North East and Cumbria

Transforming Care
Community Model for people with Learning Disabilities and/or Autism
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1. Executive Summary

In April 2015 The Transforming Care national team announced a programme of transformation in the delivery of Learning Disability and Autism services.

This model included significant reductions in learning disability inpatient beds and a greater focus on the provision of early intervention and crisis preventative community services.

The collective vision and ambition to deliver an integrated co-produced set of principles and standards was fundamental to delivering care and support closer to home, avoidance of unnecessary hospital admissions and the prevention of missed opportunities for people with a Learning Disability and/or Autism to have happy and productive lives within the community of their choice.

A new National Service Model (NSM) for people with Learning Disabilities and/or Autism has been developed to support the Transforming Care vision. It is recognised that to support the delivery of the new NSM a greatly enhanced community infrastructure is needed, together with a whole process for organisational development and culture change - not just within professional groups and organisations, but within the community itself.

The North East and Cumbria Transformation Board and partner agencies have developed a model to describe the principles and pathways necessary to deliver the best opportunities for people with Learning Disabilities and/or Autism.

This document outlines the framework for Local Implementation Groups to design new care models that will deliver the vision and collective ambition. A key principle underpinning the design and implementation of these new care models is that services are affordable within the available resources of Clinical Commissioning Groups, NHS England Specialised Services Commissioning and Local Authorities, and that services are efficient and financially sustainable.

During a transitional phase before new care models are fully embedded in the community, it is acknowledged that costs are likely to be higher, and local organisations will need work in partnership to identify additional financial resources for a limited period to fund the transformational change required. Supporting this change, further funding may be available from national transformation budgets, and Local Implementation Groups will be required to assist in producing a compelling case and demonstrate good progress in programme delivery to maximise the potential success of any bids.

This model seeks to describe the functions, intentions, outcomes and expectations of the care, support and interventions that are required to deliver the collective ambition of individuals their families and carers and those agencies that support them. The model integrates health and social care in a single model approach and seeks to ensure that a stepped care approach includes both health and social care service provision.

This document is intended as a framework to be used by Local Implementation Groups (LIGs). It is not prescriptive and should be adapted to meet local variations. How the model is delivered and commissioned will need to be agreed and determined locally, building on current good practice.

The model should be read in conjunction with the National Service Model, NICE Guidance and additional national guidance/commissioning specifications and should be used to inform local commissioning intentions.
The model encourages greater use of the voluntary sector and social care providers and where possible the use of direct payments to encourage individual choice and control.

The national model will provide an opportunity to further develop the North East and Cumbria’s regional model and the local outcomes form the LIGs will tell us if we are succeeding in making a difference.

Finally, acknowledgment must be made of the hard work and commitment from all of the partners within the North East and Cumbria Transformation Board.

Their vision, determination and commitment to deliver and provide new opportunities and outcomes for people with Learning Disabilities and or Autism has been a pleasure to lead and watch grow over the past 18 months.

1.1 The Collective Ambition

The ambition is for the North East and Cumbria to be as good as anywhere in the world to live for people with a learning disability and / or autism and a mental illness or behaviour that challenges.

1.2 The Vision

This vision was developed by all stakeholders, including people with a learning disability and/or autism, before Winterbourne View, the Bubb report or Fast Track transformation programmes. However from Building the Right Support and the National Plan October 2015, a task and finish group has developed the model further.

1.3 Overview

This document seeks to describe the functions, intentions and outcomes/expectations of the care, support and interventions that are required to deliver the collective ambition.

This document is not prescriptive and how the model is delivered and commissioned will need to be agreed and determined locally, building on current good practice. The model should be read in conjunction with the National Service Model, NICE Guidance and additional national guidance.

1.4 Building on Core Principles

The principles which underpin the national service model build on what has been described before, including in *Valuing People (2001)* and *Valuing People Now (2010)*, all of which focus on rights, independence, choice and inclusion for people with learning disability and/or autism.

The North East and Cumbria Community Model incorporates the nine principles outlined above and draws upon the Emotional Health and Wellbeing Strategies of Children and Young People, Crisis Care Concordats, Futures in Mind, the National Autism plan, and the wider National and Cumbria and the North East’s Transforming Care Programme.

Individuals and their families should be at the heart of a system designed *with* not *for* people, with co-production in delivery as well as design.

Throughout this model, parity of esteem is considered the norm and the expectation is that wherever possible the person will receive services based on need not diagnosis.
Appropriate training and development opportunities for staff at all levels of health and care organisations, for the voluntary and community sector, and for families and carers themselves, together with positive culture change, is integral to delivery of the model.

For people with learning disabilities and/or autism in Cumbria and the North East this means protecting their right to access primary, acute, mental health and social care services wherever possible through reasonable adjustments, appropriate advocacy and joint support from specialist learning disability and/or autism teams across the lifespan.

Within localities, consideration needs to be given to ensure a lifespan approach to meeting needs within and between teams. Longer term, consideration could be given to the application of a lifespan model.

The model particularly reflects the needs of the 5 cohorts described in the national service model:

**Cohort 1**: Children, young people or adults with a learning disability and/or autism who have a mental health condition such as severe anxiety, depression, or a psychotic illness, and those with personality disorders, which may result in them displaying behaviour that challenges.

**Cohort 2**: Children, young people or adults with an (often severe) learning disability and/or autism who display self-injurious or aggressive behaviour, not related to severe mental ill health, some of whom will have a specific neuro-developmental syndrome and where there may be an increased likelihood of developing behaviour that challenges.

**Cohort 3**: Children, young people or adults with a learning disability and/or autism who display risky behaviours which may put themselves or others at risk and which could lead to contact with the criminal justice system (this could include things like fire-setting, abusive or aggressive or sexually inappropriate behaviour).
Cohort 4:- Children, young people or adults with a learning disability and/or autism, often with lower level support needs and who may not traditionally be known to health and social care services, from disadvantaged backgrounds (e.g. social disadvantage, substance abuse, troubled family backgrounds) who display behaviour that challenges, including behaviours which may lead to contact with the criminal justice system.

Cohort 5:- Adults with a learning disability and/or autism who have a mental health condition or display behaviour that challenges who have been in hospital settings for a very long period of time, having not been discharged when NHS campuses or long-stay hospitals were closed.

1.5 North East and Cumbria Service Model

The model adheres to the North East and Cumbria principles identified at the start of this work and aims to:

- Enhance community care and support and alternatives to inpatient admission.
- Ensure people have better and more fulfilled lives.
- Ensure advocacy, care and support is planned, proactive and co-ordinated.
- Ensure individual choice and control over how health and social care needs are met.
- Ensure prevention, early identification and early intervention.
- Avoid crisis and better management of crisis when it happens.
- Ensure effective care and support from mainstream services.
- Improve access to specialist health and social care support in the community.
- Have less reliance on in-patient admissions, delivering a 50% reduction in admissions to inpatient autism/learning disability service by 2020.

2. The North East and Cumbria Community Model

This model aims to provide the foundation on which to build and enhance the locality models and service specifications.

The model of care and support focuses on 7 key strands:

- Choice and control at the heart of ALL service provision and planning.
- Systematic, early identification and intervention.
- Planned, proactive and coordinated care and support in the community.
- Effective prevention and management of crisis.
- Helping people who need it to stay out of trouble and supporting people who enter the Criminal Justice System.
- A consistently highly skilled, confident and value driven workforce.
- Equitable service provision and high quality evidence based care and support.

This model has been developed by listening to what matters to people with learning disabilities and/or autism and their families. The levels of organisational change and cultural development needed to meet the outcomes described in the model will be dependent on what is working well, or not so well in the locality. This will need to be co-produced and tested with local people and carers in each locality through the Local Implementation Groups (LIG’s).

Local implementation should focus on building individual capacity and reablement. Commissioning should consider the establishment of local community support, inclusion of key services, for example provision of advocacy, considering the role of the voluntary and community sector (VCS) and managing expectations for families with children’s services, recognising that community services are difficult to navigate for people with learning disabilities and/or autism and their families and often fall short of their expectations. Workforce development programmes should include paid and unpaid carers (and others) who do not work within the NHS or Local Authorities.

The model will expect localities to:

- Ensure easy access to services and support.
- Develop roles such as social and health care navigators.
- Use co-production to lead, shape and deliver services and support.
- Develop and support meaningful outcome measures to promote inclusion and independence.

The model describes what is required to develop an empowering community infrastructure and change the culture from dependence and treatment to support and independence, developing the workforce and service and support providers, ensuring resilient and responsive services, to support pathways of care. This needs to be considered across the lifespan, including all transitions; recognising the changing needs for family support as people get older.

The model describes service design expectations and outcomes to meet the complexity of needs of the cohorts as described in Building the Right Support, whilst also recognising the needs of the wider population. In doing so the model describes and emphasises early intervention with a proactive, preventative approach to support.

The model describes how to support people with learning disabilities and/or autism, ensuring that, everyone has a chance to live as a valuable member of their community; as close as possible to the important people in their lives and supported by those who understand and care for them.

Early identification and intervention is critical to ensure successful outcomes for people and families. However, some people may need a lifespan approach to support them through differing life stages, through to later life strategies.

NICE guidelines and recent policy both propose an investment in supporting families of children and adults who present with behaviour that challenges. It is therefore important as a region that we set out a clear strategy that ensures widespread delivery of high quality parent training and
support across a wide range of services and localities. The emphasis will need to be on ensuring all services are based on Positive Behavioural Support (PBS) and values based.

The model supports the development of a PBS pathway with all providers which requires wider PBS skills development initiatives to build on current PBS programmes. It also supports wider workforce development in Leadership, Mindfulness and Therapeutic programmes.

This includes developing skills for the social care workforce, including unpaid carers and those employed through direct payments in order to pick up the key role they have to play in supporting complex people and preventing people from requiring specialist services.

The model will provide people with learning disabilities and/or autism the opportunity to challenge commissioners, service providers and professionals.

The model will help localities reduce the reliance on hospital provision in line with the national programme of systematic closure of learning disability inpatient hospital beds.

To achieve the model commissioners and services will work together with individuals, advocates and families, with an aim to provide:

- Integration/Co-location of health and social care services.
- Collaborative working within localities.
- Collaborative work across the localities and the region where the demand for particular services may be low, in order to achieve more cost effective, efficient and better quality of care and support.

2.1.1 The Collaborative Approach

Within the foundations of the model is the need for a collaborative approach with individuals, families, and partners across health, social care and the third sector to significantly strengthen support in the community for individuals and their families.

To achieve this everyone has a part to play in supporting people with learning disabilities and or autism, for all ages:

- Health, Social Care and Education.
- Housing – consider prioritisation of allocation and link with local planning departments.
- Occupation, training & employment – Employment Pledge.
- Social care providers.
- Leisure and community resources.
- Self-advocacy, access to advocacy.
- Keeping safe and working with agencies in the Criminal Justice System (CJS).

There is a commitment from all stakeholders to think differently in delivering this large scale transformational change. In introducing the model, the localities will need to ensure a collaborative approach, at all levels, across all service boundaries, with a collaborative vision of achieving shared outcomes.
These outcomes will be measured in relation to quality of life and quality of care and support and will require changes and developments in service provision and culture.

The model has clear outcomes required for commissioning:

a) Pooled budgets – health and social care;
b) Clear expectations for community services;
c) Processes for co-design/production and listening to local people; providing opportunities for people and advocates to challenge providers and commissioners;
d) Good monitoring of services: regular monitoring (involving people with lived experience and/or their families, including Quality Checkers);
e) Development of new models of service and support delivery including voluntary sector;
f) Information sharing processes to aid collaborative approaches:
   • Information sharing agreements,
   • Processes for raising areas of concerns and good practice,
   • Dynamic Support Register information;
g) Outcome focused commissioning rather than by hours or contacts with key deliverables/outcomes: Development of service specifications to hold to account service providers against quality of care and life indicators.

The collaborative approach will assume a commitment to robust evaluation and involvement in developing an evidence base to inform future commissioning cycles.

2.1.2 Advocacy

Central to the successful delivery of the transforming care model is the inclusion of those individuals it is aiming to support. People need help to have a voice, understand their rights and help to feel empowered.

Advocacy has a pivotal role to play at numerus points along a person’s lifespan. It is important that this is recognised and enshrined in care and support.

Advocacy provides people with an independent ally; someone who is solely on their side, independent of national policy, local practice or organisational factors.

The role of the advocate aims to ensure that the person is at the centre of planning and implementing improved care.

Access to advocacy is a legal right as laid out in the following legislation:

- Mental Health Act 2007
- Mental Capacity Act 2005
- Care Act 2014; and
- Health and Social Care Act 2012.

Professionals have a statutory duty to refer a person for advocacy support to recognised advocacy providers.

Advocacy is needed to ensure that a person has independent support to understand what is happening to them and why, to understand the system and to understand what their rights are.
Advocates can help a person to understand their options and choices and the consequences both positive and negative of any particular one.

Many of the people the Transforming Care model is aiming to support have had to overcome numerous challenges and find meetings and expressing themselves difficult. Advocates can support family members and carers, helping them to understand processes and systems and supporting them to speak up for themselves and for the person they care for.

Many people have had to move away from their home to get the kind of support that they need. Being away from a person’s community can make that person even more vulnerable, often disconnected from their families and communities. Advocacy should, where possible, be local, which helps a person to stay connected to home.

When advocates have been able to build up a good relationship with a person over a period of time they can help the system to retain a memory of the journey that a person has been on, a person’s life history and their experiences which lead them to be who they are today.

**The Advocacy Charter** The full Advocacy Charter can be found [HERE>](#)

The Advocacy Charter was published in July 2002 by Action for Advocacy. The Advocacy Charter principles and the Code of Practice were revised in 2014, by Empowerment Matters CIC and the National Development Team for Inclusion (NDTi), to reflect changes in legislation as well as developments in advocacy practice. The charter sets out the key principles of advocacy:

- Clarity of Purpose
- Independence
- Persons centred approach
- Empowerment
- Equal opportunities
- Accessibility
- Supporting advocates
- Accountability
- Confidentiality
- Complaints and
- Safeguarding.

Involving advocacy at the right time can have highly positive consequences; advocacy providers will be able to support professionals to understand what benefit advocacy can bring to an individual in addition to the professional duty to refer a person for advocacy.

Statutory advocacy can work better with Self Advocacy to deliver a more rounded package of advocacy support; not only helping the person when there is a crisis, change or issues but supporting a person to develop speaking up and self-advocacy skills. Advocacy services help people – particularly those who are most vulnerable in society to:

- Access information and services
- Be involved in decisions about their lives
- Explore choices and options
- Defend and promote their rights and responsibilities
- Speak out about issues that matter to them
There are different types of advocacy:

- Professional Statutory Advocacy
- Care Act Advocacy
- Independent Mental Capacity Advocacy
- NHS Complaints Advocacy
- Mental Health Act Advocacy
- General Advocacy: Where an advocate is helping a person to have a voice but now working under statutory legislation
- Peer Advocacy: Where the advocate and the advocacy partner share similar experiences
- Self-Advocacy: People coming together to speak up for themselves
- Citizen Advocacy: Volunteers developing long term relationships with people and speaking up for them
- Specialised Advocacy: Where the advocate has very specialised knowledge about a particular condition/field
- Non-instructed advocacy: where the advocacy partner is unable to instruct the advocate and therefore the advocate acts in their best interest
- Natural Advocacy: where friends and family members play a part in advocating for an individual

2.2 The range of services in the models

The model describes a range of components and pathways which will support people's individual needs. Individual service specifications for these services will need to be further developed. Community planning should be based upon meeting the requirements of the model and housing and support options should take account of the Market Position Statement (MPS) for the North East and Cumbria (Appendix 5).

2.2.1 The community services are based on meeting the needs of the population of people with learning disabilities and/or autism, with a focused collaborative approach to meet the needs and complexity of the cohorts described in Building the Right Support and the regional MPS.

This will include social care and health provision and short term inpatient treatment and assessment. To make the Community service part of the model easier to understand and where further detail has been requested it has been broken down into:

a) Community social care;
b) Social care complex need;
c) Health provision;
d) Transition into adulthood;
e) Discharge support for people.

Education provision is documented and described within the Special Educational Needs and Disability guidance and the local offer.

Individual Service Design should be the default position when looking to identify support for an individual. Individual Service Design is a way of developing support around an individual and their needs and desires rather than trying to fit people into pre-existing services and support. The voluntary, community and social enterprise sector can aid this (see appendix 6).
The essence of individual service design is in understanding what matters to and for an individual and then designing the support accordingly.

An effective training programme needs to be in place that will support service providers and commissioners as well as individuals and their family carers to effectively bespoke design the support an individual needs, this will include accommodation and staff matching.

Consideration should be given to opportunities where health action plans may be enriched by looking at alternative ways to improve health and wellbeing, mental health, physical health and complimentary support to assist with promoting positive behaviour. This may be in other sectors such as; culture, arts, sports and leisure.

Individual Service Design is not about finding a perfectly fitting set of services – it’s about designing support that is right for the person. A key element of Individual Service Design is to ensure that individual outcomes are identified.

There are a number of key elements that are a measure of successful support. These are:

- **Community Presence** - Increase a person’s “presence” in local community life.
- **Community Participation** - Expand and deepen their relationships.
- **Encouraging Valued Social Roles** - Enhance a person’s reputation and increase the number of valued ways they can contribute.
- **Promote Choice** - People have more control and choice in life.
- **Supporting Contribution** - People play a personal role in their local community.

2.2.2 **The specialised commissioned services** (Offender health) required to meet the needs of people who have been within the criminal justice system.

This includes hospital and community provision.

To describe what is required this has been broken down into:

- a) Hospital provision.
- b) Community provision – with a focus on risk prevention and prevention of reoffending.

2.2.3 **The Autism specific pathways**, which will be delivered to meet the individual needs of people with Autism following diagnosis, supporting access to mainstream and universal services.

It is essential that there are smooth and effective interfaces/transitions between services to ensure good planning for the individual and their family.

Protocols developed within service provision and localities should be followed and adhered to by professionals. Protocols should be based upon shared objectives and will need to be robust, flexible and inclusive. Services should have a “can do, hands on” approach, working in multiagency collaboration where appropriate.
2.3 Autism Pathway

A life course approach should be taken to supporting people with Autism. Staff working with people with autism should:

- work in partnership with children/adults with autism and, where appropriate, with their advocates, families, partners or carers;
- be competent to deal with the autism issues and actively work with people with autism;
- offer support and care respectfully;
- take time to build a trusting, supportive, empathic and non-judgemental relationship as an essential part of care.

Parity of esteem is considered the norm and the expectation is that wherever possible the person will receive support based on need and not diagnosis wherever possible through reasonable adjustments and joint support from specialist teams. However there will be some children/adults who will require access to specific autism expertise.

In order to effectively provide care and support for people with autism, local autism multi-agency strategy groups should include representation from managers, commissioners and clinicians from children/adult services, including mental health, learning disability, primary healthcare, social care, housing, education and employment services, the criminal justice system and the third sector.

NICE standard 51 states that teams conducting assessments for children, young people or adults should be a specialist integrated autism team with age-appropriate expertise, and should be part of the local autism diagnostic pathway. In each area a specialist community-based multidisciplinary team for adults with autism (the specialist autism team) should be established.

Membership should include clinical psychologists, nurses, occupational therapists, psychiatrists, social workers, speech and language therapists, support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills). There should be meaningful representation from people with autism and their advocates, families, partners and carers.

Specialist autism teams should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services;
- specialist care and interventions;
- advice and training for other health and social care professionals on the diagnosis, assessment, care and interventions for adults with autism (as not all may be in the care of a specialist team);
- support in accessing and maintaining contact with housing, educational and employment services support to families, partners and carers where appropriate;
- care and support interventions for adults with autism living in specialist residential accommodation; and
- training, support and consultation for staff who care for adults with autism in residential and community settings.
The model would indicate for people with autism without a learning disability or with a mild learning disability:

- Access to all mainstream health services, including primary mental health services and psychological therapies
- Support in education
- Support to gain employment for those who are having difficulty obtaining or maintaining employment, for example: consider an individual supported employment programme.
- Access to a diagnosis
- Access to Autism specialists
- Access to voluntary and community sector services for follow-up post-diagnosis

2.3.1 Organisation and delivery of care and support

Autism strategy groups are responsible for developing, managing and evaluating local care pathways. The group should have a lead professional responsible for the local autism care pathway. The model would expect for localities to engage with these groups.

The aims of the strategy group should include:

- Developing clear policy and protocols for the operation of the pathway.
- Ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway.
- Making sure the relevant professionals (health, social care, housing, education and employment services and the third sector) are aware of the local autism pathway and how to access services.
- Supporting the integrated delivery of services across all care settings.
- Supporting the smooth transition to adult services for young people going through the pathway.
- Auditing and reviewing the performance of the pathway.

2.4 Working with young people and children with learning disabilities and/or autism:

The model recognises the need to ensure the wellbeing of all children with a learning disability and/or autism, along with the complexity of need in the identified cohorts. Commissioners may need to consider age ranges up to 25 years.

The aim will be to:

- Ensure access to mainstream services with reasonable adjustments.
- Identify and provide intervention as early as possible.
• Support mainstream services to meet their needs, reducing health inequalities and access to annual health checks.

• Support children, young people and families to reach their full potential.

• Reduce out of area placements – inpatient and residential.

• Provide specialist care and support near their home or in school when needed.

• Provide co-ordinated care and support across education, social care and health systems (Education health care plans).

• Ensure PBS approach across health, education and social care.

• Support people to stay out of trouble and ensure longer-term planning is in place where appropriate.

• Provide access to advocacy.

Parents and carers will:

• Receive early help and support when they need it.

• Have easy access to primary health care services like GPs and hospitals.

• Get support and training to manage behaviours that challenge – eg. Positive Behavioural Support.

• Have access to a personal budget.

• Receive consistent care and support in stopping things becoming a crisis.

• Experience a smooth move/transition from children’s to adult services.

Interventions for this group can take longer to complete than typically developing children and fall outside of current models of delivery being adopted in some Children and Young People’s services. Local scoping is required to ensure access for all parents of a young child with learning disabilities to have access to routinely offered parenting interventions across the region and linking with other partner agencies who provide these interventions.

Access to parenting approaches using the principles of PBS should be available locally to all parents, e.g. Triple P, Webster Stratton, and Incredible Years. A number of professionals are already trained in a range of these interventions across areas; to ensure consistency and to embed the change this will need to be developed more widely to ensure application across health, social care and education.

2.4.1 Transition to Adult Services

Some young people with learning disability and/or autism will be “coping” (THRIVE, 2014) within the structures of support available to them as a child, but will experience more challenges and difficulties post-18. This means that some young people present to adult services with their needs not having been identified as a child. Throughput models where children are discharged
from services mean the necessary scaffolding can cease and also difficulties not picked up at an early enough stage necessitating increased levels of intervention at a later age. Transitions should be considered a 0-25 process with people’s profiles reviewed on an ongoing basis.

Effective and timely information sharing processes between partners and agencies will ensure parents and carers know what to expect and it will assist with the transition period and planning.

There should be transparency about funding and early identification of need not necessarily condition or diagnosis. Services should consider pooling resources, be proactive not reactive and include self-management preparation support.

Education service involvement is critical in the process. For example, for school leavers where it is clear that some Local Authorities do not know the people in that cohort and many do not have plans in place for them.

Consideration should also be given to EHCPs, including mapping and referral to make sure people are identified earlier than the actual transition process.

2.4.2 Development of Positive Behavioural Support (PBS) pathways - Children/schools

The model supports the development of a PBS pathway with care providers for a more robust offer to schools with wider PBS skills development initiatives. These should also include skills development for workforce in specific parenting interventions adapted for parents of children with a learning disability. Skills development plans should involve both PBS assessment and intervention skills alongside inclusion of delivering evidence based parent packages when more intensive intervention based around functional understanding of behaviour needed. There is an additional need to develop evidence base/research proposals with pilot projects across the region to define and evaluate outcomes.

Early identification and intervention is critical to achieving successful outcomes for individuals and families. Intensive support for children with a more significant learning disability/autism, who display behaviour that challenges is being proposed currently. This needs further development and investment and requires multi-agency working. This is one of the recommendations of this model. This needs to match those being developed in adult services, with consideration given to compatible models. Scoping is needed for remit of such a team to potentially deliver other functions of the PBS pathway and it links to Intensive Support work, and reduction of hospital admissions.

3. The Community Based Services

3.1 The model for Commissioned Support within Community Setting is based on national guidance and policy drivers.

The White Paper, “Caring for our Future” sets out the national vision for a reformed care and support system: “The government supports the diverse range of care providers that currently offer care and support, including user and carer led organisations, small and micro enterprises and social enterprises”.

The model suggests the range and diversity of care and support providers will grow, as will the need and ability to offer choice and control to people with learning disabilities and/or autism and the role of advocates in this provision. In doing so use of personal budgets needs to be embedded in localities. Outcome measures should include the uptake of personal health budgets.

The Care Act 2014 is a significant piece of legislation relating to an individual’s social care and health care which aims to transform the care system.

Whilst primarily introducing changes to the provision of adult social care, the Act will have significant implications for the local health economy as a whole. The Government’s Vision for Adult Social Care: Capable Communities and Active Citizens (DH 2010) sets out the case for the reform of the social care system; delivering the vision requires a confident, capable and skilled workforce.

People are required to work in new ways to help others decide and pursue their goals, recognise the strengths and assets individuals have, stay connected to their community, maintain independence, work in partnership and above all take pride in delivering high quality care and support to the most vulnerable people in society.

There are key national drivers for Adult Social Care and Health therefore the model must include implementing the requirements of the Care Act 2014 and supporting people with learning disabilities and/or autism to:

- Have increased choice and control over how their needs are met.
- Be offered a personal budget and, where appropriate, that a direct payment is in place.
- Have access to a range of preventative services.
- Have access to the same opportunities as the wider population in relation to housing, social involvement/activities, education, employment, health, transport and family and community life.
- Move from a caring role to enabling and developing independence. A “progression model” of support is favoured to maximise the independence for individuals and support them to achieve short, medium and longer term goals, achievements and outcomes.
- Be involved / included in the decision making process by means of person centred approaches.

The model cannot describe what service provision will look like in each locality, however the model can describe intentions and outcomes for supporting people in their local community and accessing training and development programmes for people and their families and carers:

- Shaping the local market in line the national guidance and policy, ensuring that there is sufficient appropriate provision available, at the right price to meet needs now and deliver effective outcomes both now and in the future.
- Focus on meeting the individual’s needs and wishes, involving families and advocates.
- Assess the individual not their behaviour.
Ensure the individual and family are fully involved in decision making processes in line with the Mental Capacity Act and the Service be consistent with the key principles of the Mental Capacity Act 2005 and the associated code of practice which includes a presumption of capacity, individuals being supported to make their own decisions, unwise decisions, best interests, least restrictive option.

Ensure care and support is based on dignity and human rights in line with the Equality Act and respecting that people with a learning disability and/or autism have the same human rights as everyone else.

The individual has maximum freedom (when possible) and is supported to feel safe and manage risks.

Support the individual to have an independent life which includes friendships, relationships, meaningful activities and education.

Ensure the individual has access to appropriate health services.

Ensure services are accessible and inclusive to all including those who present with the greatest degree of challenge, ensuring fair access for all and that the service reflects the needs of people with protected characteristics as defined in the Equality Act and other seldom heard groups involving appropriate advocacy.

Address health inequalities in community health services, primary care, ambulance and acute hospital services.

3.2 Social Care complex need:

The model reflects the need for social care support required for people within the cohorts and the further population. The model adopts a stepped care rather than progressive approach offering a range of care based on the premise that people with learning disabilities and/or autism, including people with complex and behaviour that challenges and/or mental health needs can lead fulfilling lives in the community.

Social care and support may be provided at different levels; independent support, direct payments, to 24/7 level care and support, however it may not be generally described as stepped care.

It is recognised that “Stepped Care” make take different forms and terms, but the approach and methodology should be reflected locally.

It is recognised that, across health and social care, models with complex care support may be referred to in different ways and by different names.

This model describes levels of support based on keeping people as independent as possible, and with the least restrictive care.

The model recognises that people and their needs can change and/or do fluctuate. Therefore, the level of care and support required may go up and down at times. This approach supports contingency planning and ensures that support is reviewed and remains appropriate.
The stepped approach is an integrated approach across health and social care so there should be no hand offs or gaps in provision.

The example below describes a range of housing and support providers as an expanded care pathway. This approach describes the more traditional step down option and an opportunity to move straight into a person’s own home.

Fluctuation of need and the opportunity to enhance a package in someone’s own home to prevent a move should be considered at any step or stage in the change of level of care and support required.

Stepped care recognises the range of levels of need from those with fewer support needs who manage and thrive with support of family, friends and mainstream health and community services to those requiring intensive specialist support.

The objectives of providing stepped care are to enable people with assessed needs, to preserve maximum independence and quality of life while being responsive to an individual’s changing needs. Stepped care offers the most effective intervention which supports the person in their home without being overly restrictive or intrusive.

It is crucial that support is person centred with a focus on maintaining the individual living in the community, available from a range of sources, both formal and informal and responsive to specific needs at any given time. This is built into care plans and packages.

Every individual within a stepped care in the model will have a person centred care plan and contingency planning. This contingency plan will detail resources, which will have the ability to respond to changing need, crisis or circumstances. In this the model this will offer a speedy response with the ability to “step” up, down or across the range of support (both health and social care) and appropriate advocacy provision.

Determining the level of support required will need to meet the needs of the individual, their family carer and the care provider, acknowledging the need to reduce / avoid unnecessary hospital admission, and that needs may change over time, and may require flexibility in the level of support.
Crisis beds or alternative accommodation options: when the person cannot stay in their own home is not described in the model. This will need to be developed / commissioned in localities.

Workforce development includes developing of skills to enable good quality commissioning and review of commissioned services. Working with individuals and family to identify and facilitate delivery of interventions along with other agencies. The commissioning function also requires a level of understanding to enable the staff to ensure that people are receiving a good quality service for example following the PBS guidance. Scoping of the skills training required to enable more robust assessment of quality of services will need to be carried out initially.

### 3.3 Service provision within complex care

Providers (who wish to provide complex care) must be able to demonstrate an asset based approach in the delivery of high quality care and support that is based on a values and evidence based approach leading to improved measurable outcomes for individuals.

The Service Provider is expected to comply with the model of care and support and deliver the Service based on the following ‘Making It Real’. Where a person needs more specialist support, including that arising from complex behaviour that challenges, the care provider will need to ensure a skill level to meet the persons’ day to day needs, and where necessary; they will have access to skilled support staff. In order to ensure these outcomes significant long term investment and competency are required within the workforce.

In adopting this model and knowing the local population including people returning from out of area placements, children’s education/ residential placements and hospital, each locality will need to decide how many providers/ services will be required to provide care to meet their locality need.

The model aims to ensure additional support for the social care service provider within complex care stepped care:

Key elements of a safe and effective model to support the stepped care approach are:

- Person centred care plans: inclusive of Proactive, preventative contingency plans which identify the agreed and funded multiagency response.
- Support for transitions between services, at times of significant change.
- Transitional support into adulthood.
- Specialist crisis support, and /or responsive ability for services/ community supporting an individual need to be able to respond by increasing or decreasing the level of support required for as needs change. This may be referred to as stepping up or down.
- To provide assessment and treatment in the persons own home, which previously may have been provided in hospital.
- In-patient care, only when really required and if appropriate, which should be as close to home as possible and for the shortest period of time, supporting early discharge.
- Supported by cross-sector multi-agency working and care pathways.
- Ensure Community Care and Treatment Reviews (CTR’s), effective early in-patient CTR’s and a Care Programme Approach are embedded.
This additional support will come from specialist multi-disciplinary professionals, including (when required) behaviour analysts. Who will be available to assist assessment and help plan more effective individualised support proactively and as and when required.

The aim will be to support social care ‘complex care’ providers to meet this challenge, by working alongside them, offering training and support to staff and modelling personalised care, similar to an intermediate care model.

This support will be from a community resourced team, dependent on the person’s needs, and may be part of the secure offender transitions service role. This will be described in the following sections.

3.4 Health provision

The model aims to ensure that people with learning disabilities and or autism can access effective care from mainstream NHS Service, and universal community services and when required access to specialist health and social care support in the community.

In developing a robust community infrastructure, the model describes what is required for a Community Learning Disability Pathways and Inpatient Assessment and Treatment provision; this would be accessible to people who have a learning disability and autism.

Autism without an associated learning disability is not described within this pathway but is described elsewhere in this document. However as stated previously in the model wherever possible will ensure the person will receive services based on need not diagnosis.

The community components include access to mainstream services, planned assessment and interventions, step up/down approaches, with intensive support /intermediate care, crisis support, and supportive early discharge.

Access to mainstream: Part of the role of specialist learning disabilities services is to provide support and advice on reasonable adjustments to mainstream services, this may include providing training and facilitation within health and social care settings.

The Model describes how the pathways will work and the components of the pathway/outcomes, including professional resources, rather than indicating teams. Localities will need to decide how best they operationalise this model, dependent on their population’s need and strength / development of other services.

As with all the support services close integration with primary care, social care and voluntary and community sector organisations will be crucial to delivering good quality care and good communication and liaison is vital throughout the service user pathway and the needs of their carers.

3.5 Access to psychological interventions for mental health

Recognition is made that people with learning disabilities and their families tell us that they find it harder to get support to think or talk about mental health problems in the same way that they get increasingly with physical health. This can be particularly difficult for parents who have health and social care needs themselves.

If a mental health problem presents, for whatever reason, it is more likely to be attributed to their learning disability (diagnostic overshadowing) or classed as behaviour that challenges.
A person with learning disability and/or autism and a mental health problem should, wherever possible, receive treatment based on NICE guidelines within mainstream service. This may require additional reasonable adjustments to make this happen involving support from learning disability services.

This support should be proportional to the need of the individual and may range from someone to accompany the person to therapy to joint sessions with a learning disability therapist. This can apply to all aspects of mainstream mental services. Using mainstream psychiatric beds with additional support from learning disability nurses has been shown as a way of accessing services successfully.

Increasingly, more people with learning disability are being diagnosed with Personality Disorder. The interventions for personality disorders should be aligned with the Personality Disorder services. The specialist learning disability mental health and wellbeing pathway is to ensure the timely recognition and effective treatment of mental health problems in individuals who are unable to access mainstream mental health services and require specialist learning disability service intervention.

The pathway supports a more bespoke approach to support their needs. It is accepted however that people with a significant learning disability and associated mental health needs will require different / additional interventions to those routinely offered through the mandated cluster pathway treatment packages. Within the new model, this will be delivered wholly or jointly with staff with specific learning disability expertise.

The crisis response for people with learning disability and mental health and/or behaviour that challenges presentations requires a different approach to that of the other pathways. It is recognised that people with behaviour that challenges should be managed within the community and not be accessing inpatient services unless there is a separate mental health element.

A 'step up' function is key to maintain people within the community and prevent admission through a timely and more intensive response to reflect the needs of the individual at that time.

This function is not described as a separate function within the model as continuity for individuals is key so is seen as integral to the broader Learning disability pathway.

People with a cognitive decline will be managed via the physical health stream with scaffolding/joint working from the cognitive pathway/dementia services.

Autism without an associated learning disability is not described within this pathway but is described later in this document.

In embracing the principles of transforming care it is recognised that there needs to be a shift in spend from high cost inpatient provision to reinvestment in the community teams to:

- Support the implementation of extended working hours over 7 days.
- Provide a step up and step down function to avoid crisis, hospital admission, facilitate early discharge and support longer term monitoring where required.
- Release capacity within the workforce to deliver focused, evidence based intervention.
- Support and facilitate access to mainstream services.
- Build on existing personal strengths and resilience through training and support to social care providers and families.

As with all the support services close integration with primary care, social care and third sector organisations will be crucial to delivering good quality care and good communication and liaison is vital throughout the service user pathway.

**Liaison nurse posts**

The model would expect liaison posts to be developed across a range of services, such as Primary Care Liaison and Acute Liaison posts for children and adults and for there to be community links to support the care pathway, support planning of appointments, making reasonable adjustments, reducing unplanned admissions, and reducing frequent attendance at A&E.

### 3.6 Integrated crisis response

To ensure a viable option to inappropriate hospital admissions, it is essential to develop crisis response services that are accessible and able to offer sufficient support and help over and above the ‘step up’ provided by the community teams, e.g. out of the extended hours or for protracted periods of time that lead to disruption in terms of the planned work of the community teams.

The crisis response for people with a learning disability and/or autism and mental health and/or behaviour that challenges often can be managed within existing mental health crisis services.

When the person’s needs are complex a different approach may be required to support and maintain community living.

It is recognised that people with behaviour that challenges and mental illness should be managed within the community and should not be accessing inpatient services unless there is a specific mental health need that cannot be treated in the community.

Often a crisis may result from not only a deterioration of the person’s mental health but environmental factors and/or the breakdown in the provision of support.

It is considered that flexible advance planning for crisis with a clear offer to individuals and families before crisis, with families listened to, is critical to the success of crisis response.

Early identification and support is required to give families and others affected by crisis confidence to care, act, resolve and get help that is person-centred. Support should be given to the person as crisis incidents are often frightening for all involved. It is further recommended that:

- The definition of “crisis” should be defined to include reference to personal/clinical/family crises.
- Crisis assessments should be done with the person and others, no done to/on the person.
- Contingency Planning: Early and pre-trigger point identification work may help prevent occurrence and escalation.
• Community Care and Treatment review processes should be used.
• Putting a label to behaviour should be avoided.
• Number of incidents and patterns should be analysed for learning and opportunities for positive affirmation.
• Training should be given to families so they understand what happens in a crisis.
• Support for parents and children out of hours should be considered with advance care planning.
• Work should include diversion from the Criminal Justice System.
• Support should be considered for parents/peers/siblings who are involved or affected.
• Families and carers should be given the opportunity and ability to challenge decisions.

Blue light/Multi-Disciplinary Team (MDT) processes should be refined to deliver and assess service quality and experience, supporting alternative options, for example; use of “Places of Safety” and the location/environment, and that the crisis response meets the need.

This could be use of extended family networks, shared lives approaches, crisis accommodation or short break options.

Often there can be a build up over a period of time which is amenable to early intervention and advocacy to avoid a crisis.

The community infrastructure therefore needs to be sufficiently integrated, informed, responsive and effective in meeting the needs of people with learning disability in order to prevent admissions to assessment and treatment beds.

To achieve this, the step up function in response to a crisis situation must be timely, accessible and responsive in order to maintain people within the community.

This coordinated response from community teams will ensure that any potential crisis is:

• Identified and supported early within the joint pathway meetings and CTR processes.
• Supported by a further assessment and well-developed Behaviour Support Plan.
• Managed in line with the crisis contingency plan which specifically states how resources would be accessed to offer any required interim short term alternative placement in an emergency.
• Managed through a step up package of support which will wrap around the individual.

3.7 Children and Young People’s Pathway

Further information on support and care for children and young people including the THRIVE model is included at Appendix 2.

There are three main care pathways which focus on the individual and their family, describing skills and good practice. The care pathways seek to use generic skills to manage the needs of the service while developing and maintaining specialist skills. It is recognised that the community pathways also need to work alongside inpatient wards and support an in-reach model to facilitate timely discharge.
The three main pathways are:

1. **Physical health and wellbeing** - supporting and facilitating access to primary and acute health care e.g. physical health checks, health action plans and access to speech and language therapy or physiotherapy.

2. **Positive Behavioural Support** - as described above.

3. **Mental health and wellbeing** - including supporting access to mainstream.

Focus should be on universal need and prevention first and the offer of improved support and advocacy early in a child’s life. This may include 24 hour, one to one support in the home as an alternative to 52 week residential education where children rarely return to their family home or a home of their own.

**3.7.1 Information Sharing**

Good information sharing is critical and relies upon effective communication between professionals, between organisations, and between everyone involved with the person and their family, carers, advocates or other interested parties. It requires effective strategic leadership and strong partnership across health, social care and education services in partnership with families and the Voluntary and Community Sector (VCS). The right information should be available at the right time in the right format, which may involve standardisation and a single-system approach where possible and appropriate.

The VCS have a part to play, for example via “Contact a Family”, Carer’s Centre, Parent Networks, etc. They are expert in supporting other parents and the systems that are required to do this effectively, in addition to providing effective early signposting to supporting agencies.

It is recommended that:

- All areas should include learning disabilities and autism on their Disabled Children’s Register (some may already but may not be explicit on their information).
- Early provision of appropriate information to new parents and parents of young children to help them cope with behaviour that challenges.
- Sufficient information should be shared with families – provide information at the right time in the right format and ensure that they understand the local offer, including easy to understand informed consent for parents to agree to information sharing process, access to advocacy and voluntary and community organisations that can help.
- There is SEND agenda & training for all relevant agencies involving all the right people.

**3.7.2 Early Intervention & Risk Stratification**

Key aspects for successful early intervention involve:

- Understanding the skill base across the region, existing delivery models and expertise, and self-audit processes.
A competent, trained, universal workforce using Positive Behavioural Support, Mindfulness and person-centred support as basis for core competencies in service delivery starting at an early age. This should include using the right language.

A variety of programmes to deliver care recognising individual need, together with appropriate advice and guidance for parents and carers.

Early identification of warning signs to allow appropriate signposting based upon work of the Early Intervention Foundation.

Health Services and Local Authorities should work together wherever possible, sharing local initiatives.

Parents and Peer Networks should be further developed and helped to develop parent trainers, with support and advocacy for families with English as a second language.

Further development of Community and Primary Care Services for children and young people.

### 3.7.3 Education Services

It is widely recognised that children with learning disabilities and autism, particularly where their conditions are not recognised at an early stage, may not be appropriately supported.

This may lead to an escalation of behaviour that challenges, isolation from peers, mis-diagnosis and reputational damage that can follow a young person into adulthood. People with learning disabilities, parents, carers and professionals recommend:

- Professional response should start in nursery schools to allow for early intervention and positive behavioural support.
- Training for staff in education services should include staff Continuing Professional Development in early identification and response to behaviour that challenges.
- Health Services should be involved in EHC plans.

### 4. Transitions for Children with Learning Disabilities/and or Autism to Adulthood

Young people’s transition from children and young people’s mental health and social care services to adult services in England is a significant issue for service users and their families.

Transition to adult services will be strengthened by:

- Talking to the person about what they want and need.
- Transition being about what is needed and not just somebody’s age.
- Understanding what somebody will need as an adult.
- A named worker making sure services and support joins up.
- Talking to parents/carers about what is needed in the future.
Children with learning disabilities and/or autism will be accessing services from a range of providers across multiple agencies and tiers of the current mental health service model.

Assessment and treatment will be offered by mainstream mental health, specialist learning disability services and through packages of care and support drawn from both areas of specialism and the local Authority/ Education.

Terminology of diagnosis/ education need assessed is often different to terms used in adult services.

On transition to adulthood, young people will be faced with accessing similarly complex patterns of service provision. The aim of the model is to make this transition easier by identifying children and young people earlier, and being aware of their level of need, creating a dynamic support register to support planning of service provision.

Children and young people will access inpatient and residential school provision to meet a range of need –some emanating from their developmental disability but also relating to social care, psychological and mental health needs.

Some young people with ‘developmental’ disability are placed through Youth Justice Systems in hospital or the Secure Estate owing to behaviour that poses a significant risk to themselves or others.

Discharging young people from hospital or Local Authority Care needs to be planned so that local community services are available to support step down or provide a stepped care to maintain complex care placements.

Some young people with learning disability and autism will be “coping” (THRIVE, 2014) within the structures of support available to them as a child, but will experience more challenges and difficulties post-18 – 25. This means that some young people present to adult services with their needs not having been identified as a child.

Throughput models where children are discharged from services mean the necessary scaffolding can cease and also difficulties not picked up at an early enough stage necessitating increased levels of intervention at a later age. CYP IAPT focusses on the needs of children and young people with typical rather than atypical patterns of development.

So the challenge with this diversity of the services and needs is to find the common link. The Education Health Care Plans have been developed to bring together Education, Health and Social Care services, and aim to develop one plan which will includes all the needs of the child or young person and their family. This can be used to support transitions and support the development of a dynamic register.

There are a number of key ingredients for an effective transition that cross cut transfers to inpatient care, transferring to adult services and leaving services.

Transitions need to be managed in a more robust and person centred framework ideally starting as early as possible. This needs to be factored in to any locality plan and needs to be applied to both community and inpatient services, with allocated transition roles or functions within teams.
5. Learning Disability Adult Pathway

Within the model for the Learning Disability Adult Pathway there are three main care pathways which focus on service user and carer needs, these pathways have no age limit and can support adults into old age:

- Physical health and well-being
- Positive Behavioural Support
- Mental health and well-being

5.1 How the pathways will be provided

The model does not describe all the roles or grades of the professionals within the pathways; however the model does recommend the pathways are provided by a core multidisciplinary team, inclusive of Psychiatry, Psychology, Social work, Nursing, Speech and Language Therapy, Occupational Therapy, Physiotherapy, Behaviour Analysts, Creative Therapies, CBT Therapists, Health Care Support workers, Dietitians and Support Workers.

In line with workforce development and developing specialisms, localities will need to understand current staff skills and competencies, and what will be required to deliver the model. This should include training and development opportunities for people, families, carers and staff, including Leadership, Positive Behavioural Support, Total Attachment and Mindfulness.

Each pathway will have access to full multidisciplinary team, and there will be flexibility between pathways for professionals to maintain skills and knowledge, along with meet the complex needs of the individual, who will not fit into one pathway.

The model broadly describes three care pathways. These may be managed within a single service/team to facilitate flexibility. This will support multidisciplinary planning / responsiveness and allow capacity within the service to deliver none planned interventions and step up/ step down functions (including resources to support the Social care ‘complex care’ providers).

Allocation to pathway will be based on primary need however individual needs will be holistically assessed and care planned.

It is recognised that within the community services and pathways there will be a number of posts which could sit within other services, in line with mainstream services, or Assessment and Treatment units and support a pathway model.

Therefore some posts such as Primary and Acute Liaison posts, Transition post will be described in the model, and localities will need to decide on which service /team they are managed.

Transitions into adulthood require support across all 3 pathways – there will be a clear transitions pathway for young people and their carers to introduce them in to adult services.

Further work is required to understand the specific support requirements within this area; however the model would suggest that each locality ensures that transition planning is integral to the services they develop, and Transition posts will support this development.

The model describes what is included in each pathway.
Physical health and well-being

This pathway aims to reduce health inequalities for people with learning disabilities and needs to consider proactive preventative strategies, (in line with public health strategies, and targeted work for known life reducing health inequalities).

This should include health promotion, advocacy and education for individuals and carers. Whilst also supporting and facilitating access to primary and acute health care services, this will include awareness raising and joint working with mainstream colleagues.

The pathway also delivers specialist assessment and interventions, when co-morbidity and complexity requires a specialist service to be involved; e.g. understanding sexual health, care of epilepsy, end of life, desensitisation and physical screening, along with a range of long term conditions, dysphagia, and access to speech and language therapy or physiotherapy for specialist interventions. (This list is not exclusive)

Outcome measure for this pathway will be included in self-assessment frameworks, such as take up of annual health checks and health action plans, screening and Health Equalities Framework (HEF).

Professionals within the pathway will follow NICE guidance in line with long term conditions, for example Epilepsy.

Liaison nurse posts

The model would expect acute liaison posts to be in place for children and adults and for there to be community links to support the care pathway, support planning of appointments, making reasonable adjustments, reducing unplanned admissions, acting as reviewers for mortality reviews, supporting MDT care around long term conditions/ medication reviews, and reducing frequent attendance at A&E.

Liaison with Primary Care

The uptake on Annual Health Checks 14+ remains poor. Service users have told us that they do not feel understood at their appointments and would like staff to have specialist learning disability knowledge.

For people with a learning disability and/or autism, Health Action Plans and Health Passports should be in routine use and appropriate medication reviews must be made. The model supports a full time liaison post working across Primary care (GP’s, dentists, Opticians etc.

This role should support early identification and intervention, and ensure that through education and support that all staff in mainstream services have better knowledge of how to support their patients that have learning disabilities, and autism.

Outcome measures; once again health outcomes and measuring the reduction of health inequalities will be linked to Self-assessment framework.

This post could also work across the locality ensuring that service users, families and carers are empowered to develop health passports and health action plans and support work around medicines management and mortality reviews. They would also ensure that in any health promotion work the voice of the learning disabled is heard.
Access to mainstream services is key in delivering good holistic care for people with a learning disability and or autism. Two key areas are highlighted below and need to be factored in when looking at the wider model implementation to ensure people are aware of good practice and to ensure equality of access to health care. Appropriate advocacy can assist with this.

**Health improvement programs**

There are a number of programs aimed at improving health inequalities, within the public health agenda and targeted at people in vulnerable groups.

Both the Acute and primary care liaison posts will be in a position to support these initiatives, working both across agencies and with people and their families and carers.

All localities will need to complete Mortality reviews and be part of the program to reduce over medicating people with learning disabilities (STOMP), along with ongoing work around annual health checks and screening programs.

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6. **Medicines optimisation – working with GPs**

In June 2015 NHS Improving Quality issued a report on the *Winterbourne Medicines Programme*. This report commented on the use of psycho tropic medication for people with a learning disability and behaviour that challenges services.

It comments; “*Used well and appropriately, these medicines [psychotropic] have a place in clinical care. Used poorly and inappropriately, they can take the form of restraint or a chemical coosh*”. This report is complemented by others, including the NICE Quality Standard published October 2015 *Learning Disability: behaviour that challenges*.

A medicines optimisation sub group of the North East and Cumbria Transformation Board, representing the local authorities, psychiatry, pharmacy and primary care has been working in collaboration with a confirm and challenge group (service users and carers) to provide practical, safe and person centred guidance on how the use of psychotropic medication can be reviewed in light of current best practice (e.g. the Stop Over Medication of People with a Learning Disability (STOMPLD) pledge).

In 2016 a series of briefing notes were sent to CCGs, Local Authorities, GP Practices, providers of community care and pharmacists, proposing processes that should give assurance that the medications are being used appropriately or should be reduced and even withdrawn.

Weighing up the risks and benefits of continuing or reducing medication may be complex and it may take time to reach a decision. The individual should be involved as much as possible and carers also need to be closely involved.

People in the community who see a psychiatrist regularly are having these discussions as are people currently in or being discharged from hospital.

The indication for, and monitoring arrangements for, any psychotropic medication should be clearly communicated. Some people on psychotropic medication will not have seen a psychiatrist for some time, receiving repeat prescriptions via their GP.
CCGs need to work with GP Practices to understand what resources will be required for multi-disciplinary medication reviews to take place.

Integrating this work into day to day practice will be required, such as ensuring reviewing medication is part of annual health checks or within CPA meetings, or social care reviews/ EHCP and CTR's and as part of behaviour support plans/ mental health recovery plans.

Dynamic registers could support identifying people at most risk of being over medicated. Community services will need different levels of awareness dependent on their roles and medication prescribed for the individual.

Learning Disability Pharmacy Service

The pharmacist will form part of the wider multidisciplinary team (MDT) helping to deliver the principles of medicines management to optimise the use and monitoring of prescribed medication.

This will be focused on patient/carer education, correct prescribing and monitoring of medicines as well as acting as a liaison between primary and secondary care providers ensuring a holistic approach to medicines issues.

The pharmacy service will “scaffold” across the main pathways providing the following interventions upon request and referral;

- Medicines reconciliation between primary and secondary prescribers.
- Holistic review of all medicines with the patient/carer.
- Provide a pharmacy-led NMP clinic within the team.
- Prescribing support to the MDT including the optimisation of prescribing, especially psychotropic medicines.
- Educational support to the team and service users.
- Liaison with Community pharmacy contractors to ensure seamless supply of medicines.
- Medicines information and enquiry service.
- Management of the correct monitoring related to specific medicines use.
- Audit activity related to medicines use and adherence to National/Local guidance.

7. Dietitians working with people with Learning Disabilities and/or autism

People with mental health problems are at greater risk of physical health problems and people with serious mental illness (SMI) are more likely to develop cardiovascular disease, obesity, abnormal lipid levels or diabetes.

People with learning disabilities are at greater risk of developing nutritionally related health problems. Issues around body weight, swallowing difficulties, bowel disorders, reflux, diabetes
and oral health are all commonly seen. These factors may increase the likelihood of a person with mental illness or Learning Disability to develop or be at risk of malnutrition.

The presence of mental illness and malnutrition have both separately been shown to be strong predictors of poor outcomes such as increased mortality, morbidity and length of hospital stay, all of which incurs cost and puts further pressure on health care resources.

Care for people with mental illness and a learning disability requires a multidisciplinary approach due to the co-morbidities and complex nature of the illness/disability often associated with this population.

The role of the specialist Dietitian is invaluable within specialist mental health/learning disability teams is diverse and will include:

- A specialist knowledge of the complex nutritional problems faced by this group such as weight gain and raised lipid in people taking antipsychotic medications.
- An understanding and appreciation of social, environmental and psychological factors which may have an impact on a person’s ability or motivation to make changes to their diet.
- By reducing or eliminating the need for medications in the management of constipation and other gut problems in learning disability.
- Making improvements in nutrition that can promote an individual’s learning and development and so reduce their need for support in the future.
- Minimising medical problems that can result in increased need for medical care for example in weight management, malnutrition, swallowing problems, tube feeds and diabetes.
- Individual care planning to help optimise nutritional status.
- Development of educational resources.

Community teams need to ensure quick and ready access to specialist dietitians to provide individual support and also to support the development and delivery of healthy eating programmes which could be delivered alongside voluntary sector groups.

8. **Expert by Experience Post**

All local implementation groups will need to demonstrate co-production in the development and implantation of the model in their locality. Localities currently have people involved in groups and as individuals working as experts by experience for Care and treatment reviews, and service improvement projects. NHS England is encouraging NHS trusts to lead the way in employing experts by experience. The model demonstrates options for posts being developed.
These posts includes peer workers working as health promoters with the Liaison Nurse and Transitions person to give their expert by experience knowledge at training and engagement events, and supporting health action planning, quality checking of primary and secondary health care settings.

This person could also advise on the use of accessible information and the inclusivity of the service. These roles could be developed across a range of services and/or commissioning.

9. Positive Behavioural Support (PBS)

The pathways aim to meet NICE guidelines and recent policy which both propose an investment in supporting families of children and adults who present with behaviour that challenges.

It is therefore important, as a region, there is a clear strategy that ensures widespread delivery of high quality parent training and support across a wide range of services and localities.

The model states that this pathway will be required to have strong links and robust interface/transitions procedures with children and young people’s services.

This will mean working to develop joined up pathways, with agreed multidisciplinary assessment and interventions (based on NICE guidance) and production of the similar products, for example: Behaviour support plans.

Key elements of this would include;

- Positive Behavioural Support (PBS) and Family Support Adult services.
- Required parent training course based on PBS and help to live with stress to be made available by local community professionals. This will be completed in partnership with other parent trainers as in Behaviour that challenges Foundation model.

To achieve this, flexible use of ‘hands on staff’ available to support key parts of an assessment or intervention package within the family home is required.

The model suggests support worker posts and qualified practitioners to provide such a hands on approach and this support will also be available to Social Care ‘complex care’ providers.

Advocacy services should also be involved as appropriate.

Other developments to be considered in the model are:

- PBS and Secure Outreach services - There would be benefit in developing a specialist workforce in this area and a range of care pathways and processes. However, consideration of offender health models is required as they may provide this or have an interface to work jointly, without duplicating roles.
Family involvement and support: In those circumstances where an individual is significantly supported by family members, and wishes for them to be involved in their care directly, ways of better facilitating this and involving them in the development of PBS plans and training will need to be provided.

‘Step up’ function and contingency planning are integral to this pathway as described in crisis/ step up section.

The model identifies the need to work with all people with Learning disabilities and/or autism who exhibit behaviours which challenge, during any significant change in their life and this would include transition into adulthood.

Planning is essential, opportunities to support getting to know / phased introduction to new situations and contingency planning must play part of the pathway. There is the requirement to work in partnership with all mainstream and Learning Disabilities services to support people transitioning between any services.

Wider workforce programmes should also be considered for people, families, carers and all staff including for example; Learning Disabilities Commissioning Leadership, Tomorrows Leaders, Total Attachment Training, and Mindfulness.

10. Mental health and wellbeing- including supporting access to mainstream

In the model the principle is; “A person with learning disability and a mental health problem should, wherever possible, receive treatment based on NICE guidelines within mainstream service”. This includes people with learning disability who are diagnosed with Personality Disorder.

Within the model there is recognition that people with learning disabilities and their families tell us that they find it harder to get support to think or talk about mental health problems. If a mental health problem presents, it is often more likely to be attributed to their learning disability (diagnostic overshadowing) or classed as behaviour that challenges. Therefore greater access to psychological interventions for mental health is required.

To challenge this and support access, there may be the need for additional reasonable adjustments and involving support from specialist learning disability services and advocacy services.

New posts such as Learning Disability liaison posts in mental health settings should be developed to support and implement this. Support should be proportional to the need of the individual and may range from a community team support worker to accompany the person to therapy, to joint sessions with a learning disability practitioner.

The pathway will include support and guidance to mainstream mental health services; this may include awareness training, either via liaison post or specialist community resource.
The pathway supports a more bespoke approach to support their needs. It is accepted however that people with a significant learning disability and associated mental health needs will require adapted or different / additional interventions to those routinely offered through the treatment packages in mental health.

Within the new model, this will be delivered wholly or jointly with staff with specific learning disability expertise.

**Access to mainstream mental health services**

The aim to access mainstream services should be applied to all aspects of mainstream mental services including:

- Crisis Support.
- Mainstream psychiatric beds with additional support from learning disability nurses/support workers as a way of accessing services successfully.

The diagnosis of mental illness can often be overlooked leading to undetected symptoms causing distress to service users, families and carers, in the past often leading to crisis placement in out of area placements.

In order to ensure access to the appropriate assessment and intervention and ensure integrated pathways between learning disabilities and mental health services: The following characteristics must be in place:

**Individual:**

- Diagnosis of mild-moderate learning disability with additional mental health needs should routinely access mental health services.
- The service user will have adequate communication skills to engage in a diagnostic process with which advocacy services may be involved.
- Service users with a severe learning disability and limited communication may have their needs best met in specialist learning disability services.
- Choice and control; Service user choice on service should be respected; this will include the views of those using and also those supporting people who may use the service, including advocates.

**Learning Disability service**

- A single point of referral which applies agreed eligibility criteria/protocols and signpost to correct service.
- Agreement between Mental Health and Learning Disability services, ensuring that people will receive an appropriate service based on need rather than service availability.
- The specialist learning disability services will have an enabling role in supporting people with learning disability disabilities and their families make best use of mainstream services.
• Provide training on learning disability and autism to mental health teams.

• Provide expertise by regularly attending team meetings and ward rounds in mental health service.

• Regular joint meetings with general mental health service managers to develop the strategic direction of the full range of services.

General Mental Health Service

• Referral route shared with learning disability services and jointly agreed eligibility/protocols criteria and adhere to them, flagging when reasonable adjustments are required.

• Work jointly as required with the learning disability services.

• Support people with learning disability to access full range of mental health services not just inpatient beds e.g. early interventions, home treatment and crisis response.

• All staff must be trained in the presentation of mental illness in learning disability, including increased knowledge of Mental Capacity Act as it applies to adults with a learning disability.

• Awareness of communication needs and ability to access specialist communication assessments and interventions via the Learning disability service.

• Provide all individuals with information guides and leaflets to be available in easy read format including Care plan and CPA documentation to be presented in an accessible format.

• An awareness of the greater prevalence of physical ill health in adults with a learning disability and access to the relevant support from physical health liaison services.

• Use outcome measures specific to learning disability e.g. HoNOS LD, Lifestar, Health equality framework.

• Provide advocacy services that are experienced and skilled in working with people with a learning disability.

Commissioners of Service

• Ensure that effective and high-quality care and support is offered to people with learning disability. It should be based on evidence, provide value for money, and reflect local needs and resources.

• Ensure that eligibility criteria/protocols are in place within services and support agreed principles.

• Monitor use of mental health/specialist learning disability beds and access to community services.
• Measure outcomes of improvement in quality of life and quality of care.

• Use Community Care and Treatment Reviews (CTR’s) to ensure access to the appropriate service is available.

• Ensure in-patient CTR’s are timely and effective.

• Scrutinise any ‘out of area’ referrals which act as a red flag to problems within joint systems.

• Ensure information systems are available that facilitate and promote this joint working.

10.1 Helping people avoid and stop getting into trouble

Community services require development in order to deliver change in a sustainable way in the medium to long term.

There are three main elements to this part of the model; primary, secondary and high risk prevention.

**Primary prevention**

This involves identifying those at particular risk through working with education, children’s services, housing, health, criminal justice agencies, etc.

Elements of primary prevention are discussed in the children and young people’s section.

Work should also happen alongside the adult community teams to prevent adults starting to get in to trouble with the police. This will be through the training and liaison functions of specialised community services and the involvement of appropriate advocacy services.

**Secondary prevention**

This involves identifying those whose behaviour is escalating towards offending/reoffending and doing intensive support work alongside community services whilst developing their awareness and skills.

**Risk Prevention and Minimisation**

Services for people with conditions on discharge or historical high risk and complex needs, often labelled as ‘Forensic’ or identified as in contact with Criminal Justice services, should:

• Help people stay out of trouble.

• Involve specialist teams who will work with people who have been in trouble with the police or courts.

• Lead to hospital admission only if they cannot be treated in the community.

• Help people to move out of hospital and find somewhere to live and things to do.
People in the community on a Community Treatment Order or Conditional Discharge (S41 restriction) need to remain open to health services as they must have a named responsible consultant and ongoing monitoring should have a multiagency approach.

Care processes should overlap with those available within Adult learning disability and or mainstream mental health pathways in order to increase opportunities for the development of care plans which are transferable for those moving between services and allow better continuity of care.

Further to the clinical care processes, a range of training should be developed including PBS awareness sessions aimed at increasing staff’s knowledge and understanding.

In providing the level of support needed for this group of people, there will need to be significant workforce development both in terms of the resources and the skill set of clinicians working within the community.

To achieve this community care pathways and processes should be developed possibly by adapting some of the care processes provided in inpatient services and use the knowledge and skills of the inpatient staff.

In order to provide a service in line with the principles of Transforming Care, varying levels of intervention would be required. For example, the application of PBS to supporting those who have longstanding ongoing behavioural needs would be different to that required to support service users in crisis who may be at risk of placement breakdown or hospital admission.

Care processes need to reflect this and include preventative, enhanced and intensive levels of provision in a way that enables continuity to include social care ‘complex care’ services.

A staged option may be appropriate, over a number of years, using specialist commissioned services proposal of secure transitions team within the first few years to give sufficient time to develop the community pathways and infrastructure.

This would use skills and knowledge of staff currently providing services within inpatient services. Locality infrastructure will determine how these models are implemented and commissioned.

10.2 Crisis and Step up responses within the three pathways

It is recognised that people with behaviour that challenges and mental illness should be managed within the community and should not be accessing inpatient services unless there is a specific mental health need that cannot be treated in the community.

Often a crisis may result from not only a deterioration of the person’s mental health but environmental factors and/or the breakdown in the provision of support.

There is typically a build up over a period of time that is often amenable to early intervention to avoid a crisis. The community infrastructure therefore needs to be sufficiently integrated, informed, responsive and effective in meeting the needs of people with learning disability in order to prevent admissions to assessment and treatment beds.

To achieve this, the step up function in response to a crisis situation must be timely, accessible and responsive in order to maintain people within the community.
This coordinated response from community teams will ensure that any potential crisis is:

- Identified and supported early within the joint pathway meetings.
- Supported by a further assessment and well-developed Behaviour Support Plan or care plan.
- Supported in a timely manner via use of dynamic register and risk stratification to target interventions.
- Managed in line with the crisis contingency plan which specifically states how resources would be accessed to offer any required interim short term alternative placement in an emergency.
- Managed through a step up package of support which will wrap around the individual.
- Provided flexibly through enhanced support to individuals, families and care providers.
- Avoid inappropriate admissions to hospital.

The crisis response for people with learning disability, autism and mental health and/or behaviour that challenges presentations require different approaches dependant on the person’s needs and their environment.

These functions are not described as a separate function within the model as continuity for individuals is often key, therefore is seen as integral to the broader Learning disability pathway.

The model recognises the difference between a mental health crisis and the need for urgent or more intensive support.

**Crisis Response**

This is required when a person’s mental health state leads to a crisis episode. They may be experiencing suicidal feelings, or self-harming behaviour, extreme anxiety or panic attacks. Emergency responder organisations may be involved including ambulance, police and search and rescue services. (Mental health crisis: Mental Health Concordat Feb 2014)

**Step up response**

This can be defined as; the need for immediate attention to something, which is very important to the person and/or their carer.

This response is in a timely manner to meet the needs of the situation. With an aim to respond and reduce the emergency situation occurring, this may require an element of Intensive support, defined as a highly focused approached which will include an increase in intervention or additional support which should involve appropriate advocacy provision.

**10.3 Step up/step down process**

To achieve a step up and step down model, the service requires a defined process. The use of risk stratification and Dynamic Support Registers (previously risk of admission registers requires local intelligence from all services, along with the use of CPA/CTR processes and commitment to urgent multi-disciplinary/multiagency response.
Where and when service users will move up and down the register, and the service will ensure they have their needs met for the appropriate amount of time, dependent on risks, complexity and urgency of need.

The aim of dynamic support registers is to proactively and responsively manage and support people before crisis occurs. Services will need to be responsive to this over a 7 day period and over extended working hours.

The risk stratification/case management tool provides an understanding of the risk and needs of their cohorts, combined with effective planning and the use of care plan and contingency plans.

**Step up within the physical health pathway**

Ill health has a detrimental effect on all aspects of life, including behaviour and mental health. Step up within this pathway will include support to have check-ups, or urgent investigations, ensuring someone is taking their medication or support long term conditions.

People with a cognitive decline will be managed via the physical health pathway with support/joint working from Dementia services, due to the complexity and co-morbidities associated.

**Step up and crisis for Behaviours which challenge**

It is recognised that people with behaviour that challenges should be managed within the community and not be accessing inpatient services unless there is a separate mental health element.

A ‘step up’ function is key to maintain people within the community and prevent admission through a timely and more intensive response to reflect the needs of the individual at that time.

Relationships and knowledge of the individual is often key to understanding the behaviour and communication style. Therefore the step up function has to be an integral part of the Positive Behavioural Support pathway.

**10.4 Crisis and step up in the Mental Health pathway**

The model supports access to mainstream mental health crisis services for people who can access that service, however for others the model focuses on an integrated crisis response, which includes step up.

Some people may be unable to access mental health services having crisis which isn’t foreseen and where step up is more appropriate.

To avoid inappropriate hospital admissions, 24/7 mental health crisis response services are required that are accessible and able to offer sufficient support and help over and above the ‘step up’ provided by the community teams, e.g. out of the extended hours or for protracted periods of time that lead to disruption in terms of the planned work of the community teams.

The crisis response for people with learning disability and mental health and/or behaviour that challenges often can be managed within existing mental health crisis services, following a contingency plan, and opportunity to joint work.
When the person’s needs are complex they may require a specialist adapted/different approach. Step up may be required to support and maintain community living and prevent admission through a timely and more intensive response to reflect the needs of the individual at that time, involving appropriate advocacy services.

Providing an integrated crisis response

Protocols and guidance should be developed for both mental health, learning disability and autism services in localities based on the model.

To support mental health services, crisis contingency plans and behavioural support plans, wellness recovery plans should be in place for all people at risk of admission, step up or crisis support.

Step up should be time bound and outcome focused, with an aim to support the person in the community in way of an intermediate care type of approach, providing home based assessment and treatment which may have previously been provided in hospital.

Flexibility and capacity within services to provide step up, needs to be factored into the staffing resources.

11. Care and Treatment Reviews (CTR)

It is recognised that there is ongoing national and local work to improve care and treatment review processes.

To be effective, Care and Treatment Reviews should act as an opportunity for external scrutiny at the earliest possible time and be supportive of planning next steps, and not purely be used as a blocker to hospital admission.

Community CTR’s (previously known as pre-admission CTR’s) should be used to support the individual and their families/ carer to consider options available and to support multiagency planning for the right reason and should not hold up planning decisions.

CTR’s should be robust process which can be aligned to CPA and other MDT processes but led by Commissioners. They should include:

- Assurance checks to ensure that MDT’s are fully involved in future planning and that there is effective formulation which turns into real action.
- Consideration of responsibility and accountability.
- Regular interagency discussions.
- Understanding of market forces.
- Needs based template required.
- Identified legal framework.
- Links with the EHCP.
Identify gaps in services and help future commissioning plans:

- Key, evidence-based learning from national to local level to include qualitative and quantitative data and information.
- Good CTR systems should shape services.

Admissions should be based on the person’s need for admission: whether in a specialist learning disability facility or a ‘mainstream mental health bed’.

The decision on which service is appropriate should be considered in line with assessment and treatment required, and the needs and wishes of the patient. Where possible, this should be indicated in care plans/contingency plans if a risk of admission has been identified.

The patient pathway should be a continuum of the community assessment or treatment pathway to avoid duplication wherever possible.

Assessment and Treatment units provide an adult inpatient admission which offers a multi-disciplinary approach to assessment, treatment and care for adults 18 and over with learning disabilities and mental health problems/severely behaviour that challenges, with an emphasis of active involvement of the individual, their family and any community based support services.

Inpatient services will apply a Positive Behaviour Support (PBS) model, which is both evidence and value based, and this allows for a less restrictive and more empowering approach to behaviour that challenges.

A range of evidence based assessment tools are used to identify patients’ needs with regards to admissions.

In line with the CTR policy, a Community CTR will take place in all but exceptional cases prior to any decision on admission.

Where this has not occurred all new admissions will have an in-patient CTR within 10 working days. The admission should be for the shortest time possible and involve joint working with the community support team. A “well enough” approach will support early discharge and options for further assessment or treatment to be continued at home wherever possible.

**Admission criteria**

To ensure that an admission is appropriate the following criteria must be met.

**The individual:**

- Requires assessment and/or treatment for a mental illness or mental disorder that cannot be provided safely in a less restrictive environment, i.e. at home, or other accommodation within the person community setting.
- Require treatments, or likely to require treatments, that are available in the inpatient setting throughout the period of admission, which cannot be delivered at home.
- To ensure that the admission is appropriate an admission requires explicit agreement of those appointed by the service as having admitting rights (For example: consultant psychiatrist).
• A Multidisciplinary/multiagency approach is involved and agree an admission is required including a Community Care and Treatment Review has been completed and it is felt an admission is appropriate or a blue light CTR has supported admission.

• Requests for admissions will only normally be considered for adults 18 and over with a learning disability.

In addition to the learning disability, there must be a presence of:

• A mental disorder of a nature and/or degree that would meet the criteria for detention under the mental health act

• Vulnerability that must be at a level that means using main stream adult acute in patients would be in appropriate or impractical due to the amount of scaffolding required

• All community assessment and treatment options should be exhausted before considering in-patient options.

The model is not descriptive to how the care within the pathway is assessed, interventions or treatments provided however practice will be expected to be in line with evidence based practice, NICE guidelines and policy and procedures of the provider. Community and inpatient models and pathways must be consistent and be aligned to provide the best possible care and intervention.

Outcome measures should be in line with NICE guidelines for Behaviour that challenges, and/or clinical treatment/interventions outcome measures. Clinical outcome measures, quality of life improvement and patient satisfaction must be part of the provider’s framework for service evaluation and improvement. These should include experts by experience, for example use of quality checkers.

12. Community Treatment Order

In the event that a person has been discharged under a Community Treatment Order (CTO) into the community and the responsible clinician initiates a rapid recall of the person, this should be to the least restrictive environment.

Where the length of stay required is greater than 72 hours, the patient’s CTO will be revoked. There will then be an urgent reassessment of need and a new discharge date set. In the event of readmission the root cause of the recall/revocation should be assessed. Early identification should allow a rapid turn-round and discharge (12-16 weeks).

The aim is to provide more robust pathways and transfers, developed with locality community services and involving advocates at each stage.
13. Specialised Commissioning Plan

NHS England Specialised Commissioning Team commission specialised medium and low secure services on a population basis for patients from anywhere in England. The services provided cover both male and female adult services and Child and Adolescent Mental Health tier 4 services (CAMHs).

The services commissioned by the team are services which meet the four factors for specialised services as described in the prescribed services manual. (NHSCB 2013).

The specialist commissioned services (Offender health) is required to meet the needs of people who have been within the criminal justice system; this includes hospital and community provision.

The model recognises that specialist commissioning provides:

- Medium and low secure services for people with a learning disability.
- Forensic community outreach service
- Prison Health and prison in reach
- Custody diversion.
- Offender Personality Disorder pathway.
- CAMHs Tier 4 learning disability services comprising an acute assessment unit, low and medium secure services as well as an inpatient assessment and treatment service for children and young people with a mild to moderate learning disability and/or behaviour that challenges and a complex neurodevelopmental community service (CNDS).

The transforming care programme affords a valuable and timely opportunity to make further improvements by reshaping services so that the focus will be on preventing avoidable admission and facilitating early discharge with the capacity to continue treatment programmes in the community and thus doing some real time assessment of continuing risk in a non-secure setting.

Specialised Commissioning is reducing hospital bed numbers to reinvest in a robust model of an enhanced secure outreach services across the region / community. In order to manage demand with fewer beds, there needs to be a much greater turnaround of people, as measured by a reduced length of stay. This can be achieved in three ways (which are not exclusive):

- Remove delays in receiving treatment (particularly access to psychological treatments to address offending behaviour).
- Where appropriate, provide treatment in the community.
- Improved integration between specialised and mainstream services to support transitions into the community.

The model is based upon using specialist knowledge from the secure services to provide support to the people in their community and support further development of local community service capability.

There has been a significant improvement in the screening, identification and management of people with learning disability and autistic spectrum disorder within the criminal justice system.
The aim is to move even further to an early intervention and diversion approach. This will be based on positive behaviour approaches. Essentially as the service will consist of both, in-patient and community arms, this will aid smooth transitions between the two thereby creating a wraparound service model.

There will be a shift of focus and resources from in-patient to specialist community-based services, but recognition for the continuing need for both. As services get better at identifying people with a learning disability and/or autism in prison, admissions under Part III of the MHA may increase, including those with restriction orders.

The model recognises the need for change in secure services and move from hospital provision to community provision:

- Reducing lengths of stay.
- Resettlement of people into communities and subsequent reduction in beds.
- Improving access to therapeutic options.
- Proactive interventions/ early interventions reduce the number of people requiring secure services.

The model will support:

- Improvements to the whole pathway from preadmission to post discharge.
- Providing treatments personalised to individual need rather than a prescribed approach.
- Supporting developments in the workforce both in the community and in secure services.
- Changing the approach to how and where treatments can be delivered.
- Transfer of prisoners back to prison on successful completion of treatment.
- Enhancing the function and delivery of the outreach model and roll out across the North East and Cumbria.
- Supporting early discharge from hospital.

It’s recognised that there have been several developments in the past five years including:

- The development of the Autistic Spectrum Disorder pathway.
- The custody diversion schemes in place throughout the region.
- Development of street triage and S136 suite provision.
- Improvement of prison in-reach services.
- Better access to statutory and non-statutory advocacy.
- Supporting people to live in the community.

**Community provision – Secure Outreach Transition Teams**

A specialised commissioning model should provide a secure adult outreach transitions team, seven days per week operating 0800-2000 hours. This is required in order to manage people in the community who have offending behaviours and/or convictions. See appendix 4.
The team should have a different skill mix to allow complex assessment and treatment in the community. It should include psychiatry, PBS practitioner or behaviour analyst, psychology and social work, S&LT, OT as well as specialist nurses and support workers.

The range of skills required include the ability to develop independent living skills; enhance communication and social skills; support emotional well-being; assess and support mental health needs; understand and support complex behaviour; assess and support offending behaviours; manage risk; and support and develop skills in managing a person’s own physical healthcare. Provision of statutory and non-statutory advocacy should also be considered.

Providers of specialised commissioned services have particular expertise around complex presentations, personality disorder, delivering offender treatment programmes and addressing criminogenic need. They should work alongside and into offender health and adult learning disability community pathways.

It is recognised that this will be required with the reduction of lengths of stay and the option to provide ongoing treatment and care in the community, and to safely manage risk. Teams should identify the most appropriate pathway and community service, whether through mainstream services, mental health or learning disability teams.

**The secure outreach model**

This model supports the transition of people from secure care once they have completed treatment including:

- Collaborative working with existing services
- Access to advocacy
- Risk management processes
- Increase access to specialist and crisis support
- Comprehensive and rapid assessment
- Direct input to support crisis and Liaison and Diversion teams
- Support and training of adult Learning Disability and/or AMH teams
- Step up / Intense home support e.g. if sudden increase in risk and/or reduced ability of home staff to support the person and their families/carers
- Promoting personal resilience for them and/or carers (family or paid)
- Complex case management and/or joint case management with community services
- Prevent admissions in to secure services
- Support people discharged from in-patient services that still require active treatment in community.
- Support people diverted from hospital and who require a full assessment and treatment package in the community.
14. Performance Framework

It is imperative that the Transforming Care partnerships responsible for delivering the model of care can keep track of progress and be confident that the model envisaged is the one being achieved.

The performance framework set out below constitutes both qualitative and Quantitative measures to monitor the range of activities across the whole model of care.

Some of the suggested indicators are collected nationally and these are referenced, whilst others enable performance at the local level to be more closely monitored to trigger alerts to potential problems, offer analysis of the root cause from multiple perspectives and thus optimise performance of the whole system.

All of the indicators contribute to delivering the national outcomes for the NHS, Public Health and Adult Social Care and have been linked to the relevant domains.

National Outcomes Framework

Some indicators are the same across Adult Social Care the NHS and/or Public Health reflecting the shared role in progressing. Those that are not shared are complementary to similar indicators relating to the same issue in the NHS and Public Health frameworks.

Local outcome measures

There are a number of outcome measures suggested in the model.

Localities will need to determine which ones they are mandated to measure such as reductions in admissions and lengths of stay, and which measures will add value to local assurance of quality of life, quality of care, such as real life experiences such as accessibility and quality of services and reduction restrictive practices.

Service specifications

Local implementation groups should develop service specifications/contracts across health and social care which will build on the criteria and the outcomes of the model.

Both Local Authority and Clinical Commissioning Group (CCG) commissioners will need to ensure they commission services which can ensure the totality of the model, based on shared outcome measures, ensuring smooth transitions and interface, and encouraging multiagency working.

Localities should share service specifications for parts of the model to ensure continuity in the delivery of the model.
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<td>Draft agreed in principle by NE&amp;C TCP Board</td>
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