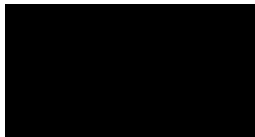


# Learning Disability Transforming Care Partnership





# Humber Transforming Care Partnership

## Joint Transformation Plan 2016 - 2019

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Supporting documents, including an Easy Read  
version, and regular newsletters will also be  
available on the same site

## 1. INTRODUCTION

This document sets out the vision of the Humber Transforming Care Partnership (TCP) for transforming care and services for people with a learning disability and/or autism, especially those who also have, or are at risk of developing, a mental health condition or behaviours described as challenging. This includes people of all ages and those with autism (including those who do not also have a learning disability) as well as those people with a learning disability and/or autism whose behaviour can lead to contact with the criminal justice system.

The Humber Transforming Care Partnership was established to work on a wider footprint than our usual learning disability planning partnerships, with consequent increased scope for economies of scale and greater opportunities for learning from the experience of other areas and organisations.

This three year transformation plan is written in response to Building the right support<sup>1</sup> and the national service model<sup>2</sup> published in October 2015, which set out a national vision for a radical shift in the delivery of care and support for people with learning disabilities and/or autism.

We hope that this plan will be helpful in understanding:

- The footprint covered by the East Riding of Yorkshire, Hull and North East Lincolnshire
- The services currently commissioned and provided across our area
- Our vision for how future services will be commissioned and provided
- What we need to change to achieve our vision and how we intend to do this
- How we will ensure effective implementation of our plan

Our plan describes our intention to improve the quality of care and life experience of people with a learning disability and/or autism in order to reduce our reliance on inpatient care to the following levels<sup>3</sup>:

- 10 -15 inpatients in CCG-commissioned beds (such as those in assessment and treatment units) per million population
- 20 – 25 inpatients in NHS England-commissioned beds (such as those in low-, medium- or high-secure units) per million population

Our vision is underpinned by the nine principles of 'Building the Right Support'. The Transforming Care Partnership is committed to improving safe care and treatment to make sure that Children, Young People and Adults with a learning disability and/or autism have the same opportunities as anyone else to live satisfying and valued lives and are treated with dignity and respect.



<sup>1</sup>Building the Right Support – a national plan to develop community services and close inpatient facilities (NHS England, LGA, ADASS, 2015)

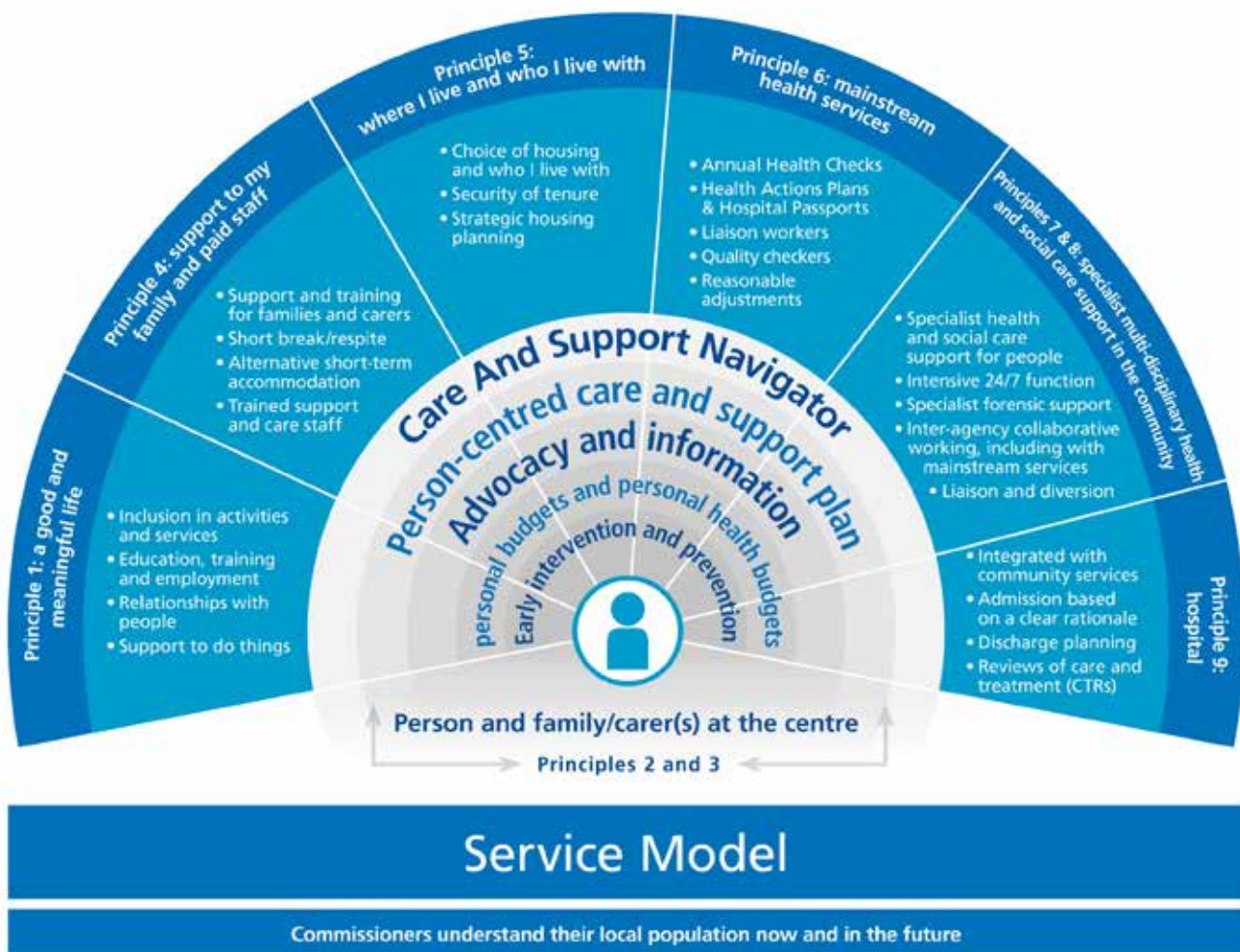
<sup>2</sup>Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition – A service model for commissioners of health and social care services (NHS England, LGA, ADASS, 2015)

<sup>3</sup>The rates per population will be based on GP registered population aged 18 and over as at 2014/15

It has long been recognised that people with learning disabilities and/or autistic spectrum conditions have poorer health outcomes than the rest of the population. There have been many reports over the past ten years, such as Six lives, A life like any other, Death by Indifference, that have highlighted the way health services have failed this vulnerable group of patients. For a minority of people with a learning disability and/or autism, we remain too reliant on inpatient care. As good and necessary as some inpatient care can be, people are clear they want homes, not hospitals. Following the national review into the Winterbourne View abuse, there has been a programme of resettling individuals from long-stay hospital placements to community living. In October 2015, this was taken a step further with the publication of the national service model which set out five “golden threads”

1. Quality of life
2. Keeping people safe
3. Choice and control
4. Least restrictive support and interventions
5. Equitable outcomes

and nine key principles:



*Building the right support* described community services in line with these key principles which would lead to a reduction in inpatient capacity nationally. It aimed to build on the early learning from six fast-track areas, which were chosen on the basis of their higher reliance on inpatient care, and to support local commissioners to implement similar changes in their services for their populations.

## The nine key principles can be expanded as follows:

1. People should be supported to have a **good and meaningful everyday life** - through access to activities and services such as early years services, education, employment, social and sports/leisure; and support to develop and maintain good relationships.
2. Care and support should be **person-centred, planned, proactive and coordinated** – with early intervention and preventative support based on sophisticated risk stratification of the local population, person-centred care and support plans, and local care and support navigators/ keyworkers to coordinate services set out in the care and support plan.
3. People should have **choice and control** over how their health and care needs are met – with information about care and support in formats people can understand, the expansion of personal budgets, personal health budgets and integrated personal budgets, and strong independent advocacy.
4. People with a learning disability and/or autism should be supported to live in the community with **support from and for their families/carers as well as paid support and care staff** – with training made available for families/carers, support and respite for families/carers, alternative short term accommodation for people to use briefly in a time of crisis, and paid care and support staff trained and experienced in supporting people who display behaviour that challenges.
5. People should have a choice about where and with whom they live – with a choice of **housing** including small-scale supported living, and the offer of settled accommodation.
6. People should get good care and support from **mainstream NHS services**, using NICE guidelines and quality standards – with Annual Health Checks for all those over the age of 14, Health Action Plans, Hospital Passports where appropriate, liaison workers in universal services to help them meet the needs of patients with a learning disability and/or autism, and schemes to ensure universal services are meeting the needs of people with a learning disability and/or autism (such as quality checker schemes and use of the Green Light Toolkit).
7. People with a learning disability and/or autism should be able to access **specialist health and social care support in the community** – via integrated specialist multi-disciplinary health and social care teams, with that support available on an intensive 24/7 basis when necessary.
8. When necessary, people should be able to get **support to stay out of trouble** – with reasonable adjustments made to universal services aimed at reducing or preventing anti-social or ‘offending’ behaviour, liaison and diversion schemes in the criminal justice system, and a community forensic health and care function to support people who may pose a risk to others in the community.
9. When necessary, when their health needs cannot be met in the community, they should be able to access high-quality assessment and treatment in a **hospital** setting, staying no longer than they need to, with pre-admission checks to ensure hospital care is the right solution and discharge planning starting from the point of admission or before.

In developing our local plan we have identified a number of issues which we are likely to face as the level of inpatient provision is reduced as per the national plan, including:

- An increase in the complexity of need of patients accessing inpatient services, both in terms of behaviour and physical health. This will be magnified as the cohort currently managed in forensic services steps down into local provision
- Supporting older families caring for adults with learning disabilities, and caring for older adults with a learning disability developing dementia
- Meeting the needs of people with complex autism and challenging behaviour, particularly young people graduating through transition who also require educational support
- Recognising and supporting individuals with autism who may have additional support needs but might not have a learning disability. Whilst we have assessment and diagnostic pathways in place, we need to consider the development of post-diagnostic support and a care pathway which identifies autism-appropriate inpatient services should the need arise
- Developing the competence and confidence of local provider teams across the NHS, social care and independent sector to manage people with complex needs and challenging behaviour, including the safe management of individuals who will be resettled from forensic services

Initial discussions have identified the following priorities for our area

- Short term accommodation options including Crisis and Short Breaks Support
- Positive Behavioural Support Team / Complex care behaviour distress pathway
- Enhanced complex care service for People with Profound and Multiple Learning Disabilities (PPMLD)
- Acute Liaison
- Advocacy
- Increased availability of communication techniques and sensory profiling to support individuals with complex neurological impairments including Autism
  - Community based living accommodation that has capacity and skills which can safely manage individuals with highly complex needs and challenging behaviour, including offending histories



The development and shaping of a market to meet these challenges in a geographical area which often struggles to attract new staff will be a significant challenge. Moving from commissioning as separate CCGs and Councils to a more integrated model of commissioning on a Transforming Care Partnership footprint offers opportunities to explore cross border arrangements including pooled budgets, shared criteria for joint funding of packages, collaborative commissioning and tendering exercises and working together to understand the impact of the return of funding from NHS England (Dowries). We will explore with other Partnerships across Yorkshire and Humber the potential for financial risk sharing agreements for high cost placements and work together to make more efficient use of contracting support by agreeing shared service specifications and lead commissioner arrangements with independent hospital providers across the region.

A key challenge for the Partnership was to identify how we would initially source the finances required to achieve the plan. We have been able to identify a number of potential match funding contributions from the different partners in order to make a bid for Transformation Funding over the three years of the plan, to enable us commission a number of schemes which are intended to drive the transformation of services.

Other than any Transformation Fund monies that we might receive our assumption is that we will need to refocus current budgets. Where we can achieve efficiencies through the pooling of funding we will do so. We anticipate there will be some transfer of resource from Specialised Commissioning budgets but recognise that this is not going to occur in 16/17. As we identify new services that are required to meet the needs of this population we will need to work together as commissioners, and sometimes with commissioners across a wider area, to procure these services. Shaping the market to meet the needs of our population, especially those within the five cohorts described in the plan, will be central to our success.

The significant changes in the way that services are commissioned and provided will need the full support of adults with a learning disability, their families, friends and carers. We will work together with them to make these changes happen through the design and provision of effective person-centred social and health care services. They will be the judge of the success or otherwise of this work.



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### 2.1 The health and care economy covered by this plan

This section describes our current arrangements for commissioning services. It is split into three sections:

- East Riding and Hull, which have a long history of working together and have many providers in common
- North East Lincolnshire
- NHS England Specialist Commissioning arrangements

#### East Riding of Yorkshire and Hull

East Riding of Yorkshire CCG and East Riding of Yorkshire Council (ERYC) are strategic partners with many strategic groups reporting to the Health and Wellbeing Board. They are not coterminous however and health services for the Pocklington area are commissioned by the Vale of York CCG, which is also represented on the Health and Wellbeing Board. The Humber TCP will work closely with the North Yorkshire TCP to meet the needs of this population.

Joint Working groups reporting to the Health and Wellbeing Board include

1. Better Care Programme Board
2. Joint Commissioning Group
3. Health and Social Care Executive

A number of streams of joint working report through these including

- Better Care Fund Programme
- Joint Health and Wellbeing Strategy
- Joint Autism Strategy
- Mental Health Crisis Care Concordat (which is a programme of work in partnership with Hull)

Hull City Council and the Hull Clinical Commissioning Group (CCG) are strategic partners working together on the delivery of a programme for improvements to health and social care across the City – taking into account 6 interdependent strategies:

1. The City Plan
2. Hull's Joint Health and Wellbeing Strategy (2013 -2016)
3. Hull's 2020 Vision
4. Hull's Autism Strategy
5. Hull's approach To Dying Well
6. Hull's Winterbourne View Action Plan

The main provider in East Riding of Yorkshire and Hull of NHS Learning Disability services is Humber NHS Foundation Trust (HFT) which delivers, across both Hull and the East Riding,

- Community Teams Learning Disabilities (CTLD)
- Continuum, a specialist team managing individual with challenging behaviour in crisis
- Inpatient services, both Assessment and Treatment and a forensic medium secure unit on the Humber Centre site
- Complex care team for people with learning disabilities and complex physical health care needs
- Targeted Children and Adolescent Mental Health Services (CAMHS) for children and young people with a learning disability, Looked After Children, and children in the criminal justice system. These provide a range of interventions and support appropriate to the targeted group both where the need would not meet access criteria for core CAMHS intervention and in place of core CAMHS interventions in many cases where the criteria are met. The service targeted at Looked After Children is not available to children placed within our area by external Local Authorities
- Assessment and diagnosis of autistic spectrum conditions for children and young people is undertaken by a multi-disciplinary panel. Post diagnosis support is provided through accredited targeted parenting programmes, inclusion support workers linked to school localities and a small number of specialist units within mainstream schools



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- Assessment and diagnosis of autistic spectrum conditions for adults is undertaken by a multi-disciplinary panel managed within adult learning disability services

In addition the Trust provides

- Community Mental Health Teams to work with adults with severe and complex mental health problems, with referrals received through a Single Point of Access triage and Assessment service
- Early Intervention in Psychosis service providing early intervention to those with first episode psychosis (aged 14 upwards)
- Children and Adolescent Mental Health Services which facilitate transfers where appropriate from CAMHS to adult services.

Mental health services will provide care and treatment to young people and adults with a learning disability where it is more appropriate for them to do so, and the Trust has implemented the Greenlight Toolkit and continues to monitor the effectiveness of joint working between learning disability and mental health services.

East Riding and Hull CCGs have a block contract with HFT to deliver these services, managed through a Contract Management Board including senior representation from HFT and East Riding of Yorkshire, Hull and Vale of York CCGs. There is a lead commissioner arrangement with East Riding of Yorkshire CCG taking on the role of lead commissioner.

In addition, there is a risk agreement between NHS Hull CCG and HFT which covers the commissioning and case management of packages of care for four named individuals. This was agreed to facilitate the return of individuals in the original March 2014 cohort to local services where possible.

Within the boundaries of the East Riding, Priory Hospital Market Weighton is a registered male independent hospital, supporting individuals with severe and enduring mental health conditions



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who may have complex presentations with behaviours that challenge. Some of the patients have a diagnosed Learning Disability. The hospital aims to provide rehabilitation, stabilise mental health, reduce the behaviours that challenge, and develop daily living skills, in order to enable a smooth transition to life outside the hospital environment. CCGs contract on an individual named patient basis.

Adult social care is facing an unprecedented level of change. The Care Act sets out a new ‘contract’ between people who use services and those who commission or provide them. There is a legal requirement that services promote an individual’s overall wellbeing and independence and put as much control as possible in the hands of the person using services. Local Authorities are promoting this is by encouraging as many people as possible to take a direct payment and are strengthening the support available to people who wish to do this. This will mean that an increasing proportion of services are purchased by individuals rather than being commissioned by the local authority and providers are encouraged to redefine their relationships with service users to respond to them as direct customers.

Across the footprint there is a range of providers of supported living schemes, residential and domiciliary care. In the East Riding these are contracted by ERYC and funded by the Council or the CCG through Continuing Healthcare or S117 arrangements. A Joint Commissioning Panel with representation from both the Council and CCG scrutinise and agree funding arrangements for these provisions, including whether or not they are fully funded by one commissioner or joint funded. Similarly in Hull there is a High Cost Panel between Hull CCG and Hull City Council who similarly jointly commission packages of care on a case by case basis. In Hull the main providers for this client group are Hull City Council, Humbercare, Avocet Trust and City Healthcare Partnership CIC.

Hull City Council also commissions a number of services across the external market. These relationships are defined either through dedicated provider frameworks, such Housing Related Support, a historic under 65yrs residential service contract (currently subject to review and re-procurement) or direct purchasing through a spot arrangement bespoke to the individual’s needs.

We know that children with learning difficulties and disabilities are six times more likely to have mental health problems than other children. Co-ordinated support for young people with complex needs is, therefore, essential to ensure their needs are met. In Hull there is a team of mental health professionals dedicated to ensuring that the mental health needs of children and young people with learning disabilities are fully supported. The service works closely with schools in supporting those children with special educational needs and disabilities. As part of the service transformation in Hull, we are working closer and more effectively with key partners to understand the needs of this vulnerable group, and to ensure they have equal access to services in the City.



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### North East Lincolnshire

North East Lincolnshire CCG has a strong history of working together with Hull and East Riding CCGs to ensure strategic planning, collaboration and coordination, and commissioning for services that work more effectively on a larger Humber footprint – such as Cancer pathways, Neurological pathways including spinal and brain injury pathways, Trauma pathways, Mental Health Pathways, and a Humber Tier Mental Health Crisis Care Concordat. Up until recently several functions were shared through the Yorkshire and Humber Commissioning Support, the dissolution of which has supported hosting arrangements across the Humber CCGs.

The North East Lincolnshire (NEL) resident population is 156,000 residents. However, the population registered to North East Lincolnshire CCG GPs is closer to 168,000 as Primary Care serves villages outside of the NEL boundary to the west and south. Geographically North East Lincolnshire is on the periphery of greater Lincolnshire, with quicker and easier road and bus links to Hull and the East Riding. This peculiar geographical position has resulted in bespoke arrangements in service model and delivery in North East Lincolnshire.

The population's needs are met through a unique arrangement achieved through a Section 75 agreement between North East Lincolnshire CCG (NELCCG) and North East Lincolnshire Council (NELC), reflecting the high level of integration characteristic of North East Lincolnshire services. NELCCG is the responsible commissioner for Adult Health and Adult Social Care, and NELC

commissions Children's Health and Children's Social Care. Each organisation monitors and holds the other to account for its delegated responsibilities through a Partnership Board.

Over the course of five or more years North East Lincolnshire has invested and transformed Learning Disability services, implementing a Supported Living model and Community Based services. Supported Living is offered to a wide range of people. Over the last four years there has been a transformational project "Changing Lives in Partnership" which has radically changed service delivery, housing options, and person centred care in North East Lincolnshire. This is in partnership with the North East Lincolnshire Transition strategy.



The predominant market for learning disability is Supported Living in which many of the traditional residential care homes have been re-modelled or de-commissioned. This is delivered through person centred ways, including Personal Budgets and Individual Service Funds. We no longer have any block contracts for Learning Disability long term care.

North East Lincolnshire has developed a very community based integrated model which has been led by key professionals, in particular Psychologists and a Behavioural Team in which detailed assessments and person centred plans are developed in partnership incorporating positive risk management. North East Lincolnshire has a clear transition pathway in which young people with complex needs are assessed at age 14 in order that services are commissioned around their individual needs. This has resulted in a number of individuals with complex needs returning to North East Lincolnshire and offered a more personal provision and settled housing.

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North East Lincolnshire Housing was devolved from NELC to Shoreline, a Registered Social Landlord. The Supported Living Model uses independent developers and social landlords and we have had a significant history of success, providing smaller, more flexible, and more adaptable approaches to this cohort of people with complex needs.

There are no learning disability hospitals, (neither Assessment and Treatment nor Rehabilitation) within the North East Lincolnshire boundary, but an Independent Sector Low Secure Unit operates with some step-down facilities.

There are very few Registered Care Homes for people with Challenging Behaviours. The majority of care for people with a learning disability is provided through personalised packages delivered through Supported Living.

The micro-commissioning function of Adult Social Care is provided by a Community Interest Company, Focus Independent Social Work (Focus), which works closely with NELCCG in co-ordinating care and case-managing for people with Learning Disabilities. The same function for people with Mental Health difficulties is provided by another Community Interest Company, NAViGO.

### **Specialised Commissioning arrangements for forensic services and inpatient Child and Adolescent Mental Health Services (CAMHS)**

(supplied by Yorkshire and Humber Specialised Commissioning Team)

#### **National Context**

NHS England has expressed its intent, through its commissioning intentions for 2016/17, to procure CAMHS inpatient services and adult secure services nationally. The exact start date of these procurement exercises is unknown at the time of writing. Work to reduce beds for both patient groups cannot take place in isolation as there would then be a risk nationally to the whole system, and so the Yorkshire and Humber specialised commissioning team are not planning any bed closures in 2016/17. Reinvestment of resource will need to be considered once procurement has commenced and a national plan is in place.

It should also be noted that not all of the contracts for specialised Learning Disability and autism services in adult secure are held by the Yorkshire and Humber hub as for some the contract with NHS England may be held by another commissioning hub in another region.

#### **Adult Secure Inpatient Services within Yorkshire and Humber**

This includes commissioning of all forensic inpatient units, which includes high, medium and low secure services. Work has been undertaken through Care and Treatment Reviews (CTRs), Care Programme Approach (CPA) meetings and the usual case management activity to ensure appropriate access to and egress from adult secure services. NHS England case managers currently case manage patients on a host basis, ie patients who are placed in beds in Yorkshire and Humber are all case managed by the Yorkshire and Humber team, regardless of their CCG of origin. However, patients placed outside of Yorkshire and Humber are managed by the NHS England specialist commissioning team for that part of the country. This arrangement was put in place in April 2013. NHS England has recently taken the decision to revert back to previous arrangements for adult secure where patients are case managed on an originating basis – this will make planning for local populations much easier and improve pathways going forward and work is underway to ensure that all patients are identified and reviewed by the appropriate case managers.

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### Access Assessments

This process manages the access and egress into and through levels of secure care and the task is undertaken by a number of different providers across Yorkshire and Humber. The cost of these assessments is usually part of the bed day price in the respective contracts. The purpose of access assessments is to make sure that only people who really need to be cared for in secure settings are admitted.

Transformation across adult secure services and beyond will involve the development of forensic outreach services that will be able work comprehensively with local community services. The outreach definition within the adult secure specification provides a good basis on which to build this work. In terms of the autism population who access adult secure care, there is real opportunity to look at the way in which secure and local services can complement each other. Further work on specifications needs to be undertaken locally and nationally to inform this process. What is most important here is to identify resource that can be reinvested from any bed closure through procurement to support these developments. This may involve double running costs to make the pathway work more efficiently.

This creates an ideal opportunity for collaborative commissioning across NHS England and local commissioners. Work is beginning via the national Transforming Care Team to explore a service model for forensic community Learning Disability teams (alongside liaison roles, intensive



community support and local inpatient teams) and establish what good looks like. The output will be a set of model service specifications across each of the above areas. It is envisaged that these services will ensure earlier discharge can take place from secure services, to reduce length of stay where admission is absolutely required, to look at alternatives to hospital admission, and to manage crises across this patient group.

### Children and Adolescent Mental Health Services (CAMHS): inpatient units

Inpatient provision for children and adolescents with a Learning Disability and/or autism are

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commissioned by NHS England and the Specialised Commissioning team has undertaken capacity modelling for all requirements for this patient cohort. The basis of the needs assessment to inform the capacity planning was activity data from 2013/14 and 2014/15 looking at all occupied bed days for the Yorkshire and Humber population. It is anticipated that inpatient services should be flexible and geographically located centrally within Yorkshire and Humber with good travel links for ease of access across the whole geography. In addition, the national specification for autism focusses on consultation and providing assessment services to CAMHS community and inpatient services. It is anticipated from the work to date that approximately seven beds are required for the population of Yorkshire and Humber. This will be kept under review.

### Plans to explore a CCG Risk Share Arrangement Across Yorkshire and Humber

Many of the 23 CCGs in Yorkshire and Humber are experiencing the need to commission very high cost and complex packages of care specifically in relation to this cohort of patients. The placements required are not those commissioned as specialised (based on the current definitions within the Manual for Prescribed services – January 2014.) They are not only very high cost, but often require specific expertise and intensity from a commissioning and case management perspective. CCGs are exploring how to work together across the whole of Yorkshire and Humber as this would give more opportunity in terms of range of provision, provider market and contracting and less financial risk to individual CCGs.

The patient group initially could be defined as:

- Patients moving on or stepping down from specialised services. For this patient group, this would specifically be adult secure or transition from CAMHS inpatient services to adult services. The Specialist Commissioning team has the relevant data in relation to this patient group.
- Patients with existing packages of care already being commissioned individually by CCGs; many of these patients may never have accessed specialised services but exhibit the same characteristics as the previous patient group and require a similar type of service provision. An understanding is needed of the number of placements already being commissioned by each CCG.

There are a number of opportunities to this model of commissioning, these include:

- A reduction in the financial risk to any single CCG in respect of these very high cost packages of care which are often difficult to plan for or predict
- Pooled resource to enable dedicated expertise in commissioning
- Development of a case management framework that underpins an established access and egress protocol
- Pooled resource of expertise in appropriately skilled clinicians/professionals to work for the CCG collaborative as case managers, across a larger geographical area
- The development of a single contract and standard specification (appreciating the individual requirements of this patient group)
- A single operating model to ensure quality and safety are monitored with the required level of scrutiny
- More opportunity to make better use of the limited provider market and create more confidence and surety amongst existing and new providers

This work will be pursued through the Yorkshire and Humber TCP Specialised Commissioning Sub-group and the next steps are:

- Financial modelling of various scenarios and governance arrangements
- Tighten up the scope in relation to access and egress to the risk share
- Consider opportunities for financial support to this project via the TCP plans, specifically in relation to any double running costs for specific patients and also project support, commissioning and case management expertise to develop the project further

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### 2.2 Our Governance arrangements for this transformation programme



A local Transforming Care Programme Board has been established whose purpose is

1. To oversee the development and implementation of the Local Transforming Care Plan in line with Building the right support, ensuring the NHSE/ADASS deadlines are met.
2. To act as a forum for partnership building, sharing good practice and ideas and identifying and unblocking barriers to system change.

This Programme Board meets monthly and membership includes senior leadership from the East Riding of Yorkshire, Hull and North East Lincolnshire areas, from CCGs,

Council Adult and Children Services. In addition there is senior representation from Humber NHS Foundation Trust (HFT), NHS England (Yorkshire & the Humber), Yorkshire and Humber Specialised Commissioning Team, and the Chair of the Humberside MAPPA (Multi-Agency Public Protection Arrangements) Strategic Management Board.

The SRO of the Humber Transforming Care Programme Board is Jane Hawkard, CO East Riding of Yorkshire CCG and Deputy SRO is Alison Barker, DASS Hull City Council. Terms of Reference and the Governance Structure are attached as Appendices 1 and 2

We will identify how we include people with learning disabilities and/or autism, their families and carers in the governance of the Partnership through the Learning Disability Partnership Boards (LDPB) for Hull, East Riding and North East Lincolnshire. In particular, we are keen to involve service users and carers who already receive Personal Budgets or Personal Health Budgets (PHBs) to help us build personalisation into our programmes of work.

Whilst the Yorkshire and Humber Specialised Commissioning Team is represented on our Programme Board we recognise that there are six Transforming Care Partnerships (TCPs) in Yorkshire and Humber (excluding Bassetlaw CCG, who have chosen to join the fast track site in Nottingham) and for them to work across six TCPs will be a challenge. A specialised commissioning sub-group across the six TCPs has been established to ensure good communication and engagement and the Humber TCP is an active participant. This group will also ensure that there is appropriate representation and involvement from specialised services in terms of service users and families and carers. The Yorkshire and Humber Specialist Commissioning Team has been working collaboratively with local commissioners to ensure that plans include specialised services for our populations. The challenge of resettling individuals within this patient group safely is acknowledged by the Programme Board and will provide a key focus of our engagement with the Yorkshire and Humber TCP Specialised Commissioning Sub-group.

Five Workstreams have been established by the Humber Transforming Care Programme Board

1. Pathways of Care
2. Quality and Commissioning (including Estates)
3. Workforce Development
4. Engagement
5. Finance

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Key partners not currently represented on the Programme Board will be engaged through these workstreams. These include:

- Independent sector hospitals on the TCP footprint will be engaged through individual bilateral meetings between the CCG and hospital managers
- Housing Strategy – to ensure that the needs of the client group are included in the future Housing Strategies of the Councils
- Registered Social Landlords – to ensure that supported housing development meets the needs of the client group and that we have opportunities to grow the market
- Service Providers – to ensure they have the specialisms and trained staff to meet the needs of the client group, and to ensure that the Partnership understands the issues they face as they adapt to deliver new services
- Children Services are represented on the Programme Board but we will need wider engagement with them to ensure that those young people preparing for adulthood are able to access appropriate housing, health, support, education and recreational activities
- Reports will be provided to the relevant Safeguarding Adult and Safeguarding Children Boards
- Humberside Police. Initial engagement with Humberside Police will be through MAPPA and through the established Mental Health Crisis Care Concordat groups
- Humberside Probation services to support the development of community forensic pathways and risk management
- CCGs and Councils outside the area who may place individuals within the footprint of the Partnership
- Local Education and Training Boards to support our workforce development strategy
- Voluntary and Community Sector groups will be engaged through established community networks

such as Local Links within the East Riding. VCS groups which provide services to people with a learning disability and/or autism and their carers will be engaged through a workstream relevant to their type of provision

The Programme will be supported by a Project Management Office structure which will be embedded within the current PMO arrangements of the lead CCG, East Riding of Yorkshire CCG.



### 2.3 Our stakeholder engagement arrangements

The geographical and organisational footprint of the Partnership means that some stakeholder engagement arrangements will be across Hull, East Riding and North East Lincolnshire, and some will have to be more local.

Critically we will ensure effective engagement with people with a learning disability and/or autism and their families and carers.

#### **Hull and East Riding**

Hull operates a well-established Learning Disability Partnership Board (LDPB), which rigorously



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holds the authority to account in relation to local decision making and future plans and proposals for service delivery. The Hull Safeguarding Board also operates a strong third sector forum which focuses on practice and experience within the locality. The oversight and governance of the local board in terms of operational practice is a crucial part of the authority testing its service delivery and offer in relation to all levels and intensities of need. There are also a number of local third sector organisations which operate user and parent and carer forums which provide useful sources of feedback and often the most truthful source of performance evaluation.

A regular 'Better Health' meeting is held bi-monthly as a sub-group of the Hull LDPB. The membership is predominantly self-advocates who receive a range of local services from health and social care statutory and voluntary services. Family carers and local providers also attend regularly as part of reviewing the local health care delivered to individuals with a learning disability from primary and secondary care services. Transforming Care is part of the regular agenda. On the 25th of January 2016 the group held a small event at Townend Court Assessment and Treatment unit aimed at self-advocates and inpatients who are currently receiving services there and supported them to participate in an awareness session on 'Building The Right Support' and models of care.

The East Riding Learning Disability Partnership Board, consisting of people with a learning disability and their carers, service providers and commissioners, met on 28th of January and the Board was updated on current progress towards the development of the plan.

A joint meeting was arranged between the East Riding and Hull Learning Disability Partnership Boards for Monday 1st February 2016 to consult with service providers, self-advocates and carers on the Transforming Care Programme. The event sought views on the nine principles of the national plan and the output of the event is included at [www.hullccg.nhs.uk](http://www.hullccg.nhs.uk) as will reports of future events.

The presentations to both groups will be shared with NE Lincolnshire for their local adaptation and use with their local Valuing People Partnership Board and self-advocate groups.

On the 11th May Hull City Council and Hull CCG hosted, on behalf of the partnership, a Transforming Care Plan Programme event at the Freedom Centre in Hull. This event included presentations from national and local leads and was very well received.

Parents and carers of children and young people with a learning disability and/or autism will be engaged through the existing East Riding Voices in Partnership group (ERVIP), which holds bi-monthly meetings with professionals to consider issues. ERVIP are also represented in the local SEND group and Emotional Health and Wellbeing Strategy group.

Advocates are central to the process of engagement and Councils have reviewed the provision within their localities regarding assessment advocacy under the definitions of the Care Act. The outcome of the review will be to define a register of accredited provision for value tested spot purchasing of individual advocacy service. However, this register will not replace the existing approach of referral to the current contracted Independent Mental Capacity Advocacy (IMCA) service, where life changing decisions are to be made under Best Interests, nor Independent Mental Health Advocacy (IMHA) services which advocate for people detained under the Mental Health Act.

North East Lincolnshire

Stakeholder engagement will be managed through pre-existing locality systems. The co-operation required between Social Care and Health Care to plan and deliver the plan will be achieved through close working relationships under the Section 75 agreement. Links to Community providers are well established through the Provider Forum. In addition good relationships exist between Building Developers, Social Landlords, and Specialist Care Providers as a result of ongoing work in developing

## 2 Mobilise communities

bespoke new and new-build facilities to enable people with learning disability and/or long-term mental ill-health to live in a place of their own.

In North East Lincolnshire service user involvement is gained through forums including:

- Valuing People Partnership Board (equivalent to the LDPBs in Hull and East Riding)
- Service user forums delivered by the main local service providers, Focus and NAViGO

Further User and Carer involvement can be facilitated through involvement groups and workshops facilitated by Accord, the CCG Engagement Team.

Community representatives are an intrinsic part of all commissioning decisions and developments through the CCG Commissioning Triangles structure. In this model planning for the future of health and adult social care services is agreed through teams made up of three people: a clinician who specialises in the field, a service lead from the CCG, and a volunteer from the Community Forum who makes sure that the voice of public and patients is heard. Together these three voices have an equal influence during planning and decision-making.

### NHS England

From a Specialised Commissioning team perspective, adult secure involvement and engagement is facilitated via the Yorkshire and Humber (and North East) Recovery and Outcomes Group. This group is one of nine groups nationally that include adult secure patients and staff. There is an overarching National Recovery and Outcomes Steering Group which ensures work that takes place across the local groups feeds into and informs the national agenda. A consultation event is planned for later in 2016.

For Child and Adolescent Mental Health Services (CAMHS), involvement and engagement is part of the implementation of the Local Transformation Plans, and Specialised Commissioners will support the local consultation processes to ensure that the whole system, including inpatient care, is considered. This will provide stronger plans that are aligned to TCPs, with the acknowledgement that implementation of both plans requires the whole CAMHS system transformation to enable an integrated approach to change. The Yorkshire and Humber TCP Specialised Commissioning sub-group will ensure that appropriate representation is on hand to inform the whole process during the planning and implementation stages.

### 2.4 Co-production

Please visit [www.hullccg.nhs.uk](http://www.hullccg.nhs.uk) for reports on any stakeholder engagement events which take place.

There has been individual consultation as part of Care and Treatment Reviews (CTRs) for those in Assessment and Treatment Units or in beds commissioned out of area which have included the views of future provision. This has included family members, advocates and local care co-ordinators. This has informed individual planning but we do not currently have a mechanism for collating the feedback given at CTRs. We will develop such a system as part of our transforming care programme to inform our future planning.

The plan as it develops will include feedback from self-advocates and families, including young people, children and their families. The consultation on the emerging plan will be established with current known local groups across the foot print. This will include opportunities for group and individual responses publicised via the local Partnership Board arrangements. A speech and language therapist has been identified to support this process and to ensure our communication is accessible and effective.

## 2 Mobilise communities

To engage with younger people and their families we plan to pull together a short letter or questionnaire to be circulated through services such as schools, day services, residential services and colleges inviting individual or group comments. ERVIP (East Riding Voices in Partnership) regularly send questionnaires to members and hold parent / carer events and we will seek to work with them in developing the detail of our plans.

We will also seek views through the websites of partner organisations, including Councils, CCGs and HFT. We will formalise this through an agreed communications and engagement plan and a rolling programme of engagement and regular updates will be established.

East Riding CCG has an established local network for East Riding of Yorkshire residents who are registered with an East Riding GP and who care about the NHS, called Involve. Involve members help by contributing their views. A number of members of Involve have a stated interest in Learning Disability. CCGs can also draw on the experience of members of GP Patient Participation Groups.

A detailed communications and engagement plan will be developed through Q1 of 2016/17 and the Transforming Care Programme will be a part of the CCG Communication and Engagement plans for 2016/17.

Developing services through co-production is a challenge and we will work with other TCP areas and organisations such as Inclusion North to help us. A local speech and language therapist has been identified to support this process and to ensure our communication is accessible and effective. We anticipate that future co-production may lead us to develop the plan in ways we don't necessarily expect. However, it is likely that that it will drive us to develop services which recognise the aspirations of people with a learning disability and/or autism, as well as to understand the limitations of carers, on whom the burden of care has often fallen heavily.

### **Our population / demographics**

## 3 Understanding the status quo Baseline assessment of needs and services

### 3.1

#### East Riding of Yorkshire

The East Riding of Yorkshire is a large rural area of around 1000 square miles, including coastal towns, urban fringe and remote rural towns and villages. It is largely affluent although there are pockets of significant deprivation in Bridlington, Goole, Withernsea and some parts of Beverley.

East Riding of Yorkshire CCG is not coterminous with East Riding of Yorkshire Council. As at January 2015 East Riding of Yorkshire CCG has a population of 301,745 registered with its GP practices, 313,386 resident in East Riding of Yorkshire CCG area and East Riding of Yorkshire Council is responsible for a larger resident population of 337,115 (2014 ONS projection).

A number of East Riding of Yorkshire residents are registered with GP practices in Hull CCG or Vale of York CCG.

The health of people in East Riding of Yorkshire is varied compared with the England average. Deprivation is lower than average, however about 12.6% (6,900) children live in poverty. Life expectancy for men is higher than the England average but there are variations and life expectancy is 6.1 years lower for men and 4.5 years lower for women in the most deprived areas of East Riding of Yorkshire than in the least deprived areas. Priorities in East Riding, as described in the JSNA, include healthy, independent ageing; reduction in health and wellbeing inequalities; and good health and wellbeing for children.

According to the latest LD Profiles at IHAL, the Improving Health and Lives Learning Disabilities Observatory, (2013/14) there were 1,268 people registered on learning disability registers within primary care, and 50.3% of eligible adults with a learning disability had had an annual health check. Whilst we have delivered training to GP practices on delivering the Learning Disability Enhanced Service and undertaking health checks, we know we have a relatively low take up among GP practices and there is more work to be done to support practices in delivering high quality care to people with learning disability. Feedback from service users and carers indicates a mixed experience of health checks, ranging from very good to no health check at all. There has been a significant amount of work undertaken to raise the awareness and knowledge with primary care of issues relating to mental capacity, in particular a Protected Time for Learning event which focused exclusively on the application of the Mental Capacity Act within primary care and the use of Deprivation of Liberty Safeguards.

#### Hull

Hull is an innovative and dynamic city that has faced significant challenges in respect of the health and wellbeing of its population. The city boundary is tightly forged around dense areas of deprivation. The 2010 Index of Multiple Deprivation which uses a broad range of indicators to measure poverty and other problems identified Hull as the 10th most deprived local authority in the country. Life expectancy is lower than in most of England, with a difference of up to 10 years between the least and most deprived wards, over half of people aged 65+ have a long-term illness with 1 in 5 likely to have a mobility issue.

Approximately 259,600 people live in Hull; of which approximately 15% or 38,300 are over the age of 65, and 2% or 4,900 are over 85 years. The population is expected to grow further and by 2020 we expect that there will be another 6000 people living in the City with approximately 3000 of these over the age of 65.

#### North East Lincolnshire

The North East Lincolnshire (NEL) population is 156000 residents, however the population registered to GPs is closer to 168000 as Primary Care serves villages outside of the NEL boundaries to the west

### 3 Understanding the status quo Baseline assessment of needs and services

and south. Geographically North East Lincolnshire is on the periphery of greater Lincolnshire, on the southern bank of the Humber Estuary. Census figures classify 94.2% of the population of NEL as living in an urban environment. The major population centres are the towns of Grimsby, Cleethorpes, and Immingham and there are larger and smaller villages in the surrounding area.

North East Lincolnshire has rail links to Doncaster and Lincoln, with quicker and easier road and bus links to Hull and East Riding. This peculiar geographical position has resulted in bespoke arrangements in service model and delivery in North East Lincolnshire. By virtue of being co-terminus with North East Lincolnshire Council, and through a unique Section 75 agreement, North East Lincolnshire operates an integrated Health and Social Care commissioning. NELCCG commission Health and Social Care for Adults, and NELC commissions Health and Social Care for Children together with Public Health responsibilities.

Demographically, the overall size of the population of NE Lincolnshire is stable but there are gradually increasing numbers of people in older age groups. After a long period when the number of annual births was historically low we have seen a significant growth in the number of babies born in the last few years which is putting pressure on services for this age group which will impact on schools in the next few years. The number of people from an ethnic minority in the authority remains low (4.6% in 2012) compared with most other places.

Findings from the English Indices of Deprivation 2010 (ID 2010) show that NE Lincolnshire has high levels of socio-economic deprivation, particularly within areas of Fiveways and Central neighbourhoods (East Marsh, West Marsh and South wards). Overall, NE Lincolnshire is ranked as the 46th most deprived local authority in England, out of 326. 38.5% of NEL's population reside in the top 20% areas of deprivation in England. An LSOA in East Marsh ward is ranked as the 2nd most deprived LSOA in England.

#### **Humber Transforming Care Partnership footprint**

Oxford Brookes University and Institute of Public Care provide an estimate of current and future populations of people with a learning disability or autism through their publically available websites PANSI (Projecting Adult Needs and Service Information) and POPPI (Projecting Older People Population Information System). This indicates the following changes in population over the next five to fifteen years

## 3 Understanding the status quo Baseline assessment of needs and services

Predicted Populations		East Riding	Hull	North East Lincolnshire	Transforming Care Partnership
<b>Adults 18-64 with a learning disability</b>	2016	4,678	4,048	2,295	11,021
	2020	4,656	4,013	2,261	10,930
	2030	4,531	3,975	2,176	10,682
	Growth	-3.14%	-1.80%	-5.19%	-3.08%
<b>Adults &gt; 65 with a learning disability</b>	2016	1,759	813	658	3,230
	2020	1,905	869	702	3,476
	2030	2,306	1,063	837	4,206
	Growth	31.10%	30.75%	27.20%	30.22%
<b>Adults 18-64 with autistic spectrum disorders</b>	2016	1,934	1,677	939	4,550
	2020	1,934	1,670	926	4,530
	2030	1,892	1,662	895	4,449
	Growth	-2.17%	-0.89%	-4.69%	-2.22%
<b>Adults &gt; 65 with autistic spectrum disorders</b>	2016	792	363	294	1,449
	2020	856	390	316	1,562
	2030	1,054	482	381	1,917
	Growth	33.08%	32.78%	29.59%	32.30%

Detailed projections of future population changes are given in Appendix 3. The key messages from this are that while the population of adults 18-64 with a learning disability is fairly static, the number of people over 65 with a learning disability is set to rise substantially, with a corresponding increase in the prevalence of age-related diseases within this population.

A summary of the number of people with a learning disability and/or autism receiving services as at March 2016 is as follows

	East Riding	Hull	North East Lincolnshire	Transforming Care Partnership
<b>Number of inpatients in CCG funded placements</b>	7	10	1	18
<b>Number of adults in secure hospital</b>	7	12	8	27
<b>Number of funded packages of care in community settings (adults)*</b>	515	551	253	1,319

### 3 Understanding the status quo Baseline assessment of needs and services

The national model describes five cohorts of people with particular needs

- 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.

All three localities of the TCP footprint have recently developed their transformation plans for promoting, protecting and improving the mental health and wellbeing of children and young people. The implementation of this Transforming Care plan will be in parallel with that of the Future in Mind plans. We are currently establishing project mechanisms which will ensure effective alignment of these workstreams.

Where appropriate, adults with a learning disability and/or autism will receive care and treatment through mental health services for an identified mental health condition. Providers are expected to keep services under review using the Greenlight Toolkit to guide joint working between mental health and learning disability services. One provider of primary care psychological therapies has a Learning Disability nurse within its team and is developing numerous easy read resources for patients.

- 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.

There are a number of individuals in this cohort, who have generally been well-known to services since their childhood. They are often in high cost placements and, sadly, a number of these placements have broken down putting the individual at high risk of admission to hospital. They are the focus of work seeking to develop specialist Supported Living placements which will be able to respond flexibly to the very changeable and challenging needs that these individuals have. A key outcome of the work on this plan so far has been the recognition that this is a priority group for all three localities within the partnership because of the difficulties in attracting specialist providers to the area.

- 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).

Multi-agency coordination of the care of this group will often be delivered through Multi Agency Public Protection Arrangements (MAPPAs) and we expect more people to be subject to community MAPPA arrangements as we facilitate the resettlement of individuals from the forensic inpatient estate. We have involved Probation and MAPPA as a partner to ensure we develop and maintain safe pathways. For some complex individuals with a learning disability and Personality Disorder at risk of entering the criminal justice system we have involved the regional Pathway Development Service to support the safe and effective management of individuals who otherwise would have overwhelmed the capability of local care providers.

- 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.

This group often come to the attention of services through MAPPA and can pose a challenge in that

### 3 Understanding the status quo Baseline assessment of needs and services

they may not meet the criteria for entry into particular services. However, commissioners and providers seek to work together pragmatically with our colleagues in the criminal justice system to find individual solutions and packages that will maintain public safety as well as meeting the needs of the individual

- 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.

This is a cohort of individuals which is slowly getting smaller. We have been successful in developing care packages for a number of people in this cohort, with only one readmission so far. We have plans for the resettlement of the few remaining individuals in the March 2014 cohort occurs during 2016/17.

At present we are not able to accurately quantify the number of people in each cohort as we have not sought to classify caseloads in this way until now. However, these five cohorts will be mapped against care clusters for Learning Disabilities, which are as follows:

Care Cluster 9A Maintenance, engagement and minor support needs, complicated by LD

This group will be experiencing minor difficulties with one or more of the following: emotional distress, behavioural dysfunction, vulnerability to others and history of aggressive behaviour.

They will be likely to have relatively mild levels of: cognitive impairment; impairment in adaptive behaviours and self-regulation (emotional and/or behavioural). They are unlikely to be experiencing significant social communication & interaction difficulties

Care Cluster 9B Risk to self, complicated by LD

This group will be displaying self-injurious behaviour. They will not be experiencing significant social communication & interaction difficulties. They are likely to have mild to severe: cognitive impairment, impairment in adaptive behaviours, general communication difficulties, self-regulation (emotional and/or behavioural).

Care Cluster 9C Risk to others complicated by LD

This group will be displaying physical and/or verbal aggression towards others. They will not be experiencing significant social communication & interaction difficulties. They are likely to have mild to severe: cognitive impairment, adaptive functioning impairment, general communication difficulties, self-regulation - emotional and/or behavioural.

Care Cluster 9D Risk to others, complicated by mild LD & ASD

This group will be displaying physical and/or verbal aggression towards others but not self-injurious behaviour. They will be experiencing social and communication difficulties and have relatively mild: cognitive impairment; problems with adaptive functioning; social communication and interaction difficulties; self-regulation (emotional and/or behavioural).

Care Cluster 9E Risk to others, complicated by moderate - profound LD & ASD

This group will be displaying physical and/or verbal aggression towards others but not self-injurious behaviour. They will have moderate to severe: cognitive impairment; problems with adaptive functioning, social communication & interaction difficulties, self-regulation (emotional and/or behavioural).

Care Cluster 9F Risk to others & self, complicated by moderate - profound LD & ASD

This group will be displaying physical and/or verbal aggression towards others and self-injurious behaviour. They will have moderate to severe: cognitive impairment; problems with adaptive



### 3 Understanding the status quo Baseline assessment of needs and services

functioning; social communication & interaction difficulties; self-regulation (emotional and/or behavioural).

Care Cluster 22 Physical health complicated by mild LD

This group will be experiencing significant physical health problems complicated by difficulties associated with mild learning disabilities which make unsupported access to mainstream services problematic. They will have mild: cognitive impairment; problems with adaptive functioning, impairments in self-care and communication difficulties.

Care Cluster 23 Physical health complicated by moderate - profound LD

This group will be experiencing significant physical health problems complicated by difficulties associated with moderate to profound learning disabilities (e.g. specific neurological impairments; sensory impairments). They will have moderate to severe: cognitive impairment; problems with adaptive functioning, impairments in self-care and communication difficulties.

Care Cluster 24 Physical health with dysphagia complicated by moderate - profound LD

This group will be experiencing significant physical health problems complicated by difficulties associated with moderate to profound learning disabilities (e.g. specific neurological impairments; sensory impairments). They will have definite physical difficulties eating and drinking safely. They will have moderate to severe: cognitive impairment; problems with adaptive functioning; impairments in self-care.

Throughout 2016-17, Humber NHS Foundation Trust will begin to map all new referrals to clusters, and then begin to cluster individuals on caseload in Quarter 3-4 16/17. This will enable the measurement of activity levels per cohort and help focus activity on need.

In addition we will explore how we might reflect the five cohorts in our design of an 'at risk of admission' register

#### 3.2 Analysis of inpatient usage by people from Transforming Care Partnership

##### CCG Commissioned Services

The main inpatient Assessment and Treatment unit for the Transforming Care Partnership is Townend Court, provided by Humber NHS Foundation Trust. This brand-new purpose-built facility has 14 beds for assessment and treatment purposes. Townend Court provides a 'hub' for the wider learning disability services across Hull and East Riding and can be accessed 365 days a year. In addition there are six step down and rehabilitation beds for males. All out of hour contacts are made through the unit and triaged prior to calling out on-call community nurses. This is part of the block contract commissioned by Hull and East Riding of Yorkshire CCGs. Whilst there has been interest in placing patients expressed by out of area commissioners it is not a major importer of patients to the area. Priory Hospital Market Weighton is a registered independent hospital for men located within the East Riding, supporting individuals with severe and enduring mental health conditions who may have complex presentations with behaviours that challenge. Some of the patients have a diagnosed Learning Disability. The core objectives of the hospital are to deliver rehabilitation, stabilise mental health, reduce the behaviours that challenge, develop daily living skills and actively maintain working relationships with case managers and community teams to enable a smooth and successful transition to life outside the hospital environment. This is an independent sector hospital and CCGs contract on an individual named patient basis. It is not unusual for there to be patients from out of area in the hospital.

The CCGs within the Partnership have in the past had to place individuals in hospitals out of area. This use of out of area provision has reduced substantially since the Winterbourne View scandal

### 3 Understanding the status quo Baseline assessment of needs and services

but there are still some patients placed out of area. Geographically these range from Darlington in the north to Mansfield to the south. The CCGs have arrangements for case managers to keep these placements under regular review and Care and Treatment Reviews (CTRs) are held every six months to assess whether or not discharge back to the community can be achieved.

We will work closely with Vale of York CCG and the North Yorkshire TCP to ensure that the patient flows from Pocklington, a town within the East Riding but whose healthcare is commissioned by Vale of York CCG, are understood and optimised.

Overall, the experience of the Partnership, since the development of Townend Court as a newly built Assessment and Treatment unit, has been that we have not needed to seek out of area placements and we expect to continue to manage any necessary admissions locally, with teams closely linked to community services to facilitate discharge.

Occasional admissions of individuals with autism (but not a learning disability) into acute mental health units have highlighted the need to develop “autism friendly provision” on the footprint.

#### **NHE England Commissioned Services**

There are currently 143 adult secure beds in Yorkshire and Humber area. The breakdown of these beds is as follows:

##### *Medium Secure (all male) – Total 81 beds*

- York – Stockton Hall – Partnerships In Care (York) – 24 beds (8 of these are autism beds)
- Doncaster – Cheswold Park – Riverside – 27 beds
- Wakefield – Newton Lodge – SWYPFT – 20 beds
- Hull – Humber Centre – Humber NHS FT – 10 beds

##### *Low Secure – Total 62 beds*

- Doncaster – Amber Lodge – RDASH – 23 beds
- Wakefield – Newhaven – SWPFT – 16 beds
- Grimsby – Bradley Woodlands (male & female) – Lighthouse – 23 beds

In addition, it is helpful to remember that in February 2015 Huntercombe Hospital in East Yorkshire closed. This service had 24 beds (8 male medium, 16 male and female low secure) so the closure of these beds already accounts for a reduction within the Yorkshire and Humber area.

Patients from the Humber TCP area are in a range of these placements.

#### **3.3 How Services are delivered currently**

This section describes how services are currently delivered. It is split into three sections:

- East Riding and Hull, which have a long history of working together and have many providers in common
- North East Lincolnshire
- And then some common themes across the Partnership

#### **Hull and East Riding**

The main provider of NHS Learning Disability services is Humber NHS Foundation Trust (HFT) which delivers across both Hull and the East Riding.

The local Learning Disability Service operates an open referral system. The Community Learning Disability Teams (CTLD) are the first point of contact to both inpatient and community services. Within Hull the CTLDs are integrated with Council LD services. In the East Riding there are plans for

### 3 Understanding the status quo Baseline assessment of needs and services

CTLD services to move to a more accessible team base with greater connectivity to the existing East Riding of Yorkshire Council Care Management Services, including the well-established Futures Plus Service, which has a significant role in supporting people in transition along with other vulnerable times in their lives.

CTLDs operate a core multi-disciplinary service from Monday to Friday from 8:30 am until 5:00 pm. A seven days a week service is provided by Community Nurses. A twenty four hour, 365 days a year community nursing service is available and is accessed through Townend Court Inpatient Unit. The inpatient unit also responds to community clients who require additional support, help and reassurance at any time via telephone contact. The service also triages any requests for the “on call” community nurse.

CTLDs offer the following interventions:

- Assessment and treatment inpatient services
- Care Management / Person Led Assessments
- Psychiatry
- Psychological Therapy
- Occupational Therapy Services
- Speech and Language Therapy enhanced feeding support
- Physiotherapy advanced postural management
- Learning Disability Nursing Services
- End of life integrated care packages
- Complex home care packages (PPMLD)
- Continuum (Positive behavioural support to people in situ)
- Epilepsy Assessments and Management Plans
- Dementia Assessment and Support
- Transition Planning
- MAPP / Probation support
- Autism Diagnosis and support
- Sensory Profiling
- Sex offender treatment programme including adapted model

Services are offered through a tiered model of delivery aligned to the levels of direct clinical activity. It is a connected care model, with a full pathway and wrap around support leading to inpatient admission where required. An admission panel and care and treatment reviews (CTRs) ensure effective gatekeeping to inpatient services. Where feasible additional support is delivered in the patient’s home (either family home or residential care) to provide placement safety and stability.

More detail is given below. At each level we also acknowledge the important provision of advocacy in relation to maintaining the patient/customer voice throughout the process.

Tier	Current Services
<p><b>Tier 4: Acute Interventions</b>  <b>Townend Court</b>  <b>Willows Unit 6 beds</b></p> <p><b>Lilac Unit 8 Beds</b></p> <p><b>Beech Unit 6 Beds</b></p>	<p><b>Inpatient services</b> providing specialist care and treatment for people with learning disabilities and/or autism</p> <p><b>Crisis and Assessment</b> – A 6 bedded unit including 2 crisis beds and 4 assessment beds. All admissions would be directed via this unit with individuals commencing on the STANDARD pathway. Assessment and treatment service for severe challenging behaviour and acute mental illness who have become a risk to themselves and others</p> <p><b>Treatment/Intervention</b> – An 8 bedded treatment unit implementing concise intervention plans. All individuals within this service will commence on the INTERMEDIATE pathway.</p> <p>Treatment unit follows acute support and intervention increased focus on preparation and support for return to normal community placement</p> <p><b>Step down and Rehabilitation</b> – A 6 bedded male only unit which provides a focus on rehabilitation; supporting individuals who require longer term support to facilitate safe return to ordinary community placements. This may include transition into newly commissioned services.</p> <p>The individual requires support to connect back into local support structures. This includes ongoing engagement with services to help maintain coping skills or develop practical skills that help facilitate a return to independent or supported living community living.</p>
<p><b>Tier 3: Building Capability within Specialist Learning Disabilities Services</b></p> <ul style="list-style-type: none"> <li>• <b>Continuum Service</b></li> <li>• <b>CTLDs</b></li> <li>• <b>Complex Care team</b></li> <li>• <b>Acute Liaison</b></li> </ul>	<p>Community Services providing specialist care and treatment for people with learning disabilities and/or autism</p> <p>Assertive outreach support and rapid interventions to enable people with complex needs to maintain community living and avoid exclusion from their current services. Close liaison with offender health support and MAPPA structures</p> <p>Enhanced interventions include integration with Hull City Council for social care. The team provides specialist assessment from a range of professionals. Support includes individuals with profound and multiple physical disabilities who require high levels of care to be readily available.</p> <p>Long term care management is integral to the pro-active care of individuals who are deemed complex due to behaviours that can challenge or the other end of the scale, people with a profound and multiple physical disabilities (PPMLD).</p> <p>Nursing post attached to the acute Trust linking into CTLDs to ensure both planned and unscheduled admissions of people with a Learning Disability is co-ordinated and supported to ensure a positive patient and carer journey. (NB Similar posts, delivered by other providers, exist at York, Scarborough and Scunthorpe hospitals)</p>

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Tier	Current Services
<p><b>Tier 2: Building Capability in Mainstream Services</b></p> <p><b>CTLD Community Support</b></p>	<p>Community interventions in partnership with other agencies to enable the development of capable mainstream services to address the needs of people with learning disabilities and their carers .</p> <p>Multi-agency and multi-disciplinary community teams, offering ongoing proactive and crisis support between levels of intervention.</p> <p>The CTLD provide the initial contact point for all new referrals to the service</p>
<p><b>Tier 1: Building Capability in the Community</b></p> <p><b>Generic Health Facilitation and Prevention</b></p>	<p>Interventions to promote health, wellbeing and inclusion of people with learning disabilities at a general population level</p> <ul style="list-style-type: none"> <li>• Advice and guidance support to primary care, acute Trust, education and other statutory, voluntary and independent providers of services to individuals in the community</li> <li>• Health facilitation</li> <li>• Advice and support</li> <li>• Training and development</li> <li>• Carers support groups</li> <li>• Service user engagement groups</li> <li>• Health and wellbeing facilitation</li> </ul>

### 3 Understanding the status quo Baseline assessment of needs and services

**Granville Court** provides a nursing home service for 14 adults who have profound and multiple learning disabilities alongside complex physical health problems that mean they need nursing care to be constantly available. The service has expanded to include respite care facilities and this contributes to supporting families in maintaining their caring role. A Section 75 arrangement with East Riding of Yorkshire Council enables joint health and social care to provide integrated care to support the direct delivery of services.

**Child and Adolescent Mental Health Services (CAMHS)** are also provided by HFT, who implemented a new service model in April 2014, driving a number of significant improvements. These include:

- The introduction of new local access targets - in particular a local target for 95% of referrals to result in intervention, where appropriate, within 18 weeks of referral, to achieve parity of esteem with physical health services.
- Introduction of a single point of access (Contact Point), operating Monday to Friday 8am to 6pm, accepting referrals from young people themselves, parents or carers, as well as health, education and other professionals, and also offers advice, support and information.
- A consultation service providing specialist mental health and wellbeing advice and support to professionals working with children and young people.
- Introduction of an intensive intervention service providing planned interventions over extended hours seven days per week for those who are at risk of admission to inpatient CAMHS. This service also facilitates regular contact between young people admitted to inpatient units and local CAMHS making discharge planning more effective. This is particularly important as the nearest CAMHS inpatient services are in York and Leeds, up to 70 miles from parts of the TCP area.
- Participation in the national children and young people's IAPT programme.
- Crisis assessment both in and out of normal working hours.
- Targeted services providing support to vulnerable groups, including looked after children, children and young people with learning disabilities and young offenders.
- Six specialist pathways –
  - o mood (anxiety and depression)
  - o conduct disorders
  - o ADHD
  - o eating disorders
  - o deliberate self-harm
  - o psychosis

Families of children and young people have 'choice and control' in respect of the support packages for their disabled child. The Children's Disability Team are fully familiar with the Personal Budgets and ensure personal budgets are promoted to families.

Social care provision is delivered by range of providers across the footprint of the partnership, including residential and nursing care, supported living and extra care, domiciliary and day care, and work and training opportunities.

The majority of people with a learning disability within the East Riding are supported to live in their communities and are supported by locality or specialist Care Management teams. Social care is delivered through the use of individual budgets or residential / nursing care. Short break facilities are available as are day services and work opportunities. In the East Riding there are 60+ independent supported living schemes that support the individual to maintain their tenancy and assist with meeting needs to ensure maximum independence for the individual.

There is a contract for housing related support (HRS) that enables individuals who require tenancy support to remain within their own homes without extensive use of social care staff.

### 3 Understanding the status quo Baseline assessment of needs and services

Where a person has a learning disability and mental health difficulties the mental health team and Care Management team will work together to find suitable solutions to support the individual.

Within Hull the provision of service for people with a learning disability and/or autism is delivered by Council Supported Independent Living schemes, local private Supported Independent Living schemes funded through Personal Budgets, and a (under-65yrs) complex care residential market.

A formal relationship is managed through an existing Housing Related support framework, which consists of several landlords with RP status. A planned re-procurement of the residential care sector in 2016/17 will modernise this contract.

Commissioners recently concluded a strategic review of 'complex' (under-65yrs) residential services. This review identified the need to move away from the current predominant offer of permanent residential care. Work has taken place to develop a model of 'complex care' residential service(s), building on the advantages of a stable environment to deliver outcome-focused, least restrictive interventions that can help people to make positive changes and take greater control of their lives and, in some cases, move on from residential care.

The external supported living market has also been subject to change with the Council reviewing its internal offer and the delivery of 300+ extra care units which are to be in place from early 2017. The unique position of the Hull Extra Care offer is its inclusive approach to supporting people regardless of their additional needs. Therefore, the redesign of the complex care residential sector relates directly to setting out a clear pathway for a person to achieve their independence potential.

Current challenges for local learning disability services include:

- Increase in the complexity of patients accessing inpatient services
- Supporting older families caring for adults with learning disabilities
- Limited alternative local provision which has resulted in a national picture of continued placement of patients out of area
- Incomplete pathway has sometimes restricted repatriation of existing out of area patients
- Requirement to develop and support other local providers including statutory, voluntary, and the independent sector to meet long term needs of this client group
- A need to expand local crisis services for individuals in situ
- A need to recognise and support individuals with autism who may have additional support needs but might not have a learning disability. Whilst we have an assessment and diagnostic pathway in place, we need to consider the development of post-diagnostic support and a care pathway which identifies autism-appropriate inpatient services should the need arise
- A need for local Health and social care providers to work across partnerships to offer integrated solutions to meet peoples' complex needs
- A need to develop the competence and confidence of local workforces to manage people with complex needs and challenging behaviour

#### **North East Lincolnshire**

The standard offer in North East Lincolnshire is through a Personal Budget. Adults with a learning disability supported through Supported Living in North East Lincolnshire have allocated case co-ordinators provided by Focus Independent Social Work who assess, support plan, and review, informing the individual's Personal Budget. The current Adult Learning Disability system is based strongly on the Supported Living model, funded through individual budgets. Supported Living Providers support the individual to maintain their tenancy and assist with meeting needs to ensure maximum independence for the individual.

### 3 Understanding the status quo Baseline assessment of needs and services

More complex cases are also supported in a number of ways through a specialist Community Learning Disability team hosted by the provider Care4All. The Clinical Specialist Psychologist led Intensive Support Team, hosted by Care Plus Group, provide short term intensive and highly skilled support in the community where individuals with complex learning disability needs who are in crisis or pre-crisis, and devise longer term strategies to inform planning with, for, and around the individual. These are commissioned through block contract to ensure the individual is restored to maximum independence as soon as possible. Where this intervention is insufficient there is a small amount of complex respite available. For routine care packages in a parent/carers home, short breaks are an integral and valued part of the person's plan.

When a person with learning disability also has mental health problems then mental health services may be involved. A comprehensive Mental Health service for people in North East Lincolnshire is provided by NAViGO, which has implemented the Greenlight Toolkit. The effectiveness of joint working between learning disability and mental health services is facilitated at provider level and supported through joint working protocols.

Complex and Higher Risk care packages, such as those within the identified cohorts, are required to be brought to the Risk and Quality Panel in North East Lincolnshire, a multi-agency panel including CCG as commissioner and Focus and NAViGO as micro-commissioners, to scrutinise and agree the safety, quality, and funding arrangements of the care package for the individual.

The aim is that every person with a learning disability and/or autism has a personal plan, and this is largely achieved. This whole system has been able to arrange the return of several people from out-of-area placements, enabling them to step-down from more complex care packages, and enable transition from very complex and challenging care packages from children to adult services.

The geography of the area, being a relatively isolated pocket of urbanisation over an hour from the main trunk routes on the East Coast, means that we struggle to maintain a skilled and qualified workforce to meet the needs of these small populations. This in turn leads to reduced confidence with care & outcomes possible for this most complex cohort, giving the impression that providers appear unwilling to take sufficient levels of positive risks in managing complex needs.

#### **Across the Transforming Care Partnership**

Overall, it can be seen that across the Transforming Care Partnership, north and south of the Humber, we have different systems in place and different experiences. However, when we consider the five cohorts it can be seen that we share a number of challenges and opportunities which will benefit from the closer working of the Partnership

We have challenges meeting the needs of people with complex autism and challenging behaviour, particularly young people graduating through transition who also require educational support. The low prevalence means we have not been able to attract providers who have the relevant skills. The low number of facilities locally offers the challenge of providing sufficient respite for families of people who have complex behaviours. There is an increase in demand for support of people with high-functioning autism who are not eligible for social care services, and who are not usually mentally ill, so do not generally qualify for Individual Budgets.

Our biggest challenges are

- people coming through transition where families believe specialist educational Autism placements are required
- people being discharged from low secure units where the primary need is Mental Health and risk of re-offending



### 3 Understanding the status quo Baseline assessment of needs and services

Adults with a learning disability and/or autism with a comorbid mental health problem will receive care and treatment through mental health services. Providers are expected to keep services under review using the Greenlight Toolkit to guide joint working between mental health and learning disability services. One provider of primary care psychological therapies has a Learning Disability nurse within its team and is developing numerous easy read resources for patients.

There are a number of individuals with a severe learning disability and autism who display self-injurious or aggressive behaviour, not related to severe mental ill health, who are well-known to services. They are currently in high cost placements (sometimes hospital) and are the focus of work seeking to develop specialist Supported Living placements which will be able to respond flexibly to their substantial needs. This is a significant issue for all of the partners on the Programme Board.

Multi-agency coordination of the care of individuals with offending behaviours will be delivered through MAPPA if they are eligible, or through professional meetings aligned to the statutory MAPPA processes. This is a population which is sometimes unknown to local services as the individuals often come to our attention via the Court or prison services. Sometimes the support needs attributable to learning disability or autism, or mental illness, are quite low but health and social care agencies engage with partners to seek to ensure public safety as well as meeting the needs of the individual. For some complex individuals with a learning disability and Personality Disorder at risk of entering the criminal justice system we have involved the regional Pathway Development Service to support the safe and effective management of individuals who otherwise would have overwhelmed the capability of local care providers.

#### 3.4 How does our current system perform against national outcomes?

In Building the Right Support, East Riding and Hull are identified as having a relatively high rate of both CCG commissioned and NHS England commissioned inpatient usage compared to the national average.

Appendix 4 gives a summary of the performance of the three local authority areas against national outcome measures and benchmarks them against the England and the Yorkshire and Humber average.

#### 3.5 What does the current estate look like in relation to housing for individuals?

All three local authorities are unitary, making strategic relationships with Housing much easier. We will work with Councils to review their Accommodation strategies in the light of these cohorts of vulnerable individuals.

Permanent residential care is available in the East Riding and there are 60+ independent living schemes for people with learning disabilities/autism which provides settled accommodation for many. However, it is acknowledged that work needs to be undertaken to determine which of those schemes may no longer be fit for purpose. There is also a 'Shared Lives' service that enables adults with a learning disability to live with families who are paid to offer support within their own home. This service currently supports 32 people with a learning disability.

East Riding Adult Services is working with housing providers to develop independent supported living schemes for people with complex behaviour/autism/learning disabilities: two schemes with capacity of 14 units were established in 2015/16 and the intention is that we will continue to develop schemes. In addition Adult Services is working with Housing Strategy to develop an inclusive housing policy that will be of benefit to this client group, ensuring their future housing needs are identified and met.

### 3 Understanding the status quo Baseline assessment of needs and services

In Hull there are about 37 complex care residential services, for all needs, delivered by 16 different providers. The number of people with a learning disability in long term residential care is 217. In addition there are 39 individuals in Shared Lives schemes which are seen as a positive means to providing stability and facilitative support within a family based setting.

The supported living market is currently being reviewed but Hull is committed to developing credible community accommodation options and independent supported living will play a key role in the future.

There are also developments underway in Hull to develop Extra Care Housing. New Extra care resource will be available to people with a learning disability throughout 2017 as follows:

- 15 apartments, ready for occupation 09/01/2017
- 15 apartments, ready for occupation 10/04/2017
- 30 apartments, ready for occupation 03/07/2017

The initial lets of apartments will be prioritised for people who are known to or receiving adult social care; this was part of the allocations protocol agreed in the PFI bid. The person must be in receipt of a minimum of 2 hours care and support and upwards to very high levels of support.

The aim is to share the opportunity with people currently supported within Hull City Council's own housing stock and also people with aging parents who may not be able to care for their son or daughter in the future. There are 2 bedroom apartments which will accommodate this arrangement. The assessments for this accommodation are starting shortly with people with a learning disability supported by the local authority. Information is being developed in an easy read format

Feedback at an initial provider stakeholder event indicated that changes to housing and Welfare benefit rules will have an impact on providers' ability to develop new services or to deliver rents within the Housing Benefit limits. This will be explored more fully within the finance workstream.

The vast majority of care for people with learning disabilities in North East Lincolnshire is provided through a Supported Living Model. This model is currently delivered for 156 people, through eight providers of care, within 55 properties. The properties are predominantly owned through Social Landlords, and a few private landlords, with tenancies for the Individuals.

In addition North East Lincolnshire have developed two new-build apartment complexes specifically designed with and for individuals with complex needs, offering a higher level of supported living. Alongside these we have developed four bespoke bungalows to support 4 individuals with complex needs, adjacent to the apartments.

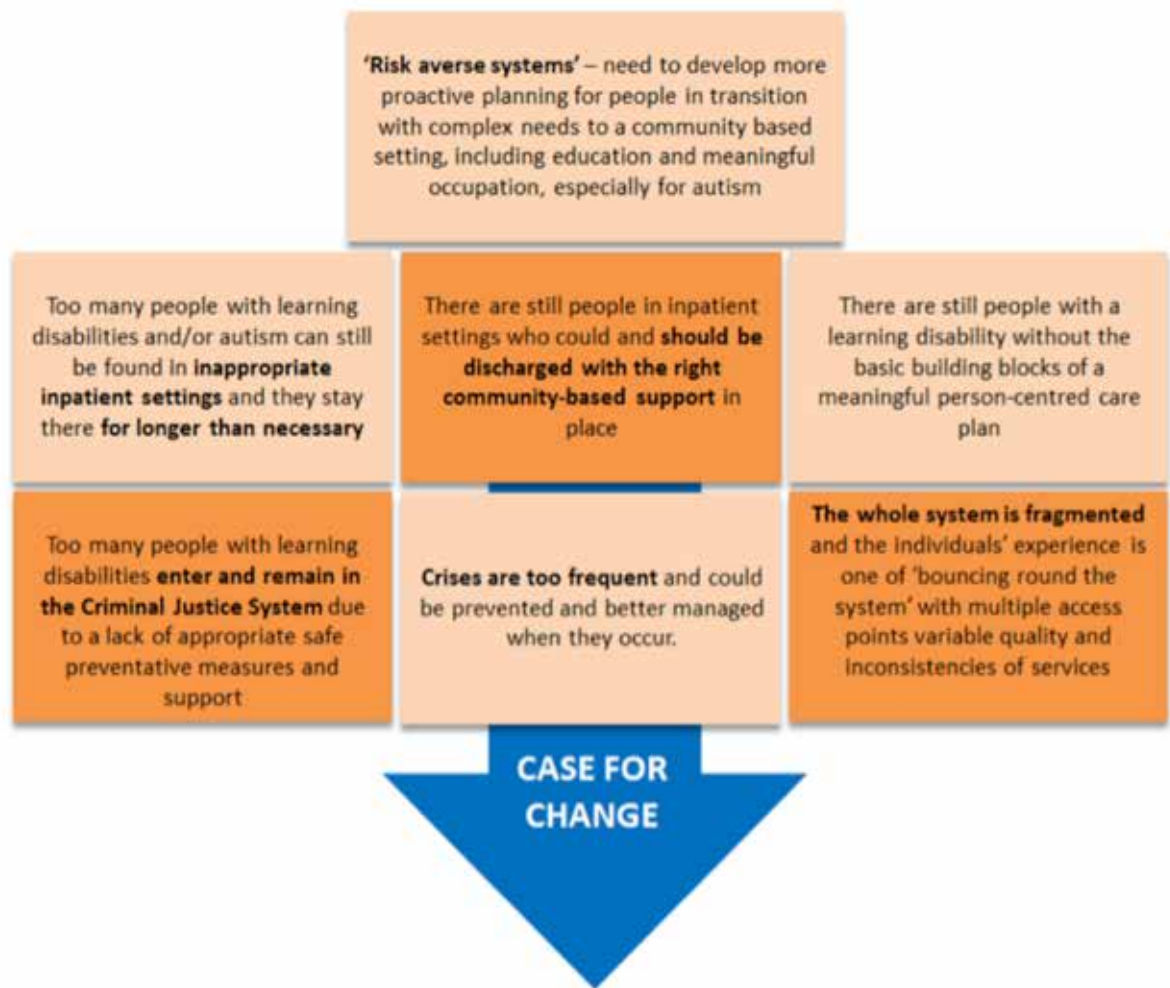
There are three residential care units, one of which is registered for people with complex needs

There are a number of properties across the partnership footprint with a legal charge held by NHS England.

#### 3.6 What is the case for change? How can our current model of care be improved?

The current experience for people with learning disabilities is very varied. This is, in part, apparent by looking at the data but also by listening to the stories of service users and families.

3 Understanding the status quo Baseline assessment of needs and services



Our local analysis of gaps across the footprint will be refined as the plan evolves. Early indicators and discussions have identified that there is a need to develop:

- Better identification of young people with complex needs who will need ongoing care and support, and for whom early intervention might prevent future development of behaviours that challenge
- Robust care pathways and services for individuals who have significant care and support needs as a result of complex autism and require ongoing or intermittent behavioural management support.
- A market shaped to attract high quality providers of services which can meet the needs of individuals with complex needs and challenging behaviours
- Further development of dedicated community based positive behavioural support services across the footprint. The Hull & East Riding Intensive Support Team is called Continuum and has an integral connection to the current inpatient services providing 365 day a year services
- Local availability of a range of planned and appropriate crisis respite services to support families in maintaining their caring role, including short-term accommodation
- Improved quality of information about services available to families and carers, especially at points of transition in the cared-for person's life
- Forensic based community support for the bespoke support needs of individuals with a presentation or history of offending behaviour
- Enhanced complex care service to expand provision for People with Profound and Multiple Learning Disabilities (PPMLD) and to develop a behavioural distress component to build up resilience of support in an individual's own home environment as part of short term crisis intervention or planned respite

## 3 Understanding the status quo Baseline assessment of needs and services

- More robust data reporting as part of the Clustering approach for NHS LD services
- More consistent specialist support for people when they are admitted to acute hospitals for their physical healthcare
- Increase capacity to enable young people (0 – 25 years) in current out of area placements who need to move closer to home as part of transition planning
- Enhance capacity and MDT working to support individuals including young people transferring into adults via the MAPPA process who also will require robust community support structures to be in place
- Increase confidence and capacity to enable Criminal Justice services have assurance that local community services can respond to individuals who are no longer detained
- Complete reviews and provide support to identify individuals who are currently in low secure who will require the development of local care pathways
- Increased capacity building across the third sector to support the development of community based resources that complement and enhance statutory services

NHS England has indicated that they seeking to establish across all health and social care communities a structured methodology for reviewing deaths of people with a learning disability. The aim is to identify themes for improvement both nationally and within local organisations. The Mazars report (an independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Disability Foundation Trust April 2011 to March 2015) sets out recommendations and best practice for the purpose of reviewing the circumstances of both expected and unexpected deaths of people with a learning disability. We will take an account of the work required across the agencies to meet the recommendations of the Mazars report in establishing local mortality reviews to make certain the local community always learns the lessons and appropriate changes are made.

## 4 Our vision for the future

Our first draft of a vision developed by the Programme Board was follows

“The Transforming Care Partnership is committed to improving care and treatment to make sure that Children, Young People and Adults with a learning disability and/or autism have the same opportunities as anyone else to live satisfying and valued lives and are treated with dignity and respect.

We will change service in line with the nine principles of the national model and by March 2019 people with a learning disability and/or autism will have greater power and control over their own care, with planned support to help them to fulfil their potential and to live in their own communities.”

We then ‘road-tested’ this at our initial stakeholder event where service users asked us to reduce it to the following statement

***Our vision is underpinned by the nine principles of ‘Building the Right Support’. The Transforming Care Partnership is committed to improving safe care and treatment to make sure that Children, Young People and Adults with a learning disability and/or autism have the same opportunities as anyone else to live satisfying and valued lives and are treated with dignity and respect.***

## 4 Our vision for the future

### 4.1 Our aspirations for 2018/19.

Our aspiration is to have a model of care in line with Building the Right Support reflecting the nine principles of that model and in so doing to reduce our reliance on inpatient care. Reductions in bed use are planned to be slow to begin with to enable community services to be built up first.

Humber TCP Total adult population 609,622	as at 31/03/16	as at 31/03/17	as at 31/03/18	as at 31/03/19	target rate
NHS England commissioned inpatients	27	26	22	16	
Inpatient Rate per Million GP Registered Population: NHS England commissioned	44.29	42.65	36.09	26.25	20 to 25
CCG commissioned inpatients	18	16	12	9	
Inpatient Rate per Million GP Registered Population: CCG commissioned	29.53	26.25	19.68	14.76	10 to 15
Total No. of Inpatients with learning disabilities and /or autism	45	42	34	25	

Note: the TCP has planned to achieve the national target of 10-15 inpatients per million for CCG commissioned inpatient services. We have planned to slightly exceed the NHS England target of 20-25 inpatients per million at the request of NHS England Specialist Commissioning in order to support the overall achievement of the target across the Yorkshire and Humber area.

Our aspiration is that by 2018/19 we will be able to say, with confidence

***“People with a Learning Disability and who present with challenging Behaviours will benefit from the least restrictive care to live and enjoy as independent a life as is possible. By engaging people with a Learning Disability and their carers throughout the delivery of the Transforming Care Programme we will ensure that the Partnership has the ambition to help this group of vulnerable people and their families achieve their aspirations and full potential.***

***To enable them to do this every person will have a Person Centred Care & Support Plan which spans their whole needs. They will have a named Care Co-ordinator in their home locality who will facilitate the assessment and planning process, and be able to offer ready access to information that meets an Accessible Information Standard to support their decision making. Appropriately trained and qualified Advocates will be routinely involved in assessment, review, and planning conversations. The person will be able to choose from several funding options including Personal Budgets, Personal Health Budgets, and Individual Budgets characterised by the ability to pool resources from***

## 4 Our vision for the future

*funding streams together from Health, Education, and Social Care. There will be options to enable people to club their funding together to enable more flexible care, including mechanisms such as Individual Service Funds.*

*Carers will be recognised as the cornerstone of many people's lives, and their health and wellbeing supported alongside the people they care for. To this end Care Packages for these most complex people will include regular and urgent short breaks or respite in ways that are safe and sensible to the person's needs. This may be through complex Respite provision, or through alternative short-term accommodation to be used in times of crisis. Carers and Parents will also be able to benefit from skills training to support them to build strategies to best cope with the stresses and difficulties of caring for someone with challenging behaviours.*

*Providers of care for this cohort in particular will operate in a market of organisations that can host staff skilled and experienced in supporting people with challenging behaviours through such models as Positive Behaviour Support. The market will support a Housing Strategy facilitating people to have a choice of housing and support to REACH standards, enabling the person to achieve settled accommodation. All services will be incorporated as part of a Quality Checker scheme.*

*The person's care will include identified opportunities for activities that are meaningful to the individual, and support opportunities to access education, training, and employment as far as possible.*

*People with a learning disability and/or autism shall experience good health. They will have an Annual Health Check, Health Action Plan, and 'Hospital Passport' where applicable. If the person needs acute hospital care there will be designated Liaison staff within the hospital setting. Where the care required is a result of poor mental health it shall be provided through a provider that is fully compliant and well audited with the Greenlight toolkit.*

*The predominant model of care around the individual will be a Collaborative Care Model, perhaps across providers, and enabling access to an integrated specialist in learning disability and autism. In times of crisis the person can receive Intensive MDT support 24/7 either in their home or through short-breaks. Inpatient stay within Learning Disability Assessment and Treatment units will be the exception and time limited and discharge planning will begin at the point of admission.*

*Close links with the Criminal Justice System will ensure people in this cohort are appropriately diverted through a Liaison and Diversion scheme, which will be supported by access to mainstream services for preventing anti-social/offending behaviours. There will also be specialist support for people in contact with Criminal Justice system. Where people are being resettled from secure hospital into community placements, this will be managed in partnership between all statutory agencies with a responsibility for public safety.*

*The Care Pathway will detail both secure and non-secure inpatient services for people in this cohort, and those in these facilities or at risk of being admitted to these facilities will be supported by the CTR processes as part of a broader care pathway, informing discharge planning."*

### 4.2 How will improvement against each of these domains be measured?

Nationally, improvement will be monitored through a number of mechanisms, including:

- The Assuring Transformation data set to monitor reduced reliance on inpatient services,
- The Health Equality Framework to monitor quality of life
- To monitor quality of care, there will be a basket of indicators developed (see Annex A); exploring how to measure progress in uptake of personal budgets (including direct payments), personal health budgets and, where appropriate, integrated budgets; and strongly support the use by local commissioners of quality checker schemes and Always Events

## 4 Our vision for the future

### Locally will know when we are succeeding when

Reduced Reliance on Inpatient Services:

- We have no one in a CCG commissioned out of area hospital placement and everyone in the original March 2014 cohort has been discharge safely to an appropriate service
- Our admission rate to Assessment and Treatment units (measured in Occupied Bed Days) is on average the equivalent to 10-15 inpatients per million population
- Our admission rate to NHS England commissioned beds (measured in Occupied Bed Days) is on average the equivalent to 20-25 inpatients per million population
- The proportion of people with a learning disability or autism readmitted within a specified period of discharge from hospital is within agreed limits
- The average length of stay in the Assessment and Treatment unit is reduced by 10% on a 15/16 baseline
- 95% of referrals that come in as a crisis / urgent (needing < 4 hour response), are managed safely in a community setting (ie admission avoidance)
- Everyone identified on the risk register has a crisis plan which is reviewed at least six-monthly

Quality of Care:

- Everyone with complex needs going through transition will have a clear pathway and detailed plan by the age of 17.5, six months before adulthood
- There is an increase in the number of Personal Budgets (including PHBs) for children (14+) and adults who have a learning disability and/or autism
- There is an improvement in the Proportion of Adults with learning disabilities in settled accommodation to (ASCOF)
- 90% of all young people (14 -25) with an EHC based on learning disability and/or autism and behaviour that challenges (or have an existing statement which will be converted to an EHC) have a Joint Preparing for Adulthood Transition Plan

In addition we will measure ourselves against the following performance indicators

- Proportion of inpatient population with learning a disability or autism who have a person-centred care plan, updated in the last 12 months, and local care co-ordinator
- Proportion of people receiving care primarily because of a learning disability who receive direct payments or a personal managed budget
- Proportion of people receiving health care primarily because of a learning disability who receive a Personal Health Budget
- Proportion of people with a learning disability receiving an Annual Health Check
- Proportion of people with a learning disability with a Health Action Plan and Patient Passport
- Proportion of people with a learning disability or autism with a crisis plan or risk management plan shared appropriately across agencies
- Waiting times for new psychiatric referral for people with a learning disability or autism

4.2

There are also a number of products by which progress will be measured in 2016/17

- Workforce strategy agreed across the Partnership
- Pathways of care agreed across the Partnership
- 'At Risk of Admission' Register in place in line with agreed information governance standards, to include children and people with autism
- Alignment of CPA and CTRs
- Published market position statements for new commissioning requirements
- Communications and Engagement plan across the Partnership which fully involves people with a learning disability and/or autism and their families and carers
- Completion of annual Learning Disability Health and Social Care Self-Assessment Framework

[www.ndti.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1/](http://www.ndti.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1/)

## 4 Our vision for the future

### 4.2 Our key principles

The key principles underpinning our plan are:

- People with learning disabilities and/or autism should have the same rights and choices as everyone else
- People with learning disabilities and/or autism have the right to choice and control and to be treated with dignity and respect
- People with learning disabilities and/or autism should have the same chances and responsibilities as everyone else
- Carers and families of people with learning disabilities have the right to the same hopes and choices as other families
- Care and treatment should be delivered in community settings with short term inpatient treatment available to enable care in the community to be re-established
- Communication across agencies and professionals is accepted as the norm in the Best interests of the person with learning disabilities and/or autism
- People with learning disabilities and/or autism should receive timely, responsive, flexible and connected support and care in the community, education, health and social care
- Specialist information, advice and a range of practical support should be available in a timely and accessible way across the lifecycle, with particular emphasis on key transition points with early intervention

All too often however, at times of crisis or when people display behaviour that challenges, it becomes difficult to manifest these principles. We will ensure that the routine care delivered will be personalised, underpinned by the principles of ordinary community living and will actively plan for early intervention and preventative support based on effective risk management and planning.

When things get difficult the plans will have strategies in place to ensure that admission to hospital is only undertaken when it is necessary and appropriate, and if admission is needed we will undertake Care and Treatment Reviews following the CTR Policy and Guidance to ensure that inpatient stays are for only as long as it is beneficial to the individual.

Personalised plans will take account of local services that are in place and working well whilst considering the developments needed to expand good support across the footprint. We will underpin the delivery of the local plan with the nine person centred principles in Building the Right Support.

## 5 Implementation planning

### 5.1 Overview of the new model of care

#### a) Care Coordination

Care Planning and Care Coordination is vital. This starts with the assurance of good physical healthcare through the development of Health Action Plans, Annual Health Checks, and Patient Passports for those at risk of admission to acute hospital. These plans should be person centred and should identify health social care and education needs as well as having contingency plans for crisis or acute hospital admission. They should recognise the strengths and aspirations of the individual and their family and carers should be recognised as partners to be supported. Where appropriate new technologies will be used to help people with learning disabilities take an active role in their care.

The individual providing the care coordination will vary according to the complexity of the person's needs. For those with very complex needs and very challenging behaviour, with frequent need for support from the CTLD, or for children needing care from CAMHS and other children's services teams, it is expected that a clinician will coordinate care and support using the Care Programme Approach (CPA). However, if the person is not on CPA, then the person coordinating the care and support need not be a health or social care practitioner, and indeed the role might be best taken by the family or carers of the person concerned, particularly if there is a personal budget or personal health budget involved. Independent advocates have a valuable part to play here in ensuring that the person's wishes are communicated, understood and acted upon.

For children the design of care co-ordination will be consistent with our 'Future in Mind' plans. All children who are looked after (under 16yrs) will have a Personal Education Plan and health assessment. The Paediatric occupational therapy services will be reviewed this year within both



## 5 Implementation planning

### 5.1

social care & health. This should then inform the service specification to ensure it is developed to meet the outcomes identified.

Plans will be shared across agencies, with the individual's consent or within the context of Best Interests. Where the individual is MAPPA eligible or identified as at high risk of offending, consideration will be given to the most appropriate level of multi-agency coordination and disclosure. In some instances that coordination might be undertaken through MARAC processes.

For those who have been identified as being at a risk of admission to Learning Disability hospital because of challenging behaviour or frequent crises, there will be a senior oversight group to ensure multi-agency cooperation and allocation of resources at the right time. Whilst our model will be to seek to avoid admission where possible, it is also important to recognise that in some instances admission is clinically the right decision and should be facilitated in a timely manner rather than being seen as a last resort. Proactive support can prevent significant breakdown and help to reduce the length of stay.

It is likely that the person coordinating the care and support, if a practitioner, will need to change as the person progresses from being a child to an adult, or because a different skill set is needed. Handovers will be done carefully and at the right point in time for the person concerned, and will make use of the continuity provided by the family and other carers to achieve this.

#### **b) Training and Education**

The delivery of a workforce strategy across a range of independent organisations as a time of financial challenge will be difficult. We will aim that all staff working with people with learning disabilities and/or autism will be trained and experienced in supporting people with behaviours that challenge. In particular, staff in those services which are identified as being appropriate for individuals with more complex needs will have an appropriate, evidence-based, range of responses to meeting people's needs and addressing challenging behaviours. In particular they should be able to deliver proactive strategies to reduce the severity and frequency of behaviour that challenges, such as positive behavioural support (PBS) including person-centred ethical reactive strategies where behaviour poses a threat to the person or those around them. This will have a significant and positive impact not only on the individual but also on their care team, developing practical skills and resilience. Staff teams with the competence and confidence to manage complex and challenging behaviour will be crucial in achieving the ambition of reducing admissions to hospital. They will be expected to be able to work in partnership with and under the clinical guidance of specialist crisis services at times of heightened difficulty.

#### **c) Mainstream Services and Community Networks**

Support given by communities and networks are an important contributor to effective care and support for the individual and their families. Peer networks will be encouraged to provide support to individuals and their families throughout the journey from childhood to adulthood and into older age.

People with a learning disability and/or autism should experience similar access to services as the general population and be seen as potentially able to offer a meaningful and valued contribution to their communities. The CTLD and other learning disability services will facilitate this by supporting mainstream services to make reasonable adjustments to cater for those with a learning disability and/or autism, including implementing the principles of positive behavioural support. Particular mainstream services that will be supported to make these reasonable adjustments include:

- Activities that enable people to lead a fulfilling and purposeful everyday life
- Education, training and employment services
- Primary care, including dentists and opticians
- Mental health services, through the use of the Greenlight Toolkit
- Acute hospitals
- Liaison and diversion schemes to enable people to exercise their rights and/or where appropriate diverting people to appropriate support from health and care services
- Generic housing services
- Settled accommodation options including home ownership or security of tenure
- Substance (drugs and alcohol) misuse services

## 5 Implementation planning

- Services that prevent or reduce anti-social or offending behaviour

### **d) Targeted Community Provision, Specialist Support and Enhanced Specialist Support**

Care and support staff will need to be trained and experienced in supporting people with behaviours that challenge. Staff should be able and confident to deliver proactive and reactive strategies to reduce the risk of behaviour that challenges, such as positive behavioural support (PBS).

We will develop more integrated multidisciplinary health and care and support for people with a Learning Disability and/or autism. This includes children, young people particularly at transition, and adults, as well as those who may have come into contact with, or be at risk of coming into contact with the criminal justice system, including people with lower level social care and/or health needs but higher levels of risk of harm to others. There will be a 'whole life' approach, providing seamless care and support as children progress into adulthood and beyond into old age. Feedback from services users and carers has been clear that we need to significantly improve the availability and accessibility of information at times of transition.

Specialist services will be targeted using a risk stratification approach and will include:

- Relatively low level community based interventions
- Enhanced support interventions to prevent or divert a crisis, and prevent family or support package breakdown
- Crisis management and stabilisation, available 24/7 365 days a year

In our new model of care we will need

- Alternative short term accommodation which is available as and when needed and for as long as needed, in times of crisis or as a place where people can go for a short period, preventing an avoidable admission into an inpatient setting. This could also provide a setting for assessment from intensive multi-disciplinary health and social care teams where that assessment cannot be carried out in the individual's home. Short-term accommodation could also provide an opportunity for young people to 'try out' living away from home in a supported environment
- Non-intensive multi-disciplinary health and social care support at home. This provides ongoing care and support for those with a learning disability and/or autism, and their families, helping them to prevent crises and reducing the frequency and severity of challenging behaviour. They work closely with providers as well as family and other support networks
- Intensive 24/7 multi-disciplinary health and social care support at home to prevent or manage a crisis, and prevent family or support package breakdown. This support is provided by a highly-skilled and experienced multi-disciplinary/agency team with specialist knowledge in managing behaviours that challenge. The 'step up' and 'step down' between specialist multidisciplinary support and this intensive support needs to be seamless and work closely with providers as well as family and other support networks
- Specialist health and care services that support people who have come into contact with or are at risk of coming into contact with the criminal justice system (i.e. offering a community 'forensic' function) including the expertise to manage risk posed to others in the community. The interventions depend on the needs of the individual and the level of risk they pose.

There will be a register of those at risk of admission to inpatient services, developed to include children, those with autism, and people stepping down from forensic services. This will provide direction as to which adults and children need to be the priority for their services. However, it is recognised that no register is perfect and individuals previously unknown may present to services in crisis, or the needs of well-known but apparently stable individuals may change at any point.

We want people with forensic needs to be better supported in the community. Although the skills development to provide this will focus primarily on specialist staff within statutory agencies, all teams will need to have an understanding of how to manage those who have come into contact with the criminal justice system, as well as identify and mitigate the risk that this presents to the person, their families and carers, and others in the community. We will also raise the knowledge and skills of colleagues within the criminal justice system through training delivered within the context of the Crisis Care Concordat.

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### e) Inpatient services

Whilst an overarching aim of this programme is to reduce reliance on inpatient care, there will still be times when this is necessary and beneficial to the patient. We will ensure that inpatient treatment is integrated into a broader care pathway, working closely with community based mental health and learning disability services. The Intensive treatment services designed to support people in their own homes during their crisis, seeking to reduce the frequency and severity of crises, will be closely linked to the team at the inpatient unit, so that transfer in and out of hospital can be seamless. Planning to avoid admission will, when necessary, progress to planning for admission, treatment and discharge. Community providers will continue to remain involved in care throughout the admission and be preparing for discharge as soon as an admission has commenced.

We expect that all admissions for assessment and short-term treatment will be to our local NHS inpatient unit Townend Court. In some cases however, individuals will need to be admitted to the NHS England commissioned estate if

- Their behaviour cannot be managed safely within an assessment and treatment unit
- Their admission to forensic inpatient provision is directed by the Courts
- Their admission to forensic inpatient provision is direct from prison

### f) Market Development

Reducing reliance on in-patient provision is predicated upon increasing the capacity and skills of a raft of services in the community, including the range of housing options we will need to enable people with learning disabilities and/or autism to live in appropriate housing. We will need to strengthen the care market to ensure we have providers with staff skilled and confident enough to manage, with support from specialist clinicians, complex and challenging behaviours. We will seek to develop the market to move on from our reliance on too few, specific, providers, to develop choice and capacity. However, we do not intend to develop so many new providers that there is a continual transfer of staff between them. Our experience is that the 'rise and fall' in quality demonstrated by providers is closely linked to changes in staffing and leadership, and we will seek stability in the market and confidence among providers that there is a consistent commissioning environment.

Our challenge will be how to implement this across children's and adults' services and across three differing localities; our opportunity is to draw on the work each locality has already done towards developing aspects of this model.

## 5.2 What new services will we commission?

A key challenge for the Partnership was to identify how we would initially source the finances required to achieve the plan. We have been able to identify a number of potential match funding contributions from the different partners in order to make a bid for Transformation Funding over the three years of the plan, to enable us commission a number of schemes which are intended to drive the transformation of services.

Other than any Transformation Fund monies that we might receive our assumption is that we will need to refocus current budgets. Where we can achieve efficiencies through the pooling of funding we will do so. We anticipate there will be some transfer of resource from Specialised Commissioning budgets but recognise that this is not going to occur in 16/17. As we identify new services that are required to meet the needs of this population we will need to work together as commissioners, and sometimes with commissioners across a wider area, to procure these services. Shaping the market to meet the needs of our population, especially those within the five cohorts described in the plan, will be central to our success.

Initial discussions have indicated the following priorities

### **Local Priority 1 – Short-term accommodation options including Crisis and Short Breaks Support**

*Short term accommodation which is available as and when needed and for as long as needed, in times of crisis or as a place where people can go for a short period, preventing an avoidable admission into an inpatient setting. Short-term accommodation could also provide an opportunity for young people to 'try out' living away from home in a supported environment. We will undertake as part of the work to implement the Crisis Care Concordat a review of the feasibility of developing a safe venue where people with a learning disability and/or autism can be temporarily supported at times when remaining in their usual accommodation would be too difficult akin to a mental health 'crisis house' provision.*

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### **Local Priority 2 – Positive Behavioural Support Team / Complex care behaviour distress pathway**

Further development of dedicated community based positive behavioural support services across the footprint, offering intensive support to avoid admission and facilitate discharge. We would also need to ensure there is sufficient capacity to manage the increased number of individuals with complex needs and challenging behaviour that will be living in the community, and to develop skills to provide for the bespoke support needs of individuals with a forensic presentation or history of offending behaviour. Whether these functions should be delivered by one team or aligned provisions is not yet determined

### **Local Priority 3– Enhanced complex care service for People with Profound and Multiple Learning Disabilities (PPMLD)**

Services have previously identified this as a group which would benefit from a focused approach with a behavioural distress component

### **Local Priority 4 – Acute Liaison**

The provision of learning disability liaison nurses sited within acute hospitals used by residents of our footprint has greatly improved the experience of people with a learning disability and/or autism when having planned admissions for treatment. However, the reports by many service users and carers of their experience of unplanned care indicate there is still a significant issue to be resolved if we are to deliver more consistent specialist support for people when they are admitted to acute hospitals for their physical healthcare

### **Local Priority 5 – Advocacy**

We will review availability of Advocacy in line with Care Act responsibilities and the needs of the identified population.

### **Local Priority 6 – Communication techniques, sensory profiling**

We will seek to increase the availability of these interventions through a training programme for providers

### **Local Priority 7 – Supported Living Services**

Two schemes have already been developed in the East Riding in 2015/16 but there is a need for more Supported Living capacity which can manage individuals with complex needs and challenging behaviour. In particular the development of a core and cluster model providing private space as well as shared support which can be flexible dependent on need is vital for those individuals whose level of challenge is unpredictable. In addition we will need to support people with more complex behaviours including those who have been in contact with the Criminal Justice system. There will need to be market development activity to create a range of providers across our footprint to manage people with extremely challenging behaviour.

### **5.3 What services will we stop commissioning, or commission less of?**

We will reduce our reliance on inpatient care by reducing admissions and reducing length of stay. This can only be achieved once community services have been made more robust in line with this overall Transforming Care Plan.

We are already seeking to reduce our commissioning of specialist autism / education placements out of area and we will aim to commission no such placements once we are confident local provision is delivering quality services that are economically viable and sustainable with a sufficiently robust specialist health response to support those with ongoing need for clinical input.

We will seek to reduce placements in institutional care settings and as our community services build capacity and expertise we will enable people with learning disability and/or autism to have to have personalised care provided in their own communities in appropriate housing.

There will need to be a significant change in the way we commission inpatient care and this poses a potential risk (and opportunity) to providers of inpatient services. HFT currently provides both the local Assessment and Treatment inpatient unit and community learning disability services. Commissioners in East Riding and Hull will work with HFT to deliver a reduction in the use of inpatient beds by our patient population. However this is not intended to destabilise the inpatient unit which will still have a key role to play in the connected care pathway.

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Decommissioning of any in-patient beds needs to be carefully considered and close working relationships between commissioners and providers will be required to deliver this successfully. HFT is currently commissioned on a block contract. The successful prevention of admissions to hospital will impact on the numbers in assessment and treatment services. Realising cost savings from a block contract is not straightforward but the resources from this disinvestment will be utilised to fund an enhanced community based support. This will not only include meeting the direct accommodation costs but also strengthening the services that support this group.

5.4 What existing services will change or operate in a different way?

The emphasis on community provision over inpatient settings will mean that the size and extent of community provision relative to inpatient provision will need to be much more extensive than currently. We will seek to develop the capacity of the Intensive Support Team through a shift in resource away from inpatient costs.

If the national model of reduced reliance on inpatient care is to be achieved, this has a significant impact on community provision, which will need to manage individuals with substantially more complex needs. Rather than having a notional ‘inpatient population’ and ‘community population’ as now, service pathways will have to consider three groups:

- The current in-patient cohort, including those in forensic settings  
New community provision will need to accommodate those previously served by inpatient settings. This is a well-known cohort whose quality of life must be improved in safe settings with high quality care and support so that where possible they can stay in their own home and any future in-patient admissions are minimised.
- The current ‘community’ cohort  
New community provision will need to keep people with a learning disability and/or autism living well in communities, preventing deterioration in their wellbeing and crises so that their need for in-patient services is reduced.
- The wider learning disability and autism population  
This is a cohort that is currently less known to services, with the exception of primary care. Mainstream services and community networks will need to support people with a learning disability and/or autism living well in the community without the need for specialist services where at all possible.

This means community provision will need to be proactive, intervening early to address the underlying causes of behaviours so that the frequency and severity of challenging and offending behaviour is reduced. This will require effective risk stratification of the population, with the register of those at risk of admission being a key tool to do this.

Clear pathways and standards for response will be needed to enable community providers to feel more confident about managing complex and challenging behaviour because they know they will receive the support they need when they ask for help.

We will support services to change as follows:

<i>Current model Advocacy</i>	<i>New/enhanced responsibilities and skills as a result of the description</i>
<i>Currently have IMCA and IMHA services and limited non statutory advocacy available</i>	<ul style="list-style-type: none"> <li>• <i>Those with a learning disability and/or autism and behaviour described as challenging or with longer term mental health needs are likely to need access to independent advocacy support throughout their lifetimes and not necessarily just at the points where they qualify for an IMHA or an IMCA.</i></li> </ul>

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**Current model**  
**Advocacy**

**New/enhanced responsibilities and skills as a result of the description**

**Community Teams Learning Disability (CTLDs)**

CTLDs in Hull and NEL are integrated health and social care; this is not the case in East Riding. The teams provide specialist assessment from a range of professionals.

- Promoting the capabilities of families and providers
- Trained and experienced in supporting people with behaviours that challenge
- Ability to cater for those who have come into contact with criminal justice system to ensure that they can be maintained in community services rather than being referred for treatment under the offender pathway
- More integrated working between health and social care teams

**Crisis Intervention team (Continuum)**

Assertive outreach support and rapid interventions to enable people with complex needs to maintain community living and avoid exclusion from their current services. Close liaison with offender health support and MAPPA structures

- 24/7 crisis support with closer liaison with the Mental Health crisis team
- Community forensic skills integrated within the team to support people who have come into contact with or are at risk of coming into contact with the criminal justice system with a mix of early intervention and prevention work, a monitoring and support role, providing advice and support to other services and teams providing specialist and target community based support to those with a learning disability and/or autism
- To provide assessment advice and support to police custody areas and magistrates courts about assessing and managing high risk or complex behaviours.
- To support the offender pathway service to ensure access and egress from the offender pathway is a key priority
- Capacity to maintain a longer term relationship with people with Forensic needs to maintain their safety in the community and continued engagement in therapies and support
- Trained and experienced in applied behavioural analysis and the proactive support of people with behaviours that challenge

**Local Authority Transition Teams**

Help develop skills and independence for young people and adults with a learning disability preparing for Adulthood

- Will have more integrated pathways of care with CTLD and with CAMHS
- Increased ability to manage the needs of people who have come into contact with the Criminal Justice System, and manage the risk that this presents to their wellbeing, that of their families and carers and the wider community, whilst liaising with justice partners who will manage the risk of offending
- Trained and experienced in supporting children and young people with behaviours that challenge
- Greater understanding of the growing population of children with autism, and addressing their needs, including aligning eligibility for support
- Use the opportunities offered through the Education Health and Care plan (EHCP) to set-up appropriate care and support for those with a learning disability and/or autism as they progress into adulthood

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**Current model**  
**Advocacy**

**New/enhanced responsibilities and skills as a result of the description**

**Community CAMHS**

*CAMHS Tier 3 and Tier 4 support in the community, providing enhanced support interventions and crisis management*

- *Linking into the ‘Future in Mind’ programme*
- *Greater understanding of the growing population of children with autism, and addressing their needs, including aligning eligibility for support*
- *Increased ability to manage the needs of young people who have come into contact with the Criminal Justice System, and manage the risk that this presents to their wellbeing, that of their families and carers and the wider community*
- *Trained and experienced in proactively supporting people with behaviours that challenge*
- *Use the opportunities offered through the EHCP to provide appropriate care and support*

**Local Authority Emergency Duty Teams (children and adults)**

*Out of hours emergency support and assessment*

- *High level understanding of the support needs of people with behaviours that challenge*
- *Ability to respond to the needs of those who have come into contact with criminal justice system*

**Residential care providers, Supported Living providers and Shared Lives carers**

*Providing supportive accommodation options for adults with a learning disability and/or autism*

- *Market will have an increased ability to manage the needs of people with a wide range of needs including those who present with challenging behaviour or come into contact with the Criminal Justice System.*
- *Trained in a range of skills and experienced in the proactive support of people with behaviours that challenge, including communication techniques and sensory profiling*

**Community Forensic teams**

*Providing support to those living with a personality disorder in the community*

- *NHS England is expected to roll out the commissioning of Liaison and Diversion services*
- *Increased ability to manage the needs of people with autism and learning disability*

**Learning Disability Inpatient services**

*Assessment and Treatment and crisis management*

- *Hospital based specialist services are only used where community settings cannot provide suitable alternatives, and people are held in the least restrictive settings that are therapeutic and safe for all. People accessing inpatient settings will continue to access the community to ensure they do not become reliant on the institutional setting or lose skills they have acquired and so they experience an acceptable quality of life on a daily basis while an inpatient.*
- *The community care coordinator and crisis team will work with hospital staff from before the day of admission, to ensure an estimated date of discharge is determined with a clear assessment and treatment plan from when the person is admitted, with measureable outcomes-based milestones to support discharge planning*
- *A clear offender pathway (previously referred to as high, medium or low secure services) will be available for those who present with risks of significant harm to others but are not fit to plead in court and are diverted from the Criminal Justice System.*

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### 5.5 How will we encourage the uptake of more personalised support packages

As a TCP we want to maximise every opportunity for self-direction. We will engage as a footprint with the work undertaken by the regional PHB lead including attendance at regional 'Developing Your local Offer' events. We also have the benefit of a local carer who is closely linked to national work on the development of PHBs and who has agreed to contribute to our development.

The Personalised approach used in North East Lincolnshire for people with a learning disability will continue. In line with service guidance and policy individuals are able to choose from a range of different funding mechanisms in order to meet their needs creatively.

North East Lincolnshire has already established Personal Support Plans routinely for all people with learning disabilities and is able to offer Social Care funded Personal Budgets and Individually Commissioned Care packages routinely. Care packages are often blended with different elements delivered through different funding models around the needs of the individual, eg Day Opportunities, Supported Living, IST

The Local offer is being aligned with Children's services to allow planned transitions to continue. This is underpinned with a policy of joint funding with Health and Social Care. A joint Risk & Quality (R&Q) panel oversees complex and Out of Area placements to which workers can present for advice & support. Health Education Care plans are signed off by care practitioner and R&Q panel on transition for joint ownership

North East Lincolnshire is developing new opportunities to maximise personalised support packages for this cohort including the development of Individual Service Fund models, better enabling the 'clubbing together' of funds to deliver more flexible support when needed.

Hull CCG recognises that Personal Health Budgets offer a real opportunity to enable people with learning disabilities to live in their own homes or with their families, rather than in institutions. The CCG is working with key partners to ensure that people are at the centre of their care planning process and are fully involved in all aspects of their care delivery.

People with learning disabilities eligible for NHS Continuing Healthcare now have a right to have a Personal Health Budget. NHS Hull CCG is currently reviewing how it can expand Personal Health Budget to people with Long Term Conditions who are not eligible for NHS Continuing Healthcare and this includes people with a learning disability.

East Riding CCG is also offering Personal Health Budgets to people eligible for NHS Continuing Healthcare and exploring how we can increase take up in a wider range of patient groups, including learning disability and autism. Families of children and young people have 'choice and control' in respect of the support packages for their disabled child. The Children's Disability Team are fully familiar with the Personal Budgets and ensure personal budgets are promoted to families.

Across the TCP further work is required within the local market to increase the offer of brokerage and financial support services. These services will be crucial in the overall transformation of care and support for this cohort of people, particularly with regards to maximising their choice and control in terms of how their individual needs are to be met. Commissioners will be working over the next three years to engage and stimulate the market place to ensure these necessary self-directed support services are available.

#### What will care pathways look like?

Our proposed model of care and support will focus on

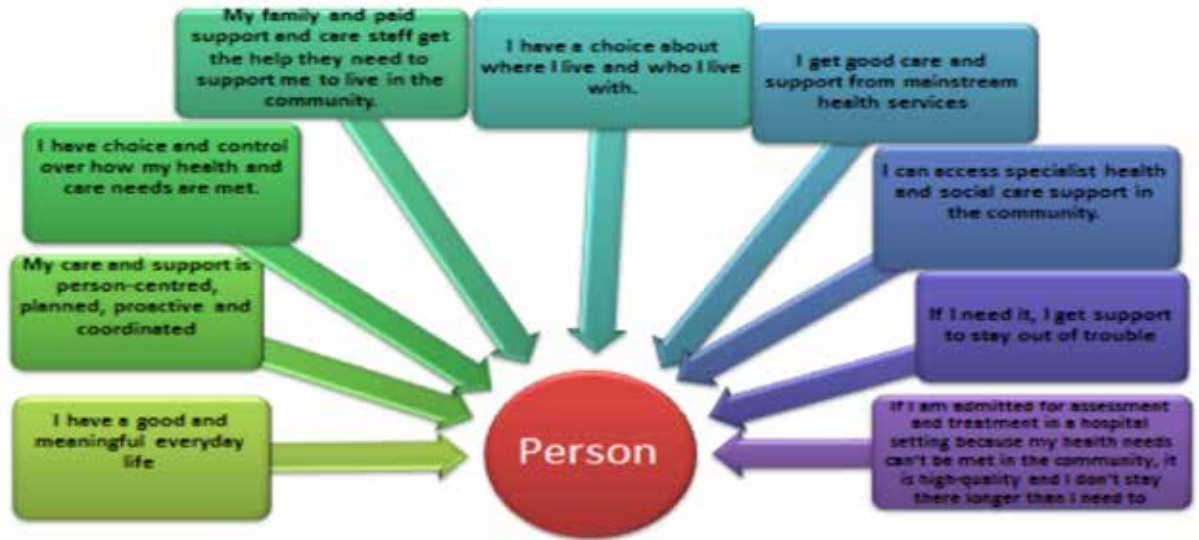
- developing access to mainstream universal and community support,
- developing and enhancing our specialist services and targeted community based support where mainstream services cannot provide the support required or people are identified as being at risk of their needs and behaviours escalating and/or deteriorating.
- Inpatient settings only being used to complement community services e.g. short breaks, crisis, or where inpatient settings are mandated.

Support and care in our Partnership will be orientated around the person and their family, friends and informal support networks as per the nine principles and the care pathway will be designed accordingly

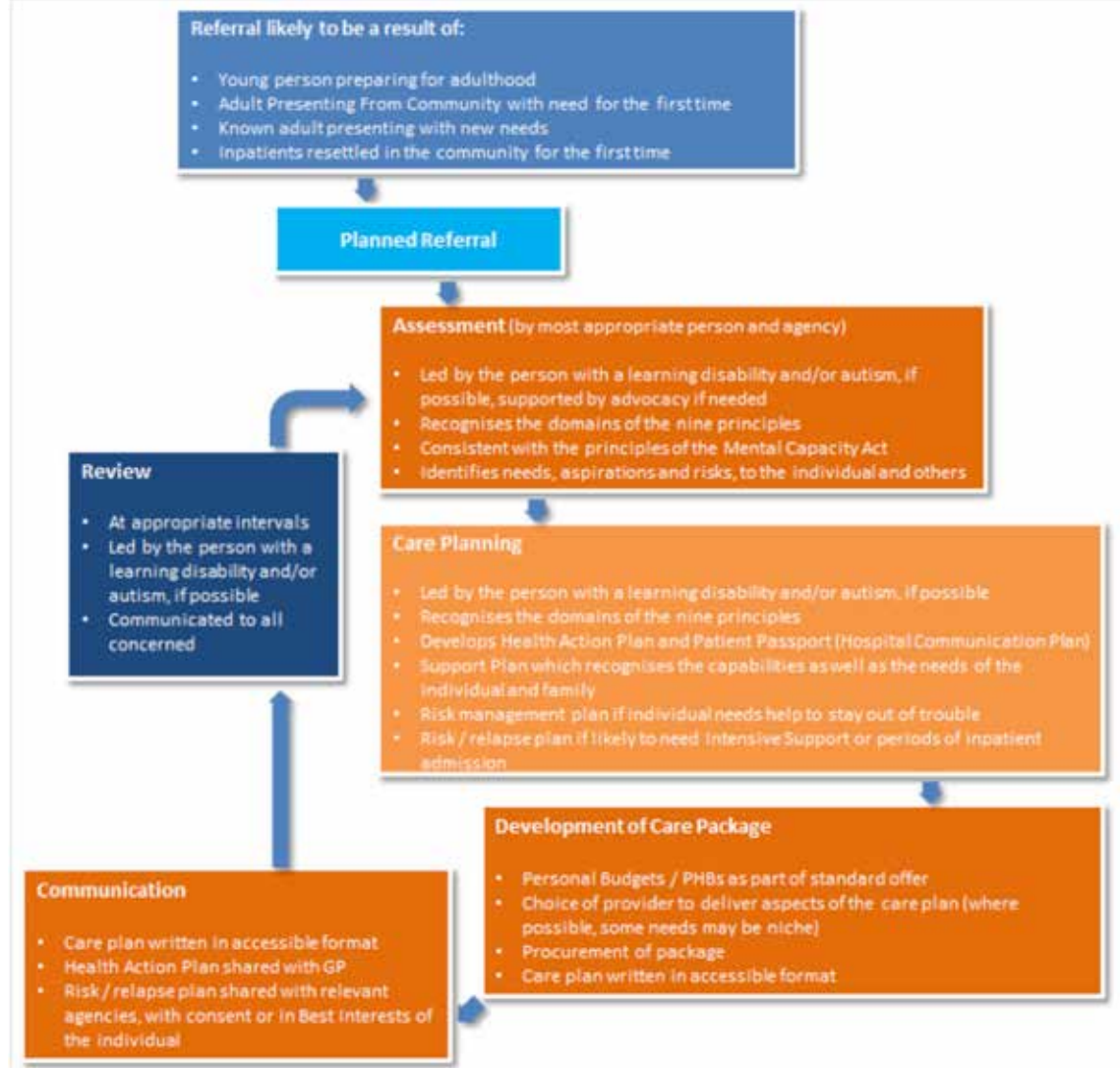


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# 9 Person centred principles

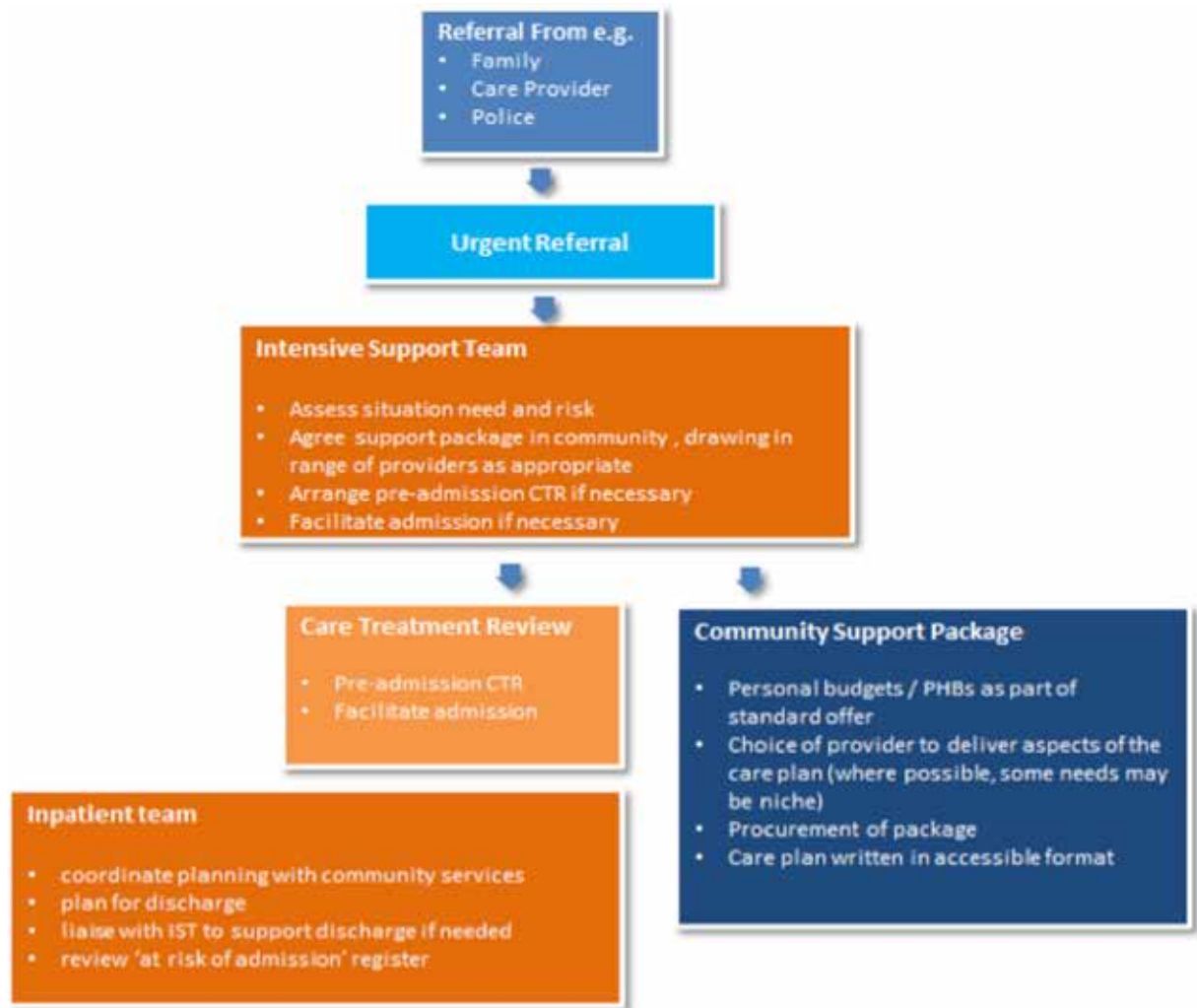


DRAFT CARE PATHWAY  
Planned referral



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Unplanned referral



5.7 How will people be fully supported to make the transition from children’s services to adult services?

In North East Lincolnshire a joint funded worker (Adult & Child services) ensures there is a clear transition pathway between Adult and Children’s services. The pathway identifies people at age 14 and a worker from Focus Independent Social Work is assigned. The case is picked up in strategic planning process where housing needs or other complexities are potentially required, to ensure sufficient lead time for adaptations etc if required. The list of complex and complex transition cases is held by IST to support and promote the full multi-agency and multi-disciplinary approach. This informs the joint health education action plan, which in turn is signed off at Risk & Quality panel

A recent project team in the East Riding gathered information about what is working and not working in relation to the four ‘Preparing for Adulthood’ outcome areas – education and employment, independent living, community inclusion and health. The findings show that there were three themes that stood out as contributing to a good outcome. These were evidence of the use of a person centred approach, good cooperation between services and skilled individual practitioners.

Those people consulted identified a number of areas where there was a need for improvement. In some cases parents and young people had little involvement in planning and were given conflicting information and advice. Information/data systems currently hinder the sharing of information and planning at either a strategic or an individual level. Generally there was evidence of a lack of aspiration for children and young people with SEND therefore limiting their choices in terms of employment, living independently and community inclusion. The way that agencies and services are currently configured can lead to some young people being unable to access the correct support as they transition into adulthood.

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There needs to be a shared vision across the TCP and its partners with young people and families. Key elements of this vision are:

- Children, young people and adults are at the **centre of decision making** using **person centred thinking**.
- The **raising of aspirations** and improving **life chances** for children, young people and adults are part of strategic planning.
- **Outcome focused multi-agency commissioning** is informed by the voice of young people and families.
- The local authority and local communities work together to create training and **employment opportunities**, **independent living** and **inclusion in the community** and **good health**
- Practitioners from all agencies work together with mutual respect and share information.
- Individual and **local strengths, needs and diversity are recognised**.
- Services work to **prevent problems** and promote **individual well-being**

As a result we want every child and young person to have the best possible chance to help them fulfil their potential. Much good work takes place across the TCP every day to support children and young people with SEND to raise their aspirations and improve their outcomes. There were significant changes in the SEND agenda driven by recent government policies centred on the Children and Families Act (2014, extending the SEN system from birth to 25 years old by progressing the reforms outlined in the document Support and aspiration: A new approach to special educational needs and disability: Progress and next steps. In line with these reforms:

- For children and young people with more complex needs, a co-ordinated assessment process and the new 0-25 Education Health and Care Plan (EHC Plan) will replace statements and Learning Difficulty Assessments (LDAs)
- Parents will have the option to receive a personal budget to pay for services
- Councils will involve children, young people and parents/carers in reviewing and developing provision for children and young people with Special Educational Needs
- Councils will have a 'Local Offer' detailing all support available for families with children who have SEN
- Councils and CCGs will have in place joint planning and commissioning of services

We are working to ensure that the needs of young people are met through to the age of 25, giving traditional 'transition points' (e.g. a child reaching 18 years of age) less prominence. Instead, support will be designed to evolve as children begin to prepare for adulthood. For children with special educational needs and /or a disability, one of the key outcomes may be for them to achieve as much independence as possible as they move into adulthood.

### 5.8 How will we commission services differently?

Moving from commissioning as separate CCGs and Councils to a more integrated model of commissioning on a Transforming Care Partnership footprint will be a challenge but it offers opportunities to explore cross border arrangements including shared criteria for joint funding of packages, collaborative commissioning and tendering exercises and to work together to understand the impact of the return of funding from NHS England (Dowries), and collaborative commissioning of providers.

Given the small numbers and high costs it may prove challenging to pool budgets effectively for this population. However there could be some useful work aligning and agreeing principles for sharing of cost and responsibility. We will review the benefit or otherwise of capitation budgets, based on the numbers of people with learning disabilities or autism who display behaviour that challenges who are in need of support from TCP partners.

CCGs will explore the potential for financial risk sharing agreements across Yorkshire and Humber for high cost placements and work together to make more efficient use of contracting support by agreeing shared service specifications with local providers and lead commissioner arrangements.

Commissioners will need to work together to plan and commission a whole system, to include

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individual packages of care in the community, supported by a high quality community team for learning disabilities providing wrap-around routine and crisis support, as well as good pathways in and out of inpatient care for the small number of people who need this from time to time. We would expect that the same staff in the community team for learning disabilities would provide intensive support in the community and follow an individual into the local inpatient setting when this is needed.

The specialist support requirements should be clearly documented in each individual care plan, so that the right resource can be made available within the community team for learning disabilities.

Commissioning for personalisation highlights the need to not just ensure assessment and care planning is centred on the person but the care package needs to be individual and, wherever possible, procured in a way which transfers power from the commissioner to the individual or family. This shift of power requires clearer information about the benefits and mechanisms of personal budgets and a workforce development process to move away from attitudes of 'knowing best' to 'working for'. To support people with a learning disability and/or autism take up the opportunities of personal budgets will need to strengthen the resources we have for brokerage which supports people in the 'nuts and bolts' of procuring their care or the care of their children.

Local commissioners have a commitment to work with the independent and third sector to ensure there is a vibrant and high quality market to support the needs of people with complex needs. As the model of care is developed local commissioners will explore the opportunities to develop an integrated model to support a range of providers. And if the market expands as we hope we will need to consider a model of care navigation as services users and their carers review a range of options available to them.

Whilst we have some examples of supported living it is anticipated that there will need to be significant market development activity to create a sustainable range of providers which can deliver some of the new or enhanced commissioning intentions. An example area is that of niche providers who are able to provide accommodation options for those with very challenging behaviours. Procurement and contracting mechanisms must not be too time-consuming or discriminate against small providers e.g. risk in terms of the size of the contract vs. the turnover of the organisation, risk and reward mechanisms. There may also be a need to encourage social enterprises as a good way to deliver services.

Since the approach and culture of providers is critical to delivering effective community services for those with a learning disability and/or autism, we will need to investigate options for commissioning services for outcomes. The outcomes we would be concerned with would involve the quality of life of people with a learning disability and/or autism, including the degree of choice and control they have over the care and support options.

There will need to be a significant change in the way we commission inpatient care and this poses a potential risk (and opportunity) to providers of inpatient services. HFT currently provides both the local Assessment and Treatment inpatient unit and community learning disability services. Commissioners in East Riding and Hull will work with HFT to deliver a reduction in the use of in-patient beds by our patient population. However this is not intended to destabilise the inpatient unit which will still have a key role to play in the care pathway.

Decommissioning of any in-patient beds needs to be carefully considered. HFT is currently commissioned on a block contract. The successful prevention of admissions to hospital will impact on the numbers in assessment and treatment services. Realising cost savings from a block contract is not straightforward but the resources from this disinvestment will be used to fund an enhanced community based support. This will not only include meeting the direct accommodation costs but also strengthening the services that support this group.

### 5.9 How will our local estate/housing base need to change?

We have a significant challenge in developing the market to create a range of options to meet the needs of people with a learning disability and/or autism.

The market and expectations will continue to be fluid as the Care Act becomes embedded and Local Authority budgets continue to reduce. However the focus on development of innovative and cost effective services that directly support those in greatest need and preventative services to delay the need for more costly interventions will continue to be key. Over the forthcoming period we intend to:

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- Develop specialist care to support people with complex and challenging needs both in the community and in care home provision
- Develop a range of specialist services which will support safe, timely hospital discharge to improve patient flow, customer experience of service and reduce overall hospital bed occupancy
- Develop specialist services for people with a Learning Disability and Dementia
- Develop a range of 'fit for purpose' short breaks for people with learning disability and autism
- In consultation with stakeholders, review models of domiciliary care with a view to supporting sufficient capacity in the sector
- Review the existing Care Home with Nursing provision to ensure cost effective, sustainable, high quality provision
- Review the existing provision of day services with the aim of identifying cost effective, sustainable and diverse, high quality provision
- In conjunction with stakeholders, develop options to improve the take up of self-directed support options

There is a need for a range of accommodation and support options to meet the needs of young people preparing for adulthood. Securing the right housing environment can help those with behaviour that challenges to be socially included, enabling them to have access to appropriate community and recreational activities, and to give a sense of security and independence. Expanding the range and choice of housing, care and support services is crucial to giving young people and their families more choice and control over their lives.

Commissioners will work closely with the local authority Housing Strategy teams to ensure the future needs of this group are understood, considered and planned for within the local housing strategy. To achieve this there will be a need to put in place robust mechanisms to capture data of housing needs to support capital funding applications when opportunities arise.

Actions required to implement this are:

- Ensure that all four Preparing for Adulthood outcomes are discussed in EHC reviews so that the aspiration of independent living is addressed early enough for provision to be developed
- Develop data systems that capture future housing needs
- Develop a range of housing options through partnership working with housing/support providers
- Review the properties available across the footprint and assess whether they still meet the needs of our population
- Review Market Position statements

### 5.10 What might a resettlement story look like?

As a partnership we have resettled a number of individuals over the last few years. Each has been individually planned and we would expect this to continue. An example is described as follows.

X is a young woman with mild learning disabilities demonstrating challenging behaviour and a personality disorder. Examples of X's challenging behaviour include verbal and physical aggression, making allegations against staff, sexually inappropriate behaviour and self-harm.

Detained in prison for a brief period following an assault and after court appearances following further assaults she received a conditional discharge. For several years she was in a succession of hospitals, detained under the Mental Health Act. The last placement was successful in providing long term treatment of her complex needs and behaviours and by 2014 there had been a significant reduction in the number of incidences of physical aggression, although incidences of verbal aggression, threats of self-harm /suicide and allegations continued.

As a result of this progress we were able to begin planning for discharge and community living. Whilst the initial thoughts were to identify a service in our own locality, in line with national policy following the Winterbourne View scandal, consultation with her family identified relatives in another locality with whom she could build up a relationship, and we looked for suitable provision there. We were aware of the challenge she would pose to any community provision and drew on the support of regional specialist services to develop a formulation and deliver training to provider staff to ensure the new care team would be able to work together and manage her behaviours.

## 5 Implementation planning

A residential care unit was identified which felt able to meet her needs and the family in that area were involved in her ongoing support. After 18 months, X and her team decided she was ready to become more independent. At this point she decided to return to the TCP area and she was helped to visit a supported living scheme. X was very keen for the move to go ahead and to have her own flat, which has long been an ambition of hers. She moved in and is now supported by local services.

Throughout this time her placements were monitored closely by a case manager. This link back to local services was crucial in making sure that X did not feel abandoned out of area but knew local services were always planning for her eventual return, if that was to be what she wanted.

There were several key lessons we learned as a local partnership from this experience and others. First, the principle of getting the plan right and spending time considering the options. Secondly, the principle of effective communication across agencies and having formulations and management plans which follow the individual from one service setting to another. Thirdly, the importance of a person centred approach which understands the contribution family members can make in sustaining a successful placement. And most importantly, to keep faith with the individual. There will continue to be difficulties on occasion but the management plans that have been developed have proved effective and have built up her own self-management skills as she works towards her ambition of a home of her own.

### 5.11 How does this transformation plan fit with other plans and models to form a collective system response?

The Humber Transforming Care Partnership is newly formed. However, the three localities have a history of working together on a range of issues and strategic developments.

Each area has recently completed a Local Transformation Plan for children and young people's mental health and wellbeing, which will include plans to increase targeted support for vulnerable groups such as those with learning disabilities and autism. As we develop this plan for learning disability and autism we are cross-referencing the interdependencies with the three Local Transformation Plans.

The Mental Health Crisis Care Concordat (MHCCC) principles are entirely relevant to the ambitions and objectives of the Transforming Care plans and provide a sound framework for whole system collaboration in managing periods of crisis both in the community and through effective access to local inpatient assessment and treatment services, including supporting timely discharge back to a community setting. There is a Hull and East Riding operational group with representation from Humberside Police, Yorkshire Ambulance Service, Acute Trusts, Humber NHS FT and both Councils which learns the lessons from cases where the management of mental health crises did not go well. Issues that cannot be resolved at an operational level are escalated to a MHCCC Steering Group which also includes representation from CCGs as commissioners, which then reports to the Strategic Resilience Group. The leads for the MHCCC across the Humberside Police area meet quarterly to share good practice and coordinate progress.

Hull, East Riding and North East Lincolnshire all have good whole system partnerships in place across to manage requests for out of area placements for children, young people and adults, including those with learning disabilities or autism who display behaviour that challenges. The guiding principle of this work is to combine resources to provide effective care and support locally, wherever possible avoiding out of area independent sector residential education placements, although there is still more to be done in this respect.

There has been steady progress implementing the new Education, Health and Care plans for children with special educational needs and disabilities; however this is limited to those who have identified special educational needs. There may be gaps for those with high functioning autism and challenging behaviour or mental health needs, which will need to be explored and planned for appropriately.

Whilst in North East Lincolnshire have made great progress with Personal Budgets and Personal Health Budgets being part of the standard offer, there is more limited progress on the north bank, where there has been less use of Personal Health Budgets other than for Continuing Healthcare packages. All Local Authorities in the Local Transformation Partnership have significant numbers of direct payments and other personal budgets for this group. There is some evidence of these being jointly commissioned and further work is needed to maintain and increase the numbers of people with learning disabilities or autism who display behaviour that challenges using such joint personal budgets to meet their care and support needs.

## 5 Implementation planning

The Autism Act 2009 remains a challenge, particularly for those without learning disabilities. Currently each local authority will have its own strategy, which in some cases is due for review and refresh. It would be sensible to combine to develop a strategy covering the whole of the Transforming Care Partnership footprint.

The Sustainability Transformation Plan 2016/21 sets out an overview of how we will work with our partner commissioners and providers over the next 5 years to ensure that the wider local NHS continues to meet the changing needs of our population. This will involve working with five other neighbouring CCGs to develop a range of collaborative work programmes

## 6 Delivery

### 6.1 What are the programmes of change/work streams needed to implement this plan?

To deliver the transformation required the Transforming Care Programme we have five key workstreams which together will seek to reduce reliance on inpatient care, improve quality of care, and improve quality of life. These workstreams, in addition to the ongoing project management function, will deliver the evaluation of the programme as the delivery of the model progresses, measuring the intended outcomes, and adjusting the model as we go along. The five workstreams are as follows:

#### 1. Pathways of care

This workstream will design and develop the pathways to deliver joined-up and integrated care and support around a Person-centred Plan and a supporting single overview plan across health and social care. There will be an emphasis on the inclusion of personal budgets and personal health budgets. We will seek to improve ICT connectivity and integration to support the improved pathways and reduce paperwork, initially in the short term using current infrastructure, with a longer term ICT solution providing a more robust way of creating and sharing the Person Centred Plan.

In addition the TCP will be represented at the Yorkshire and Humber forensic subgroup to engage with the development of step down pathways and ensure safe transfer of patients from forensic settings

#### **Deliverables:**

- Pathways of care and agreed care standards
- Preparing for Adulthood pathways. Ensure that all four Preparing for Adulthood outcomes are discussed in EHC reviews so that the aspiration of independent living is addressed early enough for provision to be developed
- Crisis care pathways including provider support
- CAMHS tier 4, Forensic step down pathway developed with Specialist Commissioning Team
- Autism (no LD) post-diagnostic pathway
- Availability of assessment and advice to Courts: Coordination between community teams and Liaison and Diversion services which are expected to be commissioned by NHS England
- Review of capacity, capability and level of integration of CTLDs to deliver the new model, including prevention and early intervention
- Describe required community based positive behavioural support services across footprint
- Review availability and use of technology to help people with learning disabilities take an active role in their care (eg My Health Guide App)
- Support programme in place for GPs to consistently provide Health Checks to those with a learning disability from the age of 14
- 'At risk of admissions register' including children and people with autism, cross referenced to cohorts
- Alignment of CPA and CTRs
- Central point for coordinating CTRs, updating HSCIC, Mechanism for collating feedback given at individual CTRs
- Review Greenlight toolkit – autism appropriate i/p services
- Monitor LD inpatient activity, by CCG and level of need

## 6 Delivery

### 2. Quality and Commissioning (including Estates)

This workstream will oversee all the actions required at various stages of the commissioning cycle. The first activity that will be undertaken is to improve our data and to better understand our population and their associated needs, including children with a learning disability and/or autism with challenging behaviours, and also the wider population of people with autism.

Market development to build new and sustainable capacity within the workplace is essential. In addition procurement and performance management activity will be involved in adjusting current contracts to include the new/changed requirements.

As the market develops and adjusts to the new model, commissioning mechanisms to deliver high quality care that improves people's outcomes, will be under constant review to see whether the current combination of block and framework contracts providing the health and social care support to those with a learning disability and/or autism and those who have/may come into contact with the Criminal Justice System is the best way forward.

Mainstream services and their accessibility by those with a learning disability and/or autism are also within the scope of this workstream. Quality checker schemes will be designed and implemented to provide assurance that they are able to be accessed by those with a learning disability and/or autism and those who have/may come into contact with the Criminal Justice System and an audit mechanism will also be put in place for mainstream mental health services for similar reasons.

#### **Deliverables:**

- Published Market Position Statements for new commissioning requirements
- Updated contracts to include new/changed requirements
- Provider capacity built or decommissioned to meet Market Position Statements
- Quality checker schemes in place
- Increased Housing options with a developing market and local developments established
- Increased proportion of adults with a learning disability in settled accommodation
- Register of accredited providers of advocacy
- Review of council accommodation strategies
- Agreed quality standards for procured services, including workforce and environmental standards
- Identify required services for people with a Learning Disability and Dementia;
- Review the existing Care Home with Nursing provision to ensure cost effective, sustainable, high quality provision
- Review the existing provision of Day Care / Day Services with the aim of identifying cost effective, sustainable and diverse, high quality provision
- In conjunction with stakeholders, develop options to improve the take up of self-directed support options
- Develop data systems that capture future housing needs
- Review the properties available across the footprint and assess whether they still meet the needs of our population as part of Estates Strategy

### 3. Workforce Development

This key workstream will deliver a workforce development programme to ensure that all staff, regardless of their employer, have the skills and knowledge to work effectively with this client group. It will oversee how to ensure successful recruitment and retention of staff into posts to deliver the model of care as providers across our footprint already experience difficulties in recruiting and retaining high calibre staff. This is crucial as it is often changes in staffing and leadership which leads to issues in quality and safeguarding concerns

#### **Deliverables**

- Improved health and social care skills and capabilities in the workforce
- A workforce across all employers with a consistent understanding and approach to working with people with challenging behaviour which enables those clients to manage their behaviour in the least restrictive setting



## 6 Delivery

- Recruitment of staff into posts to meet the requirements of the new model of care
- Mapping the current workforce across the health and social care economy to identify needs
- Providing specialist contribution to the development of service models
- Enabling competency specific service commissioning and delivery
- Foster co-production with people who are experts by experience
- Enhanced cross agency working, and an understanding of how different agencies/organisations can work collaboratively to support clients

An analysis of training needs will be carried out, using a variety of techniques, to identify the skills needed to deliver services, and the gaps within the current workforce. It is likely that these skills will include:

- An ability to build self-resilience and maintain compassion to avoid burnout
- Understanding the narrative surrounding the formulation of challenging behaviour
- Positive behavioural support techniques
- Communication techniques
- Sensory profiling
- Person centred planning inc HAP, Hospital Passport
- Carers taking on role care coordination (if CPA not needed)
- Supporting people with a forensic history
- Physical health care – catheter care, peg-feeding, tracheostomy care, diabetes, substance misuse, and helping people cope with basic health care (such as having an injection)
- Caring for older adults with LD and dementia
- Preparing for Adulthood
- Developing learning disability specific leadership capability

This workstream will engage regionally with Health Education England (HEE) and Skills for Care and will draw on the resources being made available through the Transforming Care Workforce Support. In drawing down support however we will not ignore the current skilled resources within local providers who are able to contribute to training and development across the footprint. There is already work begun as part of the Future in Mind workforce development and the workstream will ensure coordination between the two strands of work.

### 4. Communications and Engagement

We have only just begun the process of engagement with individuals, families and carers as well as the wider public and providers of care and support. This is crucial to delivering the programme, and improving outcomes for people with a learning disability and/or autism. Co-production will be an important part of our approach, recognising the expertise that the family and carers and providers have, that will be essential to delivering a successful model of care. The programme will use existing provider engagement structures, enhanced as necessary, such as Inclusion North and engagement groups organised to support the Learning Disabilities Partnership Boards.

#### **Deliverables:**

- People with a learning disability and/or autism and their carers are engaged and buy-in to the Transforming Care Programme, and have been able to influence the scope and shape of the programme
- Providers are engaged and buy-in to the Transforming Care Programme, and, through co-production, have been able to improve the robustness of Market Position Statements and commissioning plans
- Providers have responded to market development activities, and have developed capabilities and capacity in areas where it has been identified that there is little or no current provision
- Short letter or questionnaire to be circulated through services such as schools, day services, residential services and colleges inviting individual or group comments
- Seek views through the websites of partner organisations
- Quality of information about services available to families and carers, especially at points of transition
- Availability of information for service users in Easy Read formats
- Regular reporting of progress to LDPBs and through carer and service user forums

6 Delivery

**5. Finance and Performance**

This workstream will oversee the shifting of resources from inpatient to community provision, the development of aligned or pooled budgets, and the shift in commissioning from a population basis to more personalised arrangements through personal budgets (including PHBs).

Pooled or at least aligned budgets are fundamental to the success of the programme, and the financial model to support re-investment of savings in the community. The programme will need to prepare budgets to be pooled, or align them if pooling budgets is not possible or appropriate. In addition we will work with the Specialist Commissioning team to transfer and manage correctly any dowries arising as a consequence of the resettlement of individuals who have been inpatients for over five years.

**Deliverables:**

- Pooled or aligned budgets to support all community and in-patient spend on those with a learning disability and/or autism
- Shared criteria for joint funding of care packages
- Increased proportion of people with a learning disability and/or autism with personalised budgets
- Identification of any risk sharing across TCP
- Monitor spend through 2016/17
- Routine collection of indicators to monitor and report progress
- Agreed mechanism for alignment and transfer of budgets from Spec Comm to TCP
- Explore with other Partnerships across Yorkshire and Humber the potential for financial risk sharing agreements for high cost placements
- Development of bids for transformation Funding or other opportunities

Our assumption is that we will need to refocus current budgets. Where we can achieve efficiencies through the pooling of funding we will do so. We anticipate there will be some transfer of resource from Specialised Commissioning budgets but recognise that this is not going to occur in 2016/17 and are concerned that any eventual transfer may fail to fully cover all costs transferred out to the CCGs.

The TCP initially submitted a bid for Transformation Funding for a number of schemes. After learning that nationally bids to the Transformation Fund were substantially above the value available, we revised our bid and are awaiting feedback

**6.2 Who is leading the delivery of each of these programmes, and what is the supporting team.**

The Programme will be supported by a Project Management Office structure which will be embedded within the current PMO arrangements of the lead CCG, East Riding of Yorkshire CCG. The Programme Board identified workstream leads and draft terms of reference at the Programme Board meeting held 24th February 2016.

Workstream	Lead organisation
Pathways of Care	East Riding of Yorkshire CCG
Quality and Commissioning	East Riding of Yorkshire Council
Workforce Development	Hull City Council
Communication and Engagement	Hull CCG
Finance and Performance	North East Lincolnshire CCG

It was noted that there will be a significant overlap between these workstreams, especially the Quality and Commissioning and the Workforce Development workstreams and we will review the effectiveness of the workstreams as we work through the plan.

There are substantial similarities in plans across other Transforming Care Partnerships and we will engage with regional streams of work where that would be more effective. This may involve particular TCPs taking the lead in specific pieces of work which are then shared across Yorkshire and Humber.

## 6 Delivery

### 6.3 Key milestones

Workstreams will develop more detailed Delivery Plans describing milestones and timescales using Project Management templates and the Partnership will report progress monthly to NHS England

Organisational sign off by CCG Governing Bodies and Council Corporate Management Teams has been undertaken as follows:

- 3rd March 2016: Draft plan presented to East Riding HWB and approved
- 15th March 2016: draft plan presented to ERY CCG Governing Body and approved
- 21st March 2016: draft plan presented to Humberside MAPPA Strategic Management Board for information
- 22nd March 2016: Draft plan presented to Hull HWB and approved
- 18th April: Draft plan presented to NEL HWB and approved

The original route map developed by the Partnership, along with other reports, will be available at [www.hullccg.nhs.uk](http://www.hullccg.nhs.uk)

### 6.4 Risks

The original Risk Log developed by the Partnership follows as Annex B. Risks, and their mitigation, will be reviewed regularly and monthly updates provided to NHS England

### 6.5 Keeping You Up to Date

Humber Transforming Care Partnership has established the following website

[www.hullccg.nhs.uk](http://www.hullccg.nhs.uk)

We will use it to publish this plan and any future updates including our workforce plan, communications plan and milestones plan as these are developed and updated. Any feedback from engagement events will be published on this site, as will any newsletters or specific updates.

## Annex A – Developing a basket of quality of care indicators

Over the summer, a review led by the Department of Health was undertaken of existing indicators that areas could use to monitor quality of care and progress in implementing the national service model. These indicators are not mandatory, but have been recommended by a panel of experts drawn from across health and social care. Discussion is ongoing as to how these indicators and others might be used at a national level to monitor quality of care.

This Annex gives the technical description of the indicators recommended for local use to monitor quality of care. The indicators cover hospital and community services. The data is not specific to people in the transforming care cohort<sup>5</sup>.

The table below refers in several places to people with a learning disability or autism in the Mental Health Services Data Set (MHSDS). This should be taken as an abbreviation for people recorded as having activity in the dataset who meet one or more of the following criteria:

- 6.1.1.** They are identified by the Protected Characteristics Protocol - Disability as having a response score for PCP-D Question 1 (Do you have any physical or mental health conditions lasting, or expected to last, 12 months or more?) of 1 (Yes – limited a lot) or 2 (Yes – limited a little), and a response score of 1 or 2 (same interpretation) to items PCP-D Question 5 (Do you have difficulty with your memory or ability to concentrate, learn or understand which started before you reached the age of 18?) or PCP-D Question 13 (Autism Spectrum Conditions)
- 6.1.2.** They are assigned an ICD10 diagnosis in the groups F70-F99, F84-849, F819
- 6.1.3.** They are admitted to hospital with a HES main specialty of psychiatry of learning disabilities
- 6.1.4.** They are seen on more than one occasion in outpatients by a consultant in the specialty psychiatry of learning disabilities (do not include autism diagnostic assessments unless they give rise to a relevant diagnosis)
- 6.1.5.** They are looked after by a clinical team categorised as Learning Disability Service (C01), Autistic Spectrum Disorder Service (C02)

<sup>5</sup> Please refer to the original source to understand the extent to which people with autism are categorised in the data collection

Indicator No.	Indicator	Source	Measurement <sup>6</sup>
1.	Proportion of inpatient population with learning a disability or autism who have a person-centred care plan, updated in the last 12 months, and local care co-ordinator	Mental Health Services Data Set (MHSDS)	Average census calculation applied to: <ul style="list-style-type: none"> <li>• Denominator: inpatient person-days for patients identified as having a learning disability or autism.</li> <li>• Numerator: person days in denominator where the following two characteristics are met: (1). Face to face contact event with a staff member flagged as the current Care Co-ordinator (MHD_CareCoordinator_Flag) in preceding 28 days; and 2. Care review (Event record with MHD_EventType ‘Review’) within the preceding 12 months</li> </ul>
2.	Proportion of people receiving social care primarily because of a learning disability who receive direct payments (fully or in part) or a personal managed budget (Not possible to include people with autism but not learning disability in this indicator)	Short and Long Term Support statistics	This indicator can only be produced for upper tier local authority geography. <p>Denominator: Sum of clients accessing long term support, community services only funded by full or part direct payments, managed personal budget or commissioned support only.</p> <p>Numerator: all those in the denominator excluding those on commissioned support only.</p> <p>Recommended threshold: This figure should be greater than 60%.</p>

<sup>6</sup> Except where specified, all indicators are presumed to be for CCG areas, with patients allocated as for ordinary secondary care funding responsibility.

Indicator No.	Indicator	Source	Measurement <sup>6</sup>
3.	Proportion of people with a learning disability or autism readmitted within a specified period of discharge from hospital	Hospital Episodes Statistics (HES) and Assuring Transformation datasets. Readmission following discharge with HES main specialty - Psychiatry of Learning Disabilities or diagnosis of a learning disability or autism.	<p>HES is the longest established and most reliable indicator of the fact of admission and readmission.</p> <ul style="list-style-type: none"> <li>• Denominator: discharges (not including transfers or deaths) from inpatient care where the person is identified as having a learning disability or autism</li> <li>• Numerator: admissions to psychiatric inpatient care within specified period</li> </ul> <p>The consultation took 90 days as the specified period for readmission. We would recommend that this period should be reviewed in light of emerging readmission patterns. Particular attention should be paid to whether a distinct group of rapid readmissions is apparent.</p> <p>NHS England is undertaking an exercise to reconcile HES and Assuring Transformation data sets, to understand any differences between the two. At present NHS England will use Assuring Transformation data as its main source of information, and will be monitoring 28-day and 12-month readmission.</p>
4.	Proportion of people with a learning disability receiving an annual health check. (People with autism but not learning disability are not included in this scheme)	Calculating Quality Reporting Service, the mechanism used for monitoring GP Enhanced Services including the learning disability annual health check.	<p>Two figures should be presented here.</p> <ul style="list-style-type: none"> <li>• Denominator: In both cases the denominator is the number of people in the CCG area who are on their GP's learning disability register</li> <li>• Numerator 1. The first (which is the key variable) takes as numerator the number of those on their GPs learning disability register who have had an annual health check in the most recent year for which data are available</li> <li>• Numerator 2. The second indicator has as its numerator the number of people with a learning disability on their GPs learning disability health check register. This will identify the extent to which GPs in an area are participating in the scheme</li> </ul>
5.	Waiting times for new psychiatric referral for people with a learning disability or autism	MHSDS. New referrals are recorded in the Referrals table of the MHSDS.	<ul style="list-style-type: none"> <li>• Denominator: Referrals to specialist mental health services of individuals identified in this or prior episodes of care as having a learning disability or autism</li> <li>• Numerator: Referrals where interval between referral request and first subsequent clinical contact is within 18 weeks</li> </ul>
6.	Proportion of looked after people with learning disability or autism for whom there is a crisis plan	MHSDS. (This is identifiable in MHMDS returns from the fields CRISISCREATE and CRISISUPDATE)	<p>Method – average census.</p> <ul style="list-style-type: none"> <li>• Denominator: person-days for patients in current spell of care with a specialist mental health care provider who are identified as having a learning disability or autism or with a responsible clinician assignment of a person with specialty Psychiatry of Learning Disabilities</li> <li>• Numerator: person days in denominator where there is a current crisis plan</li> </ul>

## Annex B – Risk Log

Risk Area	Description	Probability (High, Medium, Low)	Impact (High, Medium, Low)	Mitigation
Finance	Financial plans fail to keep within current budget limits. As there is no new money identified, other than expected inflation and demographic growth, developments will have to be funded as a result of changes in the overall system	Medium	High	<ul style="list-style-type: none"> <li>Finance workstream establish to maintain close budgetary control</li> <li>Transforming Care Funds can be used if for temporary double running of provision rather than requiring new monies identified for matchfunding</li> <li>Work with Specialised Commissioning to identify mechanisms for dowries</li> </ul>
Finance	Unplanned cost pressures arising from Responsible Commissioner rules if other CCGs discharge patients into the local footprint (especially from the Humber Centre and Priory Market Weighton)	Medium	High	<ul style="list-style-type: none"> <li>National assurance that the Responsible Commissioner rules are under review and will change</li> <li>Exploration of CCG risk sharing arrangements for High Cost Placements</li> </ul>
Provider response	The market does not develop as envisaged, in particular a failure to attract specialist providers for the key patient cohorts	Medium	High	<ul style="list-style-type: none"> <li>Clear Market Position Statements signalling commissioning intentions</li> <li>Assurances needed on fees and market stability</li> <li>Good ongoing provider engagement including listening to providers' issues and concerns</li> </ul>
Provider response	Providers fail to find suitable properties and landlords for development of new accommodation schemes	Medium	High	<ul style="list-style-type: none"> <li>Involvement of Council Housing Strategy leads to support market development</li> </ul>
Inpatient population reduction	There may be patients in secure provision identified as TCP responsibility	Low	Medium	<ul style="list-style-type: none"> <li>Spec Comm case managers have spoken to colleagues in other regions</li> </ul>
Inpatient services	Reduction in demand for inpatient provision leads to de-stabilising of current providers leading to sudden loss of all provision rather than a managed transfer	Medium	High	<ul style="list-style-type: none"> <li>Agreed plans between providers and commissioners, both CCGs and Specialised Commissioning</li> </ul>
Inpatient services	Negative Media coverage of closures prevents decommissioning of beds	High	High	<ul style="list-style-type: none"> <li>Create PR campaign led by people with their own stories, and promoting the better outcomes for people</li> </ul>
Admission avoidance	Failure to manage crises and challenging behaviour in community settings leads to pressure for admission	Medium	High	<ul style="list-style-type: none"> <li>Build capacity within crisis intervention services, supported by current inpatient capacity and capability</li> </ul>
Admission avoidance	If we plan to avoid admission by just reacting to crises we will not succeed in developing resilience in the system	Medium	High	<ul style="list-style-type: none"> <li>Personalised care planning to reduce frequency and severity of crises</li> <li>Building resilience by supporting carers</li> </ul>

Risk Area	Description	Probability (High, Medium, Low)	Impact (High, Medium, Low)	Mitigation
Public Safety	Poorly managed resettlement of individuals with offending history and risk leads to serious offending and substantial public harm	Medium	High	<ul style="list-style-type: none"> <li>• All individuals to be assessed for MAPPA eligibility</li> <li>• Individual resettlement plans to be closely risk managed through MAPPA in accordance with statutory arrangements and timescales or through appropriately supported professionals meetings if not MAPPA eligible</li> <li>• Training in assessment of risk of serious harm and MAPPA eligibility and MAPPA arrangements to be included in workforce development plans</li> <li>• Regular review of resettlement plans and robust quality assurance processes in place</li> <li>• Timescales for resettlement will be set by assessment of risk</li> <li>• Local capability will need to be in place before resettlement</li> <li>• Contingency planning in place ensuring close links with Criminal Justice Agencies</li> </ul>
Public Safety	Poorly managed resettlement of individuals with offending history and risk leads to minor reoffending and recall to hospital or prison	High	Medium	<ul style="list-style-type: none"> <li>• Individual resettlement plans to be closely risk managed through MAPPA or appropriately supported professionals meetings if not MAPPA eligible</li> <li>• Regular review of resettlement plans and robust quality assurance processes in place</li> <li>• Timescales for resettlement will be set by assessment of risk</li> <li>• Local capability will need to be in place before resettlement</li> <li>• Contingency planning in place ensuring close links with Criminal Justice Agencies</li> </ul>
Public Safety	Failure to identify safe and appropriate service options for resettlement of individuals with offending history and risk leads to delay in transfer. There is currently limited capacity and capability within local service provision	Medium	Medium	<ul style="list-style-type: none"> <li>• Training in assessment of risk of serious harm and MAPPA eligibility and MAPPA arrangements to be included in workforce development plans</li> <li>• Regular review of resettlement plans and robust quality assurance processes in place</li> <li>• Timescales for resettlement will be set by assessment of risk</li> </ul>
Public Safety	Reputational Risk through poor service delivery resulting in serious incidents, serious further offending, complaints and high profile media cases	Medium	High	<ul style="list-style-type: none"> <li>• Local Capability in place ensuring effective risk management and personalised care planning delivered by a skilled and resilient workforce</li> <li>• Robust reporting and review process, structure and communication strategy in place for serious incidents, SFOs, complaints and management of high profile cases</li> <li>• Lessons learned to be identified and communicated across agencies and providers and inform commissioning</li> </ul>

Risk Area	Description	Probability (High, Medium, Low)	Impact (High, Medium, Low)	Mitigation
Workforce	Ageing staff population leads to critical skills gaps	High	Medium	<ul style="list-style-type: none"> <li>• Succession planning within providers</li> <li>• Review of skill mix required</li> </ul>
Workforce skills	Required workforce skills and capacity do not develop sufficiently	Medium	High	<ul style="list-style-type: none"> <li>• Clear workforce development plans</li> <li>• Sufficient funding to develop workforce skills, and recruit appropriate staff (note that it can be difficult to recruit mental health nurses and social care support workers as there is a shortage of supply)</li> </ul>
Mainstream services	Do not make reasonable adjustments to accommodate LD/autism needs leading to pressure on LD services	Medium	High	<ul style="list-style-type: none"> <li>• Senior leadership engaged so mainstream services make adjustments a priority</li> <li>• Implementation of plan needs to build community resilience</li> </ul>
Prevention	Failure to identify individuals with potential to develop behaviour that challenges	Medium	Medium	<ul style="list-style-type: none"> <li>• Preparing for Adulthood overseen by both FiM and TCP workstreams</li> <li>• Early intervention and provision of suitable models of care for young people exhibiting behaviours that challenge</li> </ul>
Pooling budgets	Changes not made nationally that would allow specialised commissioning spend to be pooled. This would prevent inpatient funding from being re-spent on community provision, a fundamental principle in the financial model.	High	Medium	<ul style="list-style-type: none"> <li>• Raise nationally as a key issue</li> <li>• If pooling is not possible, align budgets.</li> </ul>
Culture change	Lack of single vision and aims across all organisations and teams.	Medium	High	<ul style="list-style-type: none"> <li>• Create effective stakeholder engagement from the start</li> <li>• Recognise that it takes time to build trusting relationships across organisations</li> </ul>
Personalised Care	GP practices do not step up to providing health checks consistently across the footprint	Medium	Medium	<ul style="list-style-type: none"> <li>• Support GP networks to build their skills and capacity to be able to provide health checks consistently</li> </ul>
Personalised Care	Failure to increase take up of personal Budgets (and PHBs)	Medium	Medium	<ul style="list-style-type: none"> <li>• Engagement with regional lead</li> <li>• Involvement of service users and carers in developing comms to support increased take up</li> <li>• Ensure simple systems are in place to support professionals offering PBs</li> </ul>
Programme management	Failure to sequence actions carefully could lead to destabilising of current provisions before new pathways are in place	Medium	Medium	<ul style="list-style-type: none"> <li>• Ensure workstreams develop more detailed plans with realistic timescales</li> </ul>



### Terms of Reference

#### Humber Transforming Care Programme Board v2

#### Membership:

##### Member:

##### **East Riding Clinical Commissioning Group**

Chief Officer (SRO) - Jane Hawcard  
AD Services for Vulnerable People - Neil Griffiths  
Commissioning Lead (MH+LD) - Peter Choules  
Programme Management Office - Donna Dudding

##### **East Riding of Yorkshire Council**

Director of Adult Social Services - Rosy Pope  
Strategic Service Manager - Clare Brown  
Director of Children Services - Kevin Hall

##### **Hull Clinical Commissioning Group**

Chief Officer - Emma Latimer

##### **Hull City Council**

Service Delivery Lead - Vulnerable People - Mel Bradbury  
Director of Adult Social Services (Deputy SRO) -  
Alison Barker

##### **North East Lincolnshire**

Service delivery Lead - Angie Dyson  
Deputy Chief Executive - Helen Kenyon  
Director of Children Services - Joanne Hewston  
Finance Lead - Lynne Popplewell

##### **Humber NHS Foundation Trust**

Care Group Clinical Director - Trish Bailey

##### **Humberside Probation**

Kate Munson

##### **NHSE Specialised Commissioning**

MH and PoC Lead - Louise Davies

##### **NHS England**

Senior Nurse - Judith Wild

##### Deputies:

Paula South - Director of Nursing

Jackie Lown

### **Purpose:**

1. To oversee the development and implementation of the Local Transforming Care Plan in line with Building the right support, ensuring the NHSE/ADASS deadlines are met.
2. To act as a forum for partnership building, sharing good practice and ideas and identifying and unblocking barriers to system change.
3. To agree plans when required at a system level.
4. To set and agree/acknowledge the future system vision.
5. To agree appropriate work plans required from time to time.
6. Oversight of service improvement for people with learning disabilities.
7. To provide clear capacity and leadership to ensure delivery
8. To agree an appropriate governance structure for this work

### **Responsibilities:**

- 1 Responsible for agreeing the Local Transforming Care Plan as system leaders.
- 2 Providing appropriate and adequate resources to deliver agreed system change
- 3 To receive individual organisation plans and connect in to the wider system strategy
- 4 To ensure implementation and delivery of the plan within agreed timescales

### **Powers/Authority to Act:**

- 1 Authority to Act under individual organisational schemes of delegation.
- 2 Individual CEO's and Clinical Leads are responsible for communicating to the group when appropriate, internal organisational governance processes are required to be undertaken.

### **Accountability:**

All member CEO's and Clinical Leads are accountable to their organisations and are responsible for ensuring that the governance processes required by their own organisations in terms of decision making are undertaken as set out in the their organisations scheme of delegation (see attached appendix 1).

It is for leads to ensure that organisations decision-making is deliverable within the set deadline

It is the representative responsibility for each individual to obtain authority to make decisions on behalf of their GB/CMT.

### **Meeting Administration:**

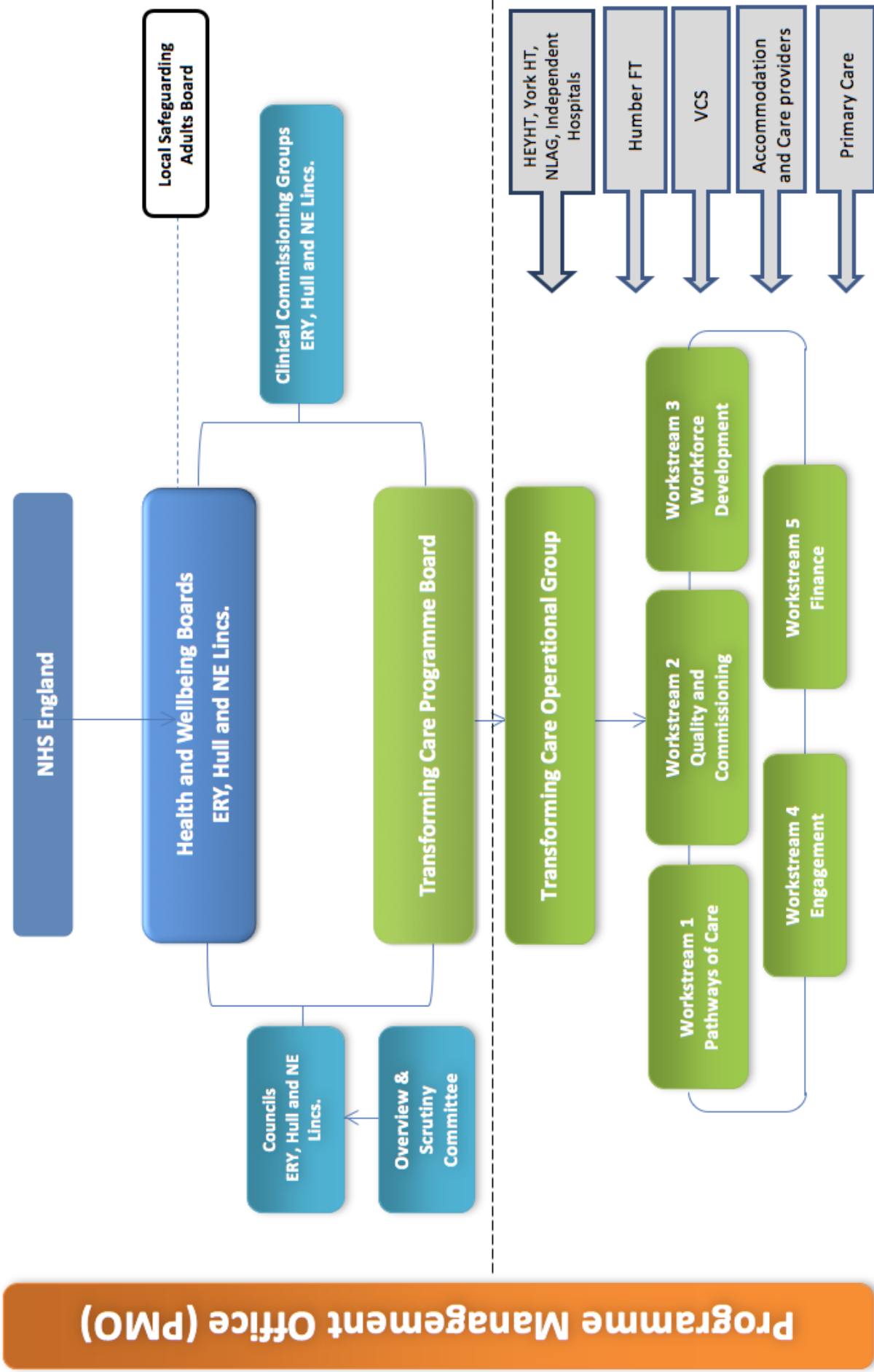
- (i) Meeting Frequency - To meet monthly from December 2015 to December 2016, thereafter at least six times per year

### **Chairing Arrangements:**

- (i) Chair expected to be rotated between the CCG Chief Officers on a regular basis to be agreed by the group, with DASS form different area as co-chair
- (ii) Action notes will be taken at each meeting.

Review date: Annually in Q1 of each financial year (Apr-June)

Governance - Transforming Care Programme



## Population Projections 2014 -2030

From PANSI (Projecting Adult Needs and Service Information) and POPPI (Projecting Older People Population Information System), Oxford Brookes University and Institute of Public Care

### East Riding of Yorkshire

LD - Baseline estimates People predicted to have a learning disability, by age	2014	2015	2016	2017	2018	2020	2025	2030
People aged 18-24 predicted to have a learning disability	656	658	652	644	632	610	594	646
People aged 25-34 predicted to have a learning disability	792	797	804	817	827	842	834	784
People aged 35-44 predicted to have a learning disability	982	960	936	915	901	899	949	991
People aged 45-54 predicted to have a learning disability	1,201	1,205	1,207	1,199	1,181	1,133	997	954
People aged 55-64 predicted to have a learning disability	1,063	1,064	1,078	1,101	1,126	1,172	1,229	1,156
Total population aged 18-64 predicted to have a learning disability	4,694	4,685	4,678	4,675	4,668	4,656	4,603	4,531
Total population aged 65+ predicted to have a learning disability	1,671	1,716	1,759	1,799	1,836	1,905	2,083	2,306
Challenging behaviour	2014	2015	2016	2017	2018	2020	2025	2030
People aged 18-24 with a learning disability, predicted to display challenging behaviour	11	11	11	11	11	10	10	11
People aged 25-34 with a learning disability, predicted to display challenging behaviour	14	14	15	15	15	15	15	14
People aged 35-44 with a learning disability, predicted to display challenging behaviour	18	18	17	17	16	16	17	18
People aged 45-54 with a learning disability, predicted to display challenging behaviour	23	23	23	23	23	22	19	18
People aged 55-64 with a learning disability, predicted to display challenging behaviour	21	21	21	22	22	23	24	23
Total population aged 18-64 with a learning disability, predicted to display challenging behaviour	87	87	87	87	87	87	86	84
Autistic spectrum disorders - all people	2014	2015	2016	2017	2018	2020	2025	2030
People aged 18-24 predicted to have autistic spectrum disorders	256	258	258	256	252	242	238	261
People aged 25-34 predicted to have autistic spectrum disorders	320	322	325	333	337	348	350	330
People aged 35-44 predicted to have autistic spectrum disorders	392	386	374	366	361	359	381	405
People aged 45-54 predicted to have autistic spectrum disorders	511	511	509	504	496	474	417	397
People aged 55-64 predicted to have autistic spectrum disorders	462	462	468	478	490	511	530	499
Total population aged 18-64 predicted to have autistic spectrum disorders	1,941	1,939	1,934	1,936	1,935	1,934	1,917	1,892
Total population aged 65+ predicted to have autistic spectrum disorders	754	770	792	810	822	856	949	1054

## Population Projections 2014 -2030

From PANSI (Projecting Adult Needs and Service Information) and POPPI (Projecting Older People Population Information System), Oxford Brookes University and Institute of Public Care

### Hull

<b>LD - Baseline estimates</b>									
<b>People predicted to have a learning disability, by age</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>	<b>2018</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>	<b>2030</b>
People aged 18-24 predicted to have a learning disability	831	817	798	784	768	732	717	791	791
People aged 25-34 predicted to have a learning disability	996	1,011	1,023	1,028	1,036	1,036	991	926	926
People aged 35-44 predicted to have a learning disability	798	793	786	782	780	793	862	892	892
People aged 45-54 predicted to have a learning disability	805	799	797	791	783	754	694	692	692
People aged 55-64 predicted to have a learning disability	620	629	643	657	671	698	716	673	673
Total population aged 18-64 predicted to have a learning disability	4,049	4,049	4,048	4,043	4,037	4,013	3,980	3,975	3,975
Total population aged 65+ predicted to have a learning disability	789	798	813	827	843	869	954	1063	1063
<b>Challenging behaviour</b>									
People aged 18-24 with a learning disability, predicted to display challenging behaviour	14	14	13	13	13	12	12	13	13
People aged 25-34 with a learning disability, predicted to display challenging behaviour	18	18	18	19	19	19	18	17	17
People aged 35-44 with a learning disability, predicted to display challenging behaviour	15	15	14	14	14	14	16	16	16
People aged 45-54 with a learning disability, predicted to display challenging behaviour	16	15	15	15	15	14	13	13	13
People aged 55-64 with a learning disability, predicted to display challenging behaviour	12	12	13	13	13	14	14	13	13
Total population aged 18-64 with a learning disability, predicted to display challenging behaviour	74	74	74	74	74	74	73	73	73
<b>Autistic spectrum disorders - all people</b>									
People aged 18-24 predicted to have autistic spectrum disorders	313	308	301	295	289	277	271	299	299
People aged 25-34 predicted to have autistic spectrum disorders	407	412	420	425	427	432	414	388	388
People aged 35-44 predicted to have autistic spectrum disorders	335	333	330	328	326	330	359	376	376
People aged 45-54 predicted to have autistic spectrum disorders	349	347	345	343	339	325	300	299	299
People aged 55-64 predicted to have autistic spectrum disorders	274	278	282	290	296	306	317	301	301
Total population aged 18-64 predicted to have autistic spectrum disorders	1,677	1,679	1,677	1,680	1,676	1,670	1,662	1,662	1,662
Total population aged 65+ predicted to have autistic spectrum disorders	353	357	363	369	377	390	429	482	482

### Population Projections 2014 -2030

From PANSI (Projecting Adult Needs and Service Information) and POPPI (Projecting Older People Population Information System), Oxford Brookes University and Institute of Public Care

#### North East Lincolnshire

LD - Baseline estimates	2014	2015	2016	2017	2018	2020	2025	2030
<b>People predicted to have a learning disability, by age</b>								
People aged 18-24 predicted to have a learning disability	371	365	354	346	338	324	312	341
People aged 25-34 predicted to have a learning disability	503	508	515	520	520	520	493	453
People aged 35-44 predicted to have a learning disability	464	454	445	438	438	443	492	508
People aged 45-54 predicted to have a learning disability	536	537	536	529	518	493	428	420
People aged 55-64 predicted to have a learning disability	433	438	445	457	464	480	493	455
Total population aged 18-64 predicted to have a learning disability	2,308	2,303	2,295	2,290	2,278	2,261	2,217	2,176
Total population aged 65+ predicted to have a learning disability	635	648	658	671	681	702	763	837
<b>Challenging behaviour</b>								
People aged 18-24 with a learning disability, predicted to display challenging behaviour	6	6	6	6	6	5	5	6
People aged 25-34 with a learning disability, predicted to display challenging behaviour	9	9	9	9	9	9	9	8
People aged 35-44 with a learning disability, predicted to display challenging behaviour	9	8	8	8	8	8	9	9
People aged 45-54 with a learning disability, predicted to display challenging behaviour	10	10	10	10	10	9	8	8
People aged 55-64 with a learning disability, predicted to display challenging behaviour	9	9	9	9	9	9	10	9
Total population aged 18-64 with a learning disability, predicted to display challenging behaviour	43	43	42	42	42	42	41	40
<b>Autistic spectrum disorders - all people</b>								
People aged 18-24 predicted to have autistic spectrum disorders	139	137	132	130	127	121	118	129
People aged 25-34 predicted to have autistic spectrum disorders	199	203	204	208	210	210	199	184
People aged 35-44 predicted to have autistic spectrum disorders	190	186	184	180	178	180	198	207
People aged 45-54 predicted to have autistic spectrum disorders	227	225	223	223	219	207	180	178
People aged 55-64 predicted to have autistic spectrum disorders	190	192	196	198	204	208	215	197
Total population aged 18-64 predicted to have autistic spectrum disorders	945	943	939	939	938	926	910	895
Total population aged 65+ predicted to have autistic spectrum disorders	282	290	294	299	307	316	345	381

## Definitions

### LD - Baseline estimates

These predictions are based on prevalence rates in a report by Eric Emerson and Chris Hatton of the Institute for Health Research, Lancaster University, entitled Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England, June 2004. The authors take the prevalence base rates and adjust these rates to take account of ethnicity (i.e. the increased prevalence of learning disabilities in South Asian communities) and of mortality (i.e. both increased survival rates of young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities). Therefore, figures are based on an estimate of prevalence across the national population; locally this will produce an over-estimate in communities with a low South Asian community, and an under-estimate in communities with a high South Asian community.

### Challenging behaviour

The prevalence rate for people with a learning disability displaying challenging behaviour is 0.045% of the population aged 5 and over. Prediction rates have been applied to ONS population projections of the 18-64 population in the years 2011 and 2021 and linear trends projected to give estimated numbers predicted to have a mild, moderate or severe learning disability, to 2030. The prevalence rate is based on the study Challenging behaviours: Prevalence and Topographies, by Lowe et al, published in the Journal of Intellectual Disability Research, Volume 51, in August 2007. In total, 4.5 people per 10,000 of the population aged 5 and over were rated as seriously challenging (representing approximately 10% of the learning disability population). The most prevalent general form of challenging behaviour was 'other difficult/disruptive behaviour', with non-compliance being the most prevalent challenging behaviour. The prevalence rate has been applied to ONS population projections to give estimated numbers with a learning disability predicted to display challenging behaviour, to 2030

### Autistic spectrum disorders - all people

The information about ASD is based on Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007 was published by the Health and Social Care Information Centre in September 2009. The prevalence of ASD was found to be 1.0% of the adult population in England, using the threshold of a score of 10 on the Autism Diagnostic Observation Schedule to indicate a positive case. The rate among men (1.8%) was higher than that among women (0.2%), which fits with the profile found in childhood population studies. The report Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP), Baird, G. et al, The Lancet, 368 (9531), pp. 210-215, 2006. found that 55% of those with ASD have an IQ below 70%. The National Autistic Society states that 'estimates of the proportion of people with autism spectrum disorders (ASD) who have a learning disability, (IQ less than 70) vary considerably, and it is not possible to give an accurate figure. Some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. Other people with ASD may be able intellectually, but have need of support from services, because the degree of impairment they have of social interaction hampers their chances of employment and achieving independence.' The prevalence rates have been applied to ONS population projections of the 18 to 64 population to give estimated numbers predicted to have autistic spectrum disorder to 2030

Appendix 4 National Outcome Measures: benchmarking  
Public Health England Statistics (2013/14 data)

Compared with national benchmark

Better	Similar	Worse
Lower	Similar	Higher

Indicator	England	Y+H	ERY	Hull	NEL
<b>Population</b>					
Learning Disability QOF Prevalence (18+)	0.5	0.5	0.5	0.5	0.6
Adults (18 to 64) with learning disability known to local authorities	4.3	4.4	4.5	4.1	3.8
Children with Moderate learning difficulties known to schools	15.6	15.1	14.6	19.0	24.1
Children with Severe Learning Difficulties known to schools per 1,000 pupils	3.7	4.0	3.5	7.7	*
Children with Profound & Multiple Learning Difficulty known to schools per 1,000 pupils	1.3	1.3	*	*	*
Children with autism known to schools per 1,000 pupils	9.1	8.1	5.0	7.8	9.2
<b>Health</b>					
Proportion (%) of eligible adults with learning disability having a GP health check	44.2	45.3	50.3	30.3	50.9
<b>Accommodation and Social Care</b>					
Adults with learning disabilities in settled accommodation	74.9	79.2	65.1	70.9	75.3
Adults with learning disabilities in non-settled accommodation (%)	21.7	17.6	30.3	28.4	23.3
Adults with learning disabilities living in accommodation whose status is unknown to LA (%)	3.4	3.2	4.0	0.8	1.4



Appendix 4 National Outcome Measures: benchmarking  
Public Health England Statistics (2013/14 data)

Compared with national benchmark

Better	Similar	Worse
Lower	Similar	Higher

Indicator	England	Y+H	ERY	Hull	NEL
<b>Population</b>					
Adults with learning disabilities living in severely unsatisfactory accommodation (%)	0.3	0.1	0.0	0.0	0.0
Adults with learning disabilities in employment	6.7	6.2	5.7	*	17.8
Adults with learning disabilities receiving direct payments (%)	30.5	30.6	45.9	36.9	40.0
Rates of referral for abuse of vulnerable person per 1,000	109.3	79.5	61.0	98.5	92.1
<b>Coordination and local planning</b>					
Comparison of LA and QOF prevalence estimates	-0.1	-0.2	-0.1	-0.1	-0.5
Comparison of pupils with learning difficulties and LA prevalence estimates	80.2	79.6	*	*	*
Comparison of pupils with severe and profound and multiple LD and LA prevalence estimates	13.5	16.7	*	*	*
Adults using day care services supported by the LA (per 1,000 people)	323.7	378.4	382.9	373.1	355.2
Adults receiving community services supported by local authorities (per 1,000 people with learning disabilities)	754.0	796.0	691.0	709.0	776.0
Children with learning disabilities known to schools per 1,000 pupils	20.6	20.3	*	*	10.2

Source: Public Health England, Learning Disabilities Profiles  
<http://fingertips.phe.org.uk/profile/learning-disabilities>



*Hull Clinical Commissioning Group*



*North East Lincolnshire  
Clinical Commissioning Group*



*East Riding of Yorkshire  
Clinical Commissioning Group*

