mental health services to regularly audit how effective they are at meeting the needs of people with a learning disability and/or autism. The Green Light Toolkit should be used to both evaluate services and to agree local actions to deliver real improvements. In many instances this will require investment in mainstream mental health services (such as Child and Adult Mental Health (CAMHS) Services, Improving Access to Psychological Therapies (IAPT))

Local areas drawing up transformation plans for CAMHS should ensure their plans cover the full spectrum of need, including children and young people with a learning disability and/or autism.
CAMHS LD must have pharmacist support from the health organisation they are sited in, for specialist advice and to enable the use of medication to follow the STOMP LD and STOMP-STAMP principles. (Stopping overuse of medication – Learning disability, Supporting Treatment and Appropriate Medication in Paediatrics’)

Challenging behaviour is not a separate diagnosis and may have multiple causes including physical, communication, environmental, social, sensory and mental health issues. Its management must be multi-agency as it may include strategies aimed at all of the above. NICE guidance states that psychotropic medication must only be used if the above strategies are not producing change or a reduction in targeted behaviours in an agreed time, or risk issues are very severe. People with LD are at risk at being left on medication for long periods of time without a clear clinical goal. (Stopping the Overuse of Medication - STOMP LD)

For children, young people and their family’s accessibility and travel can be another barrier to accessing services and multiple appointments. We recommend that this is taken into account in services and estate planning. Colocation of multi-agency services should be considered, as well as the use of outreach services or satellite clinics using locations already accessed by young people and families in the community as well as considering public transport and accessible parking.

### 3.4 Workforce

Staff within the core CAMHS LD mental health service should include:
- Child psychiatry
- Clinical psychology
- Specialist LD nursing
- Speech and language therapy
- Behavioural specialists
- Occupational therapy

The service should also include or have access to:
- Community paediatrician
- Educational psychology
- Social worker from children with disabilities
- Pharmacist

The core team would be sited in children’s mental health services, but other staff mentioned above should have input via agreed time or cases allocated via service level agreement and coordinated commissioning.

### 3.5 Adult Learning disability services and Adult Autism services

As we are recommending an age range of 0 – 25 for this framework, Adult LD services, and services working with adults with autism and no LD/autism hubs would also be part of this care pathway and would be working with young people from 19 years up to 25 years.
We would recommend that young people graduate into these services with a transition worker who would support their transition to new teams and support links with the SEND agenda and children’s services and services commissioned up to 25.

See Transition section later.


Part of the range of supports and interventions in the THRIVE framework must be a clear pathway for children and young people with autism, this will also include those with suspected autism at some stages. Work is being done on this in areas across the North West. The ODN group stakeholders have agreed to use the pathway developed by Lancashire care which has been coproduced with young people and parent carers. We would recommend that initially clear pathways for autism are provided in each transforming care area. Other neurodevelopmental conditions are discussed in the future recommendations at the end of the paper.

The diagnostic pathway should fit into the Thrive framework. It should be needs led, and person centred. We know nationally that there are long waiting times for accessing diagnostic assessments (NAS survey of waiting times here) and with a resulting impact by delaying early intervention and the use of reasonable adjustments. Therefore the assessment team cannot be a gatekeeper for support. By following the THRIVE framework, needs led support should have started before entering pathway and be continued whilst waiting for assessment outcome.

Parent and carers should be able to make referrals to the pathway and we recommend that when this happens they are offered immediate assessment of the support they are receiving and linked into support and advice from the “getting advice” and “getting help” parts of the overall pathway. Some of this support will be from universal services, and some will be more targeted for those with suspected autism (E.g. Local authority autism teams offering advice to schools for children with suspected autism, third sector organisations who are commissioned to support families and children waiting for autism assessment as well as those with autism). This also includes early access to health and mental health and Local authority Early Help/Short Breaks offer.

The diagnostic part of the pathway is an important component due to the evidence base linked with the management of autism and its impact on the type of strategies used for treatment, communication and reasonable adjustments. These may have a major impact on improving outcomes into adulthood for our children. There is also a need for diagnosis when it exists for access to national frameworks of support. There should be a case coordinator for each child and family on the pathway.

The pathway should have a single point of access with agreed referral criteria with agreed information and screening tools requested. Initially a paper triage process of the referral information given should be carried out. If the information supports assessment, a clinical face-to-face initial assessment should be carried out. The assessment should follow NICE guidance and also indicate what further assessments or comorbidities should be looked at.

It must consider differential diagnoses, and comorbidities which may include other neurodevelopmental conditions mental health physical health, learning and communication issues.

There should be an agreed template or pro forma which should be a live document held by the young person or parent/carer. The Case coordinator should ensure this is up to date. A Multiagency Panel
may be required but not for 'straight-forward' cases. The assessment process should use a Toolkit of agreed assessments/professional opinions/questionnaires.

The assessment outcome should not just be a diagnosis but also a profile of needs and strengths, as identified through the Template. Those who do not meet criteria for a diagnosis of autism may still have needs which should be met by LD or mainstream multi-agency services, for example special educational needs, support or training offered to parent carers or intervention for sensory difficulties. Some children may not meet diagnostic thresholds for autism at end of assessment but will still benefit from a similar approach after due to having social communication issues.

A post assessment support plan for children with no diagnosis – should be accepted by the multi-agency network and should be monitored by a lead professional from the multi-agency network for an agreed period of time after the assessment.

For children and young people with a diagnosis, there should be a clear post diagnostic support pathway. The assessment and diagnosis feedback meeting should also be attended by the case coordinator with a plan identified. A follow up within 6 weeks of the initial feedback appointment should occur.

### 4.1 Basic NICE Guidance compliance

- Pre-referral checklist to include trigger of review of SEND support at school and family support following Thrive model principles.

- Pre referral - Screening forms such as - lifetime SCQ (parents), SDQ (parents, teacher, young person 11+), AQ10 – adults ASD screening tool.

- 2 clinicians of different disciplines to carry out developmental history, review of diagnostic features/differential diagnoses/comorbidity, impact, functioning and observation.

- The may be, a Psychiatrist / paediatrician / plus one other - SLT/clinical psychologist/educational psychologist/OT.

- Referral to mental health pathway or community health if required.

- Feedback forms and reports from the rest of the multi-agency network

An example of Autism assessment model including clinician hours required for a standard autism assessment which is fully compliant with NICE guidance.

- Paper triage to decide whether full assessment is required. Varies from 5 minutes to 30 minutes per child depending on the complexity of the case with at least 2 clinicians using agreed screening tools (e.g. The social Communication Questionnaire, The Current Concerns Form)

- Full assessment (with no significant complexity or comorbidity)
  - 3di (Developmental history) – 3 hours
  - ADOS (Observation) – 1.5 hours x 2 clinicians = 3 hours
  - Collation of all information including obtaining and summarising multi-agency reports – 2 hours
    - Report writing – 3 hours
    - Feedback session – 1 hour
    - Follow-up session – 1 hour
  - Total = up to 13 hours including report writing time
• Full assessments often require additional time due to the level of complexity, mental health or neurodevelopmental comorbidity.

4.2 Complex autism assessments (not all components may be required).
• School observation if required including travel time = additional 2 hours
• Cognitive assessment, administration, scoring and report writing = 4 to 5 hours.
• Discussion as a focus case at multi-agency panel with community health/CAMHS/educational psychology/LA Autism team = 0.5 hours with at least 5 clinicians plus admin
Up to 7.5 additional hours for the most complex cases

Complex ASD assessments often require further additional time due to the level of complexity, mental health or neurodevelopmental comorbidity such as ADHD.

4.3 Straight forward assessments.

There will be a proportion of assessments where diagnosis is more straight forward with no concerns about differential diagnoses or comorbidity. However, there is a high level of neurodevelopmental and mental health comorbidity in this population.
The time required for the most straight forward assessments – where diagnosis is obvious, will be significantly shorter, depending on the experience of the clinician.
In these cases, a full structured 3-hour interview schedule or full ADOS may not be required.

Longer assessment waiting times, with no previous support put in, may increase the risk of developing mental health comorbidity or have a greater negative impact on other areas of functioning such as educational progress or social inclusion

4.4 Post diagnostic support should include:
• Information provided on autism, on national and local support services, and third sector organisations including local authority support for parent/carers and support for siblings, and details on how to request a carer’s assessment from local authority.
• Parents support and training including face to face parent groups such as Early bird, Early bird plus, cygnet group and access to IT/web-based training resources on autism.
• A review of educational support, and special educational needs and provisions in light of the diagnosis.
• The treatment of any comorbid mental health physical health issues. Treatment or advice on communication or sensory difficulties (check NICE).
• An immediate start on planning for transition to adult services and long-term needs if the young person is in year 9 or older, or any other future transitions, e.g. transition to secondary school for primary aged children.
• A transition worker should accompany the young person as they transition into the adult autism pathway as discussed in the transition section of this document.

Post diagnostic support: example from Cheshire West CAMHS
• E.g. Pre parents group drop in – 4 hours 2 clinicians.
• Cygnet group 6 x 2-hour sessions, plus x hours preparation – 2 clinicians.
• Post parents group drop in clinic 4 hours clinic per term.
Access to mental health, pathways, community health pathways, and local authority provision will depend on individual needs. A child or young person may also need access to mental health pathways for depression / anxiety etc or management of neurodevelopmental comorbidities such as ADHD, or behavioural support for learning disability.

4.5 Workforce.

Autism Team members:

- Core membership of a autism team should include for the under 19 population:
  - paediatrician and/or child and adolescent psychiatrist
  - Speech and Language Therapist
  - Clinical and/or Educational Psychologist.
- The Team or assessment pathway should also include access to:
  - Paediatrician or Paediatric Neurologist.
  - Child and Adolescent Psychiatrist.
  - Educational Psychologist
  - Clinical Psychologist.
  - Occupational therapist.

If not members of a core team these clinicians should have dedicated time, agreed by service level agreement, service specification and coordinated commissioning.

- Young people over 18 should access the adult autism assessment pathway as outlined in the ODN all age autism model.
- Autism assessments should start within 3 months of referral.
- The size of assessment team required for keeping waiting time to 3 months is also required.

5. THRIVE Components: Keeping our young people with behaviour that challenges in our communities.

5.1 Clinical recommendations

Intensive therapeutic short breaks model linked to commissioned respite and residential placements, and a crisis service with a clear pathway into and out of specialist inpatient beds if required.

The input of an intensive therapeutic short breaks service, must exist in the context of a pathway of prevention and support for challenging behaviour that starts with universal services when our children are “Thriving”

For all our children and young people, when thriving and accessing universal services:
• Use a person centred approach from the very start, supported by a key worker and a team for the individual.

• Universal services should be trained in making reasonable adjustments for disabilities, so that our children can access and use them when needed, thus reducing some of the risk factors for developing challenging behaviours and mental health issues.

• Staff and families supporting children and young people should be offered training on the early signs indicating behavioural or emotional health issues may develop and on the risk factors that may impact or lead to this.

• An early warning system for risk factors that may lead to a young person ‘placement being at risk should be used. The ODN recommends the use of the Dynamic Support Database.

For young people and their families who are:" “getting advice, getting help, getting more help, or getting risk support”

• When early signs are identified there should be a rapid multi-agency response to all needs. It may involve the CAMHS LD service, Social care children with disability team, education and the SEND team all working together to meet the needs of the young person and family.

• We recommend that the Common assessment Framework and EHCP if the young person requires one is used by the network. (NICE guideline)

• For parent carers accessing information and training could be accessed when thriving through web based or public training, when their children are thriving. More specific evidence based parenting programmes should be offered when “getting more Help” is required. For example “Signposting for better behaviour or Triple P stepping stones “

<table>
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<tr>
<th>Evidence based model for the Common Assessment Framework : Signs of Wellbeing</th>
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<tbody>
<tr>
<td>Parent carers have feedback that perceptions of the common assessment framework being identical to a safeguarding assessment can be a barrier to seeking early help.</td>
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The signs of safety approach to child protection work uses a collaborative approach with families, based on building on strengths, and collaborative working. It has been extended to use in assessments for other areas such as working with parent carers and children and young people with disabilities. In Cheshire East the local authority moved to this model and use the name signs of wellbeing coproducing this with parent carers

When further interventions are needed: for young people and families getting more help

Positive behavioural support should be applied across all environments accessed by young person. CAMHS LD should include practitioners trained in PBS and carry out a full assessment as outlined in NICE CCG for Behaviour that challenges, including a functional assessment. There should also be network agreement on the resulting formulation with an agreed multi-agency plan that is followed in all environments.

My family and paid support and care staff get the help they need to support me to live in the community.

All families or carers who are providing care and support for people who display behaviour that challenges should be offered information about carer’s assessments and advocacy support in their own right, access to short breaks/respite suitable for people whose behaviour challenges and which meets their own needs, and support to care for the person from specialist multi-disciplinary health and social care teams

Any services or support to be provided for parent carers of disabled children can be included in a child’s EHC plan
GOOD PRACTICE: The Ealing Intensive therapeutic short breaks service

This service is based within the Ealing Services for Children with Additional Needs (ESCAN) - multi-agency organisation. Its aim is to enable young people with LD and challenging behaviour to remain within their family and community when there is an imminent risk of residential placement.

It provides - intensive clinical psychology and social care input to the young person, family and frontline workers, including additional/intensive short breaks or respite care as needed. It uses a positive behavioural support model and whole system network training to reduce these behaviours, whilst increasing the resilience of the family with social care packages.

The interventions are individualised and include:

- Intensive clinical psychology interventions
- Ongoing family support and psychological therapy for the young person and family
- Developing a positive behavioural support plan
- Training school, home, family, short break or respite setting and others eg transport and Pas, including developing problem solving strategies.
- Liaison and consultation with all staff and professionals involved.
- Ongoing monitoring and review

This has been named as a Good Practice Example (e.g. Winterbourne View Review, DoH (2012) and Lenehan Review (2017))

The service is a close collaboration between CAMHS and Social Care. When applied locally it should involve access to placements for short breaks or respite. Although the services can be all age, short breaks placements must be age appropriate.

Workforce

- Structure and staffing of Ealing ITSB
- Population of Ealing is over 300, 000
- ITBS – posts funded by Social Care in ESCAN and managed by CAMHS-LD
  - 1.0 wte Band 8a Clinical Psychologist
  - 1.0 wte Band 5 Assistant Psychologist
  - 1.0 wte Social worker from children with disabilities team.
- The team works closely with CAMHS LD, and other services within the multi-agency Ealing Service for children with additional needs, which included community health, therapies (including SALT, Occupational therapy, Physiotherapy), SEND team, educational psychology as required.

We recommend that local areas have a model based on the Ealing Intensive therapeutic short breaks service, linked to crisis services with access to a local respite unit. Due to the resourcing issues of creating multiple new services these could be expansions of existing services into all age services, as this could be provided by extending the expertise of existing services and would support consistency across the transition from children to adult services when the risk of placement breakdown and being moved away from their communities increases for our young people.
“Anyone who requires additional support to prevent or manage a crisis should have access to hands-on intensive 24/7 multi-disciplinary health and social care support at home, or in other appropriate community settings, including schools and short break/respite settings. This support should be delivered by members of highly-skilled and experienced multi-disciplinary/agency teams with specialist knowledge in managing behaviours that challenge. The interface between specialist routine multidisciplinary support services (described above) and this type of intensive support service should be seamless.”

Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition - Service model for commissioners of health and social care services: October 2015

5.2 Early warning system and seeking alternatives to in patient admission - DSD and CETRs

The THRIVE CAMHS LD pathway includes a key worker and use of the Dynamic support Database as an early warning system by mental health teams (initially) that the child or young person is at risk of admission to an inpatient or specialist unit. The resulting ratings are linked to protocols including use of the Community Education and Treatment Review.

Any child, young person who is at risk of admission, to a specialist learning disability or mental health inpatient setting due to the nature of their mental health needs, should first have had a planned Community Care, Education and Treatment Review (CETR). All relevant agencies in the local area must be invited to be part of this review (including education, health and social care).

If the outcome of a community CETR is that a referral to specialist NHS commissioning for access to a secure or Children and Young People Mental Health Service (CYPMHS) bed is the appropriate option, the CETR will also aid in establishing a foundation for the Access Assessment undertaken to determine the most appropriate placement for the person in terms of mental health need and level of relational security required.

Any learning or gaps in the care pathway identified from CETR’s should be routinely audited and feedback for training, and commissioning purposes. There should be consideration of this information being reviewed by a northwest multi-agency group feeding back into strategic commissioning decisions after Transforming Care agenda ends.

Key Findings from the Quality Review of CETRs in the North West

Cheshire & Mersey, Greater Manchester and Lancashire demonstrated that 100% of Preadmission CETRs that were recorded resulted in admission avoidance

Factors in admission included:

• Lack of family support
• Lack of Care-Co-ordination role/keyworker
• Family dynamics and complexity
• Absence of EHCP and school absence
• Previous IP CETRs not shared with CCG
• Paediatric Ward viewed as place of safety
• Child moved GP and school so no background information available
• Families presenting at A&E unable to cope

5.3 Specialist LD and autism beds in the North West region

From separate snap shot surveys taken of inpatient admissions in the northwest by NHS England and the ODN, it was noted that only a small proportion of young people in inpatient units had a discharge plan back to family, and that there was no use of CETR before the majority of admissions.

**NHSE figures for NWE:**

11 young people admitted (1st May to 3rd September 2018)

Average length of stay was 116 days

10 out of 11 did not have a CETR prior to admission

4 were discharged home to family

For 2 the pathway led to an adult inpatient unit.

**Snap shot figures April 2018**

22 young people from the NW TCP areas were inpatients.

Admissions tended to be prompted by crises, not planned and could be due to a lack of alternative provisions or management strategies. Transitions were noted as a factor, as well as a high level of autism.

The inpatient environment was seen as not conducive to autism, with a lack of specialist skills and links to local resources and supports for young people with autism and learning disability.

There was a lack of focus on prevention of admission.

It was also noted that there are no specialist beds for young people with LD or autism in this region.

Specialist Inpatient beds which specialise in learning disability and autism are required in the North West region as part of an overall pathway linked with community services. This is to improve the quality of care, outcomes and experience of children and young people when they do require admission. This should also enable young people not to be sent out of area.

They should have close links to local community services to enable better step down for return to community via outreach work, consultation to community services or work with the local Intensive therapeutic short breaks teams and bespoke local authority care packages to reduce delayed discharges and the average length of stay.

The right to remain close to family and community when admitted is also vital. Families are already under more financial pressure than others and affected more by travel costs.

"If I am admitted for assessment and treatment in a hospital setting because my health needs can’t be met in the community, it is high-quality and I don’t stay there longer than I need to.”

**For all inpatient provision (secure or not) children admitted to hospital should be placed in an environment suitable for their age and must have access to education.**
Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition - Service model for commissioners of health and social care services : October 2015

6. Principles of transition for children with Learning disability including those with autism to adult services.

Young people will be transitioning from the CAMHS LD pathway to the adult ASD pathways and adult learning disability services and mainstream adult services.

The following NICE guidelines and standards refer to transition from children’s to adult services.

- NG43 Transition from children’s to adult services.
- CCG 142 Autism in Adults.
- NG 54 Mental health problems in people with Learning Disability.

Also relevant are:

- The accessible Information standard. DCB1605
- The Mental Capacity Act 2005.
- The Children s and Family Act 2014.

Based on the above the following principles should apply:

6.1 Starting transition planning at year 9

Transition planning for all young people under 25 years should start at year 9, (age 13 and 14) or as soon as they enter children s services if after that. Planning should be carried out with health and social care practitioners and a reassessment of their needs carried out. Local autism teams should ensure this happens for those with ASD.

(Transition from children s to adult services NICE guidance, Quality standard transition to adult autism services 1.2.1, 1.8.1)

6.2 Carrying out a comprehensive reassessment

As part of the preparation for the transition to adult services, health and social care professionals should carry out a comprehensive assessment of a young person with autism.

The assessment should make best use of existing documentation about personal, educational, occupational, social and communication functioning, and should include assessment of any coexisting conditions, especially depression, anxiety, ADHD, obsessive-compulsive disorder (OCD) and global delay or intellectual disability in line with adults, (NICE clinical guideline Autism in Adults).

For young people aged 16 or older whose needs are complex or severe, use the care programme approach (CPA) in England, or care and treatment plans in Wales, as an aid to transfer between services. (Transition from children s to adult services NICE Quality standard 1.8.4, 1.8.5, 1.8.6)

6.3 Involve the young person and parent carers

For those young people with LD ensure communication is optimised, (NICE guideline: mental health treatment in children with LD, accessible information standard, mental capacity act)

Assess the person's capacity to make decisions throughout assessment, care and treatment for the mental health problem on a decision-by-decision basis, in accordance with the Mental Capacity Act and
supporting codes of practice and (if appropriate) involving a family member, carer or other individual familiar with the person's communication abilities.

If continuing treatment is necessary, arrange for a smooth transition to adult services and give information to the young person about the treatment and services they may need.

Involve the young person in the planning and, where appropriate, their parents or carers.

Provide information about adult services to the young person, and their parents or carers, including their right to a social care assessment at age 18.

Autism quality standard: 1.8.7, 1.8.2, 1.8.8

Local authorities must have regards for the views of young people and parent carers in decision making and enable them to participate fully in this process with access to information and support to facilitate decision making (Children's and family Act 2014)

6.4 Having a dedicated key worker for the transition process

Area should have designated staff who are responsible for coordinating:

- transition between services within and across different care pathways

Young people who are moving from children to adults' services have a named worker to coordinate care and support before, during and after transfer.

(NICE guidance on MH problems in people with LD, quality standard 3 transition from children to adult services)

6.5 Annual reviews during the period of transition planning

Young people who will move from children to adults' services have a meeting to review transition planning at least annually. (Children’s transition) This is because of the length of time transition can take, the need for early planning and to review changing needs during this process.

6.6 Using the EHCP as the transition planning document if the young person needs one.

The Education Health and social care plan is meant to bring together the health education and social care plans for children and young people in order to achieve the best possible outcomes in their education, health and social care, and to prepare them for adulthood. (CAF 2014)

6.7 Introduction to adult services (with the support of a transition worker), optimising the opportunity to engage

Young people who will move from children to adults' services meet a practitioner from each adults' service they will move to before they transfer. Young people who have moved from children to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.

This is important because young people need to engage with adults' services so that they continue to receive the care and support they need. When young people disengage from services during transition
it can affect their future health, mental health and social care needs. The risk of this is increased for young people with autism due to their increased difficulties with transition.

6.8 Transition to be completed by 25 for all young people with LD, and by 18 for those with ASD and no LD.

For those young people with learning disability, the children and families act 2014, EHCP and the SEND agenda will apply up to 25 years. NICE guidance of transition from children’s social and health services to adult services.

Transition however also needs to be person centred and needs led rather than purely age led.

GOOD PRACTICE: Cheshire East Ignition Panel

Cheshire East Local Authority are currently adapting the award winning Ignition panel for care leavers to CYP with SEND.

Ignition panel is a multi-agency panel that develops a person centred package to offer individual CYP between 16 to 19 years.

- Group includes the young person, carers, children and adults social care and LA commissioning Transition Co-ordinator, Supported Employment, Continuing Care, DCO, CCG Commissioners, FE and Special School, DWP, Community Services, Parent carer Forum
- Children and parents attending Ignition feel in control, listened to and gain a better understanding of the offer.
- Could potentially be used to develop bespoke service, and to help young person and family consider options they had not thought of before.

Everyone should have access to education, training and employment (including supported internships) which they can access within their local area. To enable this, support providers and specialist multi-disciplinary health and social care teams (see principle 7) should provide training to mainstream service staff and/or provide support to individuals and their families/carers that enables them to participate in mainstream services and to access education and training within local schools and colleges. Commissioners should also seek to ensure that supported employment/training services meet the needs of this group.

Under the Children and Families Act, preparation for entry into adulthood (including employment), should be considered early and form part of transition planning.

Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition - Service model for commissioners of health and social care services : October 2015

Implications for the CAMHS LD ODN model

The neurodevelopmental pathway for CAMHS LD, that sits within THRIVE framework (including CAMHS/Health/education) –would see children with and without learning disability. This is based on various models: as it has been found that additional developmental issues such as GDD can be found when children are referred from mainstream education, it also resolves the issue of duplication of
resources. It means that professionals from both community health and mental health as well as local authority should be in the wider neurodevelopmental assessment team.

Neurodevelopmental pathways should include pre and post assessment support for children and young people referred for ASD assessment with and without learning disability. This support would be offered via the multi-agency network of services in the CAMHS LD or mainstream THRIVE pathway depending on our children’s needs.

**Transition to adult services for young people with Learning Disability and / or Autism.**

The ODN model principles describe a 0-25 years mental health services to align with the SEND agenda. We would recommend that initially Children with Learning Disability or Autism could complete transition into adult LD services at 18, but this should involve a transition worker who would be the link between children’s services and adult services to enable young person and family to access all age appropriate support up to the age of 25 years if needed.

**Transition for young people accessing the Autism pathway**

For young people receiving a diagnosis of autism an immediate planning should start for transition to adult services and long term needs if the young person is in year 9 or older. Planning for all other transitions must also start or be considered e.g. for Primary aged children receiving a diagnosis transition to secondary school planning must start early.

**Transition for young people in crisis**

We have recommended that local areas have a model based on the Ealing Intensive therapeutic short breaks service, linked to crisis services with access to a local respite unit. These could be all age services as this could be provided by extending the expertise of existing services, and would support consistency across the transition from children’s to adult services when the risk of placement breakdown and being moved away from their communities increases for our young people.

**Transition back to community services**

Transition planning from specialist in patient units should begin as early as possible and involve local authority and health. Legal frameworks include Section 117 of the mental health Act which places a statutory duty on both health and social care to provide support after discharge when certain sections of the mental health act have been used.

7. **Commissioning**

- Coordinated commissioning between Health and Local authorities is required.
- Multi-agency panels or services will be required e.g. for SPA and the autism pathway.
- Service specifications, and service level agreements about dedicated service time and job plans should support these multi-agency panels and pathways
- Agreed referral criteria and trusted assessment agreements so that children and young people do not fall between services.
- Invest to save: The cost of one residential placement for 52 weeks can be up to £500,000

Collaboration with London School of Economics to complete an economic evaluation indicated that even when you account for additional costs of children remaining locally, Ealing ITSBS is significantly cheaper than placing children in residential schools (Lemmi et al, 2016).
8. Levels of Resource across the THRIVE groupings

THRIVE Elaborated (2nd edition Wolpert et al 2016) describes the resource provision for each grouping. However, this is based on a mainstream population. Children and young people with LD or autism are at higher risk of suffering from a mental health problem.

The Multi agency provision recommended also fits into the proposals from the Green paper for transforming children and young people’s mental health provision.

The prevalence rate of a diagnosable psychiatric disorder is 36% in children and adolescents with learning disabilities, compared with 8% of those who did not have a learning disability. Young people with Learning Disability have also been found to be 33 times more likely to be on the autistic spectrum and were much more likely than others to have emotional and conduct disorders.

In 9- and 10-year olds there is a 1.16% prevalence of autism with 55% also having a significant intellectual disability

Only 16 to 50% of those identified with autism spectrum disorder in childhood become fully independent.

There are high rates of mental health comorbidity in ASD -increased rates of mood and anxiety disorders (GAD, OCD, social phobia, etc) schizophreniform psychosis, and catatonia

8.1 Thriving

For the CAMHS LD model, training at this level will be one of the most important interventions in creating an environment that supports the ongoing wellbeing of children and young people. Training of parent carers should also be offered. Digital resources should be used to maximise the use of training resource. Experienced Parent carers could also be empowered to support other parent carers by training or forming support groups. It is estimated 15% of mental health resource is used here.

8.2 Getting advice

Interventions should be more procedurally defined and could be delivered by specialist technicians in specific treatments. There should be a focus on end points if treatments are no longer beneficial. Health language (a language of treatment and health outcomes) would be used. Thrive elaborated estimated 8% of mental health resource is used here. The THRIVE model of provision would suggest that wherever possible, this provision should be provided within education or community settings, with education often (though not always) the lead provider and educational language (a language of wellness) as the key language used. This would also fit into the Green paper for transforming children and young people’s mental health provision. It is our contention that health input in this group should involve some of our most experienced workforce, to provide experienced decision making about how best to help people in this group and to help determine whose needs can be met by this approach. For children and young people with learning disability and autism, education, the SEND agenda local authority services and the third sector may be equally involved alongside the local CAMHS LD service.

8.3 Getting Help
More clearly targeted work with some young people getting more intervention and others getting less. More procedurally defined interventions can be provided. This might include behavioural interventions by CAMHS LD, or enabling self help by further training using evidence based parenting groups. Again interventions should be coordinated and multi-agency involving local authority, (social care and education) and health. Thrive elaborated estimated 56% of mental health resource is used here.

8.4 Getting more help

It is suggested that for some young people and families more extensive treatment is likely to be required and that these young people are likely to have most impairing difficulties. As well as the CAMHS LD team, the autism assessment team would provide specialist assessments in this grouping although pre-assessment and post diagnostic support would be multi-agency and could be provided at the Thriving or getting advice stage. Thrive elaborated estimated 14% of mental health resource is used here.

8.5 Getting risk support

For this group, there needs to be close interagency collaboration (using approaches such as those recommended by AMBIT (Bevington, Fuggle, Fonagy, Target, & Asen, 2013) So that common language and approaches are used between agencies) and there should be clarity as to who is leading. Social care may often be the lead agency and the language of social care (risk and support) is likely to be dominant.

The Intensive therapeutic short breaks team, respite units for local areas, and specialist inpatient beds at regional level would be some of the provisions accessed by this group.

“Thrive elaborated” estimated 7% of mental health resource is used here. 5% of children and young people seen by mental health services will require input for risk support.

9. Local implementation of the service model

Because of the overlap in therapeutic skills of the recommended disciplines in CAMHS LD/Challenging behaviour/Neurodevelopmental pathways, and because of the wide range of existing service configurations local mapping and gap analyses must occur to implement this service model at local areas.

This work will include analysis of existing workforce skills in the multi-agency network, current waiting lists for the pathways.

Local parent carers and young people must be included in coproducing services from the beginning, including seeking their views on local gaps, priorities and desired outcomes.

Local redesigns must be person centred and outcome centred.

10. Overall Recommendations

Using the Thrive model for CAMHS LD including:

- The importance of Training of staff universal services in working with children and young people with Learning disability and Autism.
- Parents Carers and Young people to be able to access training to promote wellbeing and health and prevention.
• CAMHS LD to be sited with mainstream CAMHS but with strong multi-agency links
• Allocated Key worker using the DSD as an early warning system
• Autism pathway with pre and post assessment support
• Schools consultation model
• Specialist LD /ASD inpatient unit in NW
• Transition into adult services be supported by a transition worker, with all age ITSB and Crisis service supporting young people across the age range into adulthood
• Intensive short breaks model to be piloted
• Specially commissioned respite beds to be linked to ITSB and crisis service.
• Roll out of the Dynamic Support Database
• Model linked to rolling out good practice via an IT platform and a rolling programme of good practice events in NW England.

11. Guidelines / References

1. Valuing people and Valuing people now
3. Green paper for transforming children’s and young people’s mental health provision. Dec 2018
4. NICE guidance and quality standards –
   a. NG43 Transition from children’s to adult services.
   b. CCG 142 Autism in Adults.
   c. NG 54 Mental health problems in people with Learning Disability.
   d. NG 11 Challenging behaviour and learning disabilities
5. The Lenehan report 2017 these are our children.
6. STOMP-LD: Stopping the overuse of medication in people with learning disabilities.
8. Transforming care: the DOH response to winterbourne.
10. Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition - Service model for commissioners of health and social care services: October 2015
11. Supplement : Developing support and services for children and young people with a learning disability and autism or both (October 2015)
12. Green Light Toolkit, NDTi, Revised April 2017
13. Bevington, D; Fuggle, P; Fonagy, P; Target, M; Asen, E; (2013) Innovations in Practice: Adolescent Mentalization-Based Integrative Therapy (AMBIT) – a new integrated approach to working with the most hard to reach adolescents with severe complex mental health needs. Child and Adolescent Mental Health, 18 (1) 46 - 51. 10.1111/j.1475-3588.2012.00666.x.

17. Proposals for future work and developments

1. The next work should look at the creation of a THRIVE CAMHS LD /autism audit tool for the NW England
2. The next Task and Finish group:
   a. To consider outcomes framework
      i. the Sussex behaviour checklist
      ii. Sheffield LD outcome
      iii. Developmental Behaviour Checklist
      iv. Goal based outcomes
      v. Quality of life and rights-based outcome measures.
      vi. Multi-agency measures
   b. To review the proposed Audit Tool
3. Further work on transitions across the 0 to 25 year is needed as well as a Future Good Practice event. This could include both all age autism and children and young peoples workstreams.
4. Work on access to mainstream and specialist forensic services.
5. In the longer term can we extend the use of the dynamic support database to include the wider multi-agency network such as social care?
6. A future good practice event looking at multi-agency good practice and the AMBIT model.
7. A longer-term goal for the North West would be joint Neurodevelopmental pathways for ADHD/ASD this is due to the significant overlap in populations both for ASD ADHD and shared neurodevelopmental comorbidities. Young people with LD have also been found to be 33 times more likely to be on the autistic spectrum. 30% of children and young people on the autism spectrum also have ADHD. It is well recognised that neurodevelopmental disorders frequently co-exist. In St Helens, the pathway had to expand to consider other neurodevelopmental conditions for assessment to autism, such as ADHD, language disorders, attachment and Learning disability because of the frequency of comorbidity and because they were common differential diagnoses. This has led to a decrease in autism diagnoses given, and more accurate diagnosing. Such conditions may also need to be assessed at the same time, so that a clear diagnostic formulation can be reached. This would also avoid families having to go through multiple waiting lists for assessments before an overall conclusion can be reached.

18. Questions for ODN

Should transition workers come from health or social care? Should this be based on needs led and person centred considerations for each individual.