# Transforming Care – Nottinghamshire Fast Track Site

#### 1. Background

Following the publication of the Department of Health's report '*Transforming Care: A national response to Winterbourne View Hospital*' in December 2012, and subsequent reports including the *Bubb Report* in November 2014, and '*Transforming Care for People with Learning Disabilities – Next Steps*' in January 2015, a significant amount of work has been undertaken to make improvements in the care and services available for people with learning disabilities and/or autism spectrum disorders. However, nationally there is a view that more needs to be done. Simon Stevens, Chief Executive of NHS England, said on 3 June 2015: "We have not finished the job. We need a closure programme for long stay institutions, with more power in the hands of families."

NHS England, the Local Government Association and Association of Directors of Adult Social Services announced on 12 June 2015 that five 'fast track' areas were being established that would be the forerunners of transformation of services for people with a learning disability and/or autism and challenging behaviours, or a mental health condition. The fast track areas were asked to submit a transformation plan by 7 September 2015 which described how they would strengthen community services, reduce reliance on in-patient beds (non-secure, low and medium secure) and close some in-patient facilities.

The areas were chosen based on the numbers of in-patient beds and it was felt that they had the potential to bring together a large number of local authority and CCG commissioners and specialised commissioning, each with different challenges, to test different approaches and effect the biggest change. The areas chosen were as follows

- Arden, Herefordshire and Worcestershire
- Cumbria and the North East
- Greater Manchester and Lancashire
- Hertfordshire
- Nottinghamshire (including Bassetlaw)

As part of transformation plans, fast track areas were invited to bid for a share of a £10 million transformation fund to help accelerate service redesign and shape the new national approach to transforming learning disability services and services for those with autism spectrum disorders more widely across England to embed more sustainable change. Obtaining a share of the national monies was conditional on CCG's match funding the contribution.

A national service model for those with learning disabilities and/or autism spectrum disorders is being published at the end of October 2015 which will include national planning assumptions for re-designing services. Following this all areas of the country will be expected to undertake transformation within learning disability services in line with the new service model. It is understood that this will be reflected in the planning guidance for 2016 / 2017.

# 2. Process and Arrangements for the Nottinghamshire Fast Track Site Plan Submission

Upon notification in mid-June 2015 that Nottinghamshire had been identified as a fast track site, Sally Seeley (NHS Nottingham City CCG) was nominated and agreed as the Senior Responsible Office (SRO) for the project with Caroline Baria (Nottinghamshire County Council) as the Deputy SRO. A Transforming Care Board and a Working Group were established to enable organisations to work together and create a plan to transform services for people with a learning disability and/or autism who also have, or are at risk of developing, a mental health condition or behaviours described as challenging who reside in Nottinghamshire. This includes people of all ages and those with autism (including Asperger's syndrome) 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 Nottinghamshire plan was submitted on the 7 September detailing our ambitions, how we intended to work with our population, key stakeholders and the proposed governance arrangements and bidding for £1.68 million from the national monies.

Feedback on the plan and confirmation that we had been allocated £1.21 million from the available national funding was received from NHS England on 5 October.

#### 3. Nottinghamshire Transformation Plan

Our plan aims to transform care and support for individuals with a learning disability and/or autism who also have, or are at risk of developing, a mental health condition or behaviours described as challenging so that their care is focused on keeping them healthy, well and supported in the community. Achieving this will minimise the need for inpatient care with the objective of reducing the number of beds we have available over a period of time as the redesign of services and implementation of more community based provision takes effect, for example better provision around addressing crises as they occur including accommodation options.

Our plan provided detail on the following:

- The Nottinghamshire area
- 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

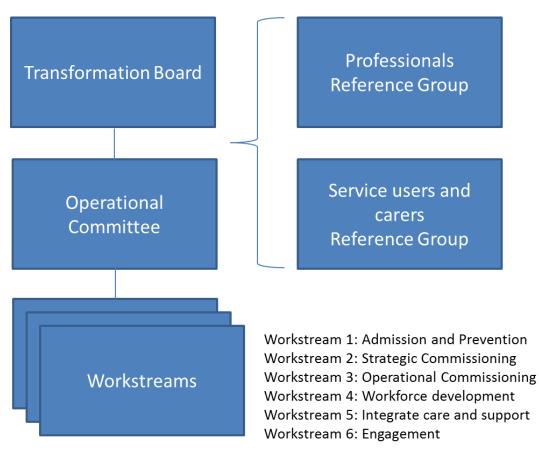
The plan recognises that to successfully deliver it, significant changes in the way that services are currently commissioned and provided will be required and that this will need the full support of adults with a learning disability and/or autism spectrum disorder, their families, friends and carers as well as from providers of services and the health and social care workforce. We have committed to working together to make these changes happen through the design and provision of effective social and health care services. The published version of the plan can be found at Appendix One.

We will also work through recommendations from Future in Mind, the national plan for improving the mental health and wellbeing of children and young people. We have developed local Future in Mind transformation plans for Nottingham and Nottinghamshire and will ensure alignment with this plan.

#### 4. Process and Arrangements for the Nottinghamshire Fast Track Site Plan Consultation and Implementation

Now that feedback has been received and we have been notified of the financial allocation we are moving into the implementation phase of the project. One of the first things that we will do is begin a formal public consultation about our proposed new service model as due to the timescales required nationally it was not possible for us to do this prior to the plan being submitted in September. Further details of this will be circulated in the near future. This paper is also being submitted to all CCG Governing Bodies, relevant Local Authority Committees and will be presented to the Joint Overview and Scrutiny Committee.

The Transformation Board is continuing to meet and we have established a robust governance structure which will oversee process and delivery of the plan which is shown below:



#### 5. Recommendations

The Governing Body is requested to:

- Note the information given and the plan for transformation of services for individuals with a learning disability and/or autism spectrum disorder.
- Provide comments on the progress to date and the suggested approach to implementation of the plan.

Sally Seeley Senior Responsible Officer October 2015

**Appendix One** 

# **Transforming Care for People** with Learning Disabilities and/or **Autism Spectrum Disorders in Nottinghamshire**

October 2015





NHS

Bassetlaw

NHS

Nottingham City

**City Council** 

NHS Newark and Sherwood Clinical Commissioning Group

NHS Mansfield and Ashfield Clinical Commissioning Group

> NHS Nottingham West Clinical Commissioning Group

NHS Foundation Trust

NHS Nottingham North and East Clinical Commissioning Group





NHS Rushcliffe **Clinical Commissioning Group** 

**Clinical Commissioning Group** 

**Clinical Commissioning Group** 

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# **1** Introduction

This document sets out the vision of the Nottinghamshire Fast Track Site for transforming care and services for people with a learning disability and/or autism 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 Asperger's syndrome) 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.

We hope that this plan will be helpful in understanding:

- The Nottinghamshire area
- 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

Delivering this plan and our vision will require significant change in the way that services are currently commissioned and provided. This will need the full support of adults with a learning disability and/or autism spectrum disorder, their families, friends and carers. We will work together with them to make these changes happen through the design and provision of effective social and health care services.

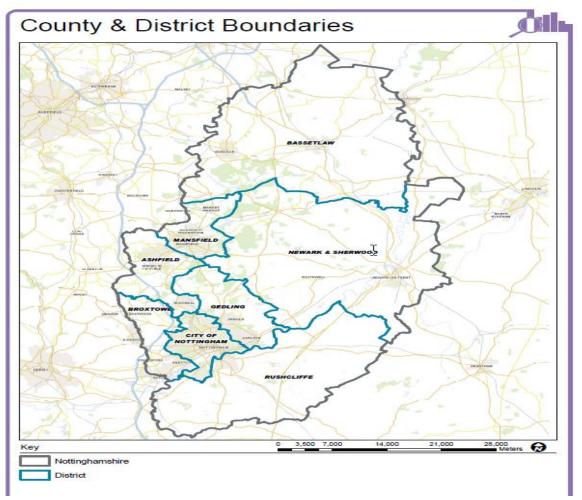
Our plan aims to transform care and support for individuals with a learning disability and/or autism who also have, or are at risk of developing, a mental health condition or behaviours described as challenging so that their care is focused on keeping them healthy, well and supported in the community. Achieving this will minimise the need for inpatient care enabling us to reduce the number of beds we have available over a period of time as the redesign of our services takes effect.

This plan contains a broad overall vision, developed by the Nottinghamshire Fast Track Transformation Board. In some areas it contains detailed proposals for how services could look different in the future but there is further work that will be required in a number of areas. In addition, we know that it will take time to turn our vision into a reality and that more detailed planning will be needed. We have included within this document a more detailed plan of the next steps required and how we intend to do this.

# 2 About Us

The Nottinghamshire Fast Track Area covers the populations of the City of Nottingham and Nottinghamshire County including Bassetlaw. There are two Local Authorities, seven Clinical Commissioning Groups (CCGs) and NHS England that are responsible for commissioning care for everyone who lives in the area. Care is delivered by a range of providers from both the NHS and the Independent Sector.

The County and District boundaries within the Nottinghamshire area are shown in the diagram below:



We have involved all the commissioning organisations noted above in the development of this plan as well as other stakeholders, including Nottinghamshire Healthcare NHS Foundation Trust (NHT), Health Education East Midlands, Positive Behavioural Support Consultancy, Challenging Behaviour Foundation and the NHS England National Team for Learning Disabilities. They have endorsed the submission of this plan via the Transforming Care Board.

There are other key partners who will also need to be engaged with the work and our plans for the future, for example Nottinghamshire Police and CCGs outside of the area who may place individuals within Nottinghamshire. This is in addition to people with learning disabilities and/or autism, their families and carers as well as wider communities within Nottinghamshire.

# **3 Background and Context**

## 3.1 Population

There are no official statistics reporting the number of adults in the UK with a learning disability and/or autism and establishing a precise or accurate figure is not easy due to the social construct of the condition and its wide spectrum.

However, data from the most recent Joint Strategic Needs Assessments for both Nottingham City and Nottinghamshire County shows that Nottinghamshire was home (2011) to approximately 21,000 adults over the age of 18 who have a learning disability and approximately 7,000 adults between 18 and 64 with autism spectrum disorders (ASD). The National Autistic Society state that as estimates of the proportion of people with ASD who also have a learning disability varies considerably, it is not possible to give an accurate figure. In 2011, there were 346 people with profound and multiple learning disabilities (PMLD) in Nottinghamshire.

There are estimated to be about 4,000 disabled children and young people, aged 0-19, of which almost 900 have severe and lifelong disabilities in the City and between 5,000 and 12,000 in Nottinghamshire County. One of the best sources of information around young people with Special Educational Needs and Disability (SEND) is data from the School Census. This provides pupil level information for all pupils in Nottinghamshire schools detailing their level of need and their primary type of SEN and/or disability. As of January 2015 the numbers of pupils with their primary type of need being a learning disability were across both city and county were: 2,271 (moderate), 90 (severe), 45 (profound and multiple) and 624 (specific).

Where people live makes a difference to the population share across Nottinghamshire with the highest populations in Nottingham City, Mansfield and Ashfield and Nottingham West (which covers the Broxtowe area).

As may be expected, there is estimated to be a four times difference in the estimated prevalence of learning disabilities and/or autism within the population and people known to be accessing services.

It is estimated that there will be an increase in people with learning disabilities by approximately 14% between 2011 and 2030. However, this overall increase masks an ageing population with large increases in people over 55 years of age and a decrease in those with a learning disability and/or autism below the age of 55. In addition, to the change in the age profile, there will be increases in people with moderate or severe learning disability, challenging behaviours and autism spectrum disorders.

The reasons for our population increase are likely to be driven by 3 main factors:

- An increase in the proportion of younger adults who belong to South Asian communities (Nottingham City is likely to have the biggest impact from this)
- Increased survival rates among young people with severe and complex disabilities
- Reduced mortality among older adults with learning disabilities

Further detail on the Nottinghamshire population and the trends we expect to see, can be found at Appendix 1.

Please see Appendices 2 and 3 for details of the public health statistics and national outcome measures that relate to this plan.

# 3.2 Commissioning Spend

Health services are expecting to spend £19.73m in 2015/2016 on providing in-patient and community care and services for our population with a learning disability and/or autism whether they are in Nottinghamshire or placed out of area. 70% of this money is spent by CCGs and 30% by Specialised Commissioning. This figure does not include spend on NHS Continuing Healthcare or Section 117 aftercare which is shown separately and totals £10.56m for NHS Nottingham City and NHS Bassetlaw. The actual spend in this area for the 5 CCG's in Nottinghamshire is not available at the time of writing this plan.

Meanwhile the Local Authorities are expecting to spend £129.13m on social care for those with a learning disability.

# 3.3 Inpatient Learning Disability Beds

There are 199 learning disability and/or autism inpatient beds in Nottinghamshire. This includes low and medium secure, locked rehabilitation, assessment and treatment beds for adults, and CAMHS tier 4 beds although these are not specifically for individuals with a learning disability.

In addition, Specialised Commissioning has 3 beds in Nottinghamshire used by Nottinghamshire residents which are non-specific LD/autism beds and therefore not included in the numbers above.

Nottinghamshire also has 56 high secure Learning Disability male beds at Rampton Secure Hospital which are provided by NHT. Although out of scope for the fast track work, they have been referenced as there are currently patients from Nottinghamshire in these beds who may stay within the Nottinghamshire area if they were to be discharged from high secure services.

In addition, there are 12 out of area non-secure beds that are occupied by people from Nottinghamshire CCGs and 10 additional low and medium secure beds occupied by Nottinghamshire residents.

# 3.4 Commissioning Implications

There are variations of provision within the area, with the City having limited inpatient hospital independent sector provision - this is predominantly found in the County. However, the County also has a high number of residential facilities for individuals with learning disabilities and/or autism. This has previously meant that people come into the area and then become the responsibility of Nottinghamshire if they are sectioned under the Mental Health Act although this has now changed with changes to the Code of Practice in April

2015. This together with the high number of inpatient beds (mainly from the independent sector) makes the area an importer of individuals.

Nottinghamshire recognises that those with a learning disability and/or autism and challenging behaviours are not best served by long term hospitalisation. There are some big challenges ahead as the population data shows that will be pressure on all services due to increasing numbers of people requiring support and the changing profile of these individuals, for example an ageing population of those with a learning disability and/or autism requires more proactive support, integrated around co-morbidities which are more common in later life. This care needs to focus on keeping people healthy and well in the community, and maintain their independence.

There is some joint work however it needs to be improved to address some of the issues in terms of commissioning, for example basing this on the type of a service rather than a population as in the current arrangements. We also struggle to influence independent sector bed provision in our area which results in more beds in the Nottinghamshire area being available than are required.

Without changes to the way we commission and provide services the problems will get worse over time. To resolve this Nottinghamshire want to have:

- A systems approach across all commissioners (CCG, NHS England and Local Authorities) for people in Nottinghamshire with a learning disability and/or autism and challenging behaviours.
- Care and support redesigned to ensure that inpatient care is only used when it is the best place for the person concerned e.g. when it is mandated by the courts or for respite or assessment and treatment when community provision not possible
- Person centred care and support planned and delivered to individuals consistently by providers
- A 'whole life' preventative approach needed for care and support with a much greater emphasis on reducing the severity and frequency of challenging or offending behaviours from a young age and beyond into adulthood.
- Greater liaison and influence at a national level about the use of new style inpatient service models and bed numbers in Nottinghamshire
- Significant market development and provider liaison to achieve the changes required by building the skills and capacity in the market whilst not destabilising it unnecessarily

These commissioning principles will link into the recent reforms for children and young people up to the age of 25 with integrated support now being provided with Education Health and Care plans.

# 4 Our Vision for Services

People with learning disabilities have poorer health than the general population, much of which is avoidable. These health inequalities often start early in life and result, to an extent, from barriers they face in accessing timely, appropriate and effective health care. The impact of these health inequalities is serious because as well as having a poorer quality of life, people with learning disabilities die at a younger age than their non-disabled peers.

The 2013 Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found that men with learning disabilities died on average 13 years younger than men in the general population and women 20 years younger. CIPOLD data also showed that people with learning disabilities are three times as likely as people in the general population to have a death classified as potentially avoidable through the provision of good quality healthcare. This suggests that if we can improve the quality of healthcare and support then we can improve their outcomes.

Our vision identifies how we think services will need to be commissioned and provided in the future to ensure that people with learning disabilities and/or autism with behaviours which challenge services who call Nottinghamshire home are supported within their local community and only require in-patient services for clearly defined purposes.

## 4.1 Scope

Children or adults with a learning disability and/or autism who have/display:

- A mental health problem, such as severe anxiety, depression or a psychotic illness which may result in them displaying behaviours that challenge
- Self-injurious or aggressive behaviour, not related to severe mental ill-health, some of whom will have a specific neurodevelopmental syndrome with often complex life-long health needs and where there may be an increased likelihood of behaviour that challenges
- 'Risky' behaviour which may put themselves or others at risk (this could include firesetting, abusive, aggressive or sexually inappropriate behaviour) and which could lead to contact with the criminal justice system
- Lower level health or social care needs and disadvantaged backgrounds (e.g. social disadvantage, substance abuse, troubled family background), who display behaviour that challenges, including behaviours which may lead to contact with the criminal justice system.
- A mental health condition or whose behaviour challenges who have been in inpatient care for a very long period of time, having not been discharged when NHS campuses or long-stay hospitals were closed

# 4.2 Values Underpinning our Vision

- 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

# 4.3 Expected Outcomes

- More people with learning disability will be supported to live in the community/at home
- The frequency of people displaying behaviours that challenge will be reduced as will the severity of episodes
- People with a learning disability and/or autism who display challenging behaviours will be kept safe in their communities wherever possible
- Fewer people will be admitted to secure hospitals and Intensive Community Inpatient Support Services beds
- Delayed discharges will be minimised
- People with a learning disability and/or autism will have a projected length of stay recorded when they are initially admitted to hospital
- Any hospital stays will be closer to the individual's home and support networks
- There will be fewer inpatient beds commissioned for the Nottinghamshire population
- People with a learning disability and/or autism who display challenging behaviours will enjoy an improved quality of care and an improved quality of life

If they were able to put into words, the individual would be able to state in relation to the care and support they receive that:

- My care is planned, proactive, and co-ordinated
- I am involved in deciding how my health and care needs are met
- I live in the community with support from and for my family and paid carers
- I am involved in deciding where I live and who I live with
- I have a fulfilling and purposeful everyday life
- I get good care from mainstream NHS services
- I can access specialist health and social care support in the community
- I am supported to stay out of trouble
- If I need assessment and treatment in a hospital setting because my health needs can't be met in the community, it is high-quality and I don't stay there longer than I need to
- If I need to be in hospital, then I only stay as short a time as is necessary

# 4.4 Principles

We, as the organisations commissioning and providing care and support in Nottinghamshire, have committed to work in partnership in line with all of the overarching principles shown below:

#### Access to Mainstream Services

- Encourage the use of mainstream services as the starting point for care and support. These will be available and accessible for those with a learning disability and/or autism
- Where mainstream services are insufficient to meet a person's needs then we will provide access to specialist multi-disciplinary community based housing and support expertise

## **Person-Centred Care**

- Work with people with a learning disability and/or autism and their families to plan and co-ordinate person centred care and support, providing them with more influence over their care including promoting a culture of positive risk taking
- Ensure a shared commitment to achieving outcomes based on "ordinary life' principles
- People with a learning disability and/or autism, and their carers and families will receive the right information at the right time to enable them to make informed decisions about the person's care and support. The way this information is delivered will take account of the communication needs of the person concerned

#### **Mental Capacity**

- Assume a person has the mental capacity to make decisions about their care, unless it is
  established that they lack capacity for that specific decision and all practicable steps
  will be taken to support them to make their own decisions
- Establish the extent of a person's mental capacity as soon as there is any doubt as to whether the person has the mental capacity to make decisions

## **Prevention and Early Intervention**

- Pro-actively identify needs, including challenging behaviour as early as possible and starting in childhood, and intervene earlier through community solutions wherever possible to prevent needs escalating. This will include:
  - Reducing the exposure to environmental conditions that may lead to behavioural changes
  - Promoting the resilience of those who face such environmental conditions
  - Providing early intervention, support and services that will meet individual needs, including communication needs, for those who are showing early signs of developing behavioural challenges
- Identify those at risk of admission to hospital or of coming into contact with the Criminal Justice system earlier and put strategies in place to manage risk
- Work to ensure that evidence-based interventions are used with people from a young age to minimise 'risky' behaviour which may otherwise put themselves or others at risk
- Protect those with a learning disability and/or autism from abuse and neglect wherever possible, and address safeguarding concerns as soon as they arise

#### **Challenging Behaviours**

- Promote a positive and proactive approach to addressing challenging behaviours
- Provide support in the least restrictive setting possible that is therapeutic and safe for all. If restrictive interventions are required they will be for the shortest time possible

#### **Community Focus**

- Work across health and social care to ensure people's homes are in the community
- Develop cost effective services which promote independence

# Skills, Knowledge and Culture

- Work with everyone involved in providing care and support to ensure expertise is shared, and that there is consistency of practice
- Develop a culture that is fair, accountable and reflective so we can learn from good practice, areas for improvement and mistakes

- Develop an evidence base by tracking the support of individuals, what has worked and not worked. This involves developing an outcomes framework and a costing analysis
- Our workforce will have the relevant skills, knowledge and appropriate values to deliver high quality care and support
- Use data and intelligence to proactively understand and predict people's needs

# 4.5 What Would 'Good' Look Like?

#### a) Community and Support Networks

Support given by communities and networks are an important contributor to effective care and support for the individual and their families. Peer networks are encouraged to establish and provide support to other individuals and their families throughout the journey from childhood to adulthood and into older age. Similar to mainstream services, access to community support is facilitated through reasonable adjustments, support staff or through the integrated specialist multidisciplinary health and care support available in the community.

#### b) Mainstream Services

Individuals with learning disabilities and/or autism experience the same level of service provided as to the general population. This is facilitated through reasonable adjustments, support staff or through specialist health and care support in the community.

Mainstream services which are particularly important for those learning disabilities and/or autism to access include:

- Activities that enable people to lead a fulfilling and purposeful everyday life
- Education, training and employment services
- Primary care
- Mainstream NHS services and MH services, including those provided by General Practice as people with learning disabilities and/or autism are at increased risk of experiencing mental health physical health difficulties
- Hospitals discharge planning needs to be effective for those with learning disabilities and / or autism as well as the wider population
- Services that prevent or reduce anti-social or offending behaviour
- 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
- Mainstream forensic services
- Dental care
- Housing, including small-scale supported living, though this choice may be circumscribed by the Ministry of Justice (MOJ) in some instances if the person is on an offender pathway
- Settled accommodation options including exploring home ownership or ensuring security of tenure
- Local housing strategies have the future needs of this group understood, considered and incorporated
- Substance (drugs and alcohol) misuse services

## c) Specialist Community based Services with Targeted Support

Specialist services centred around integrated specialist multidisciplinary health and care support in the community for people with a learning disability and/or autism. This includes children and young people including during transition to adults, 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. There is a focus on 'whole life' support, providing seamless care and support as children progress into adulthood and into old age.

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

Specific specialist services include:

- Support for all parents caring for children of whatever age who have LD and/or autism and who are at risk of developing or are beginning to develop a mental health condition or behaviour that challenges. The support includes:
  - Evidence-based parenting training and practical and emotional support
  - Access to short-breaks
- Alternative short term accommodation which is available as and when needed and for as long as needed in times of crisis or potential crisis 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.
- 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 reduce 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 need s of the individual and the level of
  risk they pose.

#### d) Hospital-Based Specialist Services

This is integrated into a broader care pathway, working closely with community based mental health and learning disability services. Hospital based specialist services are only be used where community settings cannot provide suitable alternatives and ensures that individuals are in the least restrictive settings that are therapeutic and safe for all. Hospital staff ensure that people are identified as soon as they become fit for discharge.

Hospital-based support includes both secure and non-secure beds as follows:

• Non secure

Where people cannot be supported effectively or safely in mainstream inpatient mental health services, small scale non secure assessment and treatment services integrated into community services are used. Intensive Community Inpatient Support Services will only be used if the person was sectioned under the Mental Health Act.

## Secure

Where people with a learning disability and/or autism need assessment and treatment for a mental disorder whilst preventing harm to the public and whose behaviour has often resulted in contact with the criminal justice system.

# 4.6 Enablers

In order for us to be able to deliver our vision, the following system enablers will be required:

# **Proactive Care and Support**

- An 'at risk of admission register' to provide adults and children most at risk of admission to hospital with proactive, preventative support, supported by risk stratification
- Identification of additional risk factors for:
  - Development and identification of behaviour that challenges, including during adulthood
  - Development of psychiatric disorders since those with learning disabilities
- Everyone with a learning disability over the age of 14 will have an Annual Health Check, resulting in a Health Action Plan which is integrated into the single person-centred care and support plan, including the Education Health and Care Plan for children
- Carer support to help families to lead a full family life and maintain their physical and emotional resilience
- Safeguarding policies and procedures to support whistleblowing and other activities that may prevent or lead to the early detection of abuse or inappropriate treatment

# Choice and Control

- A person centred care and support plan which people and their carers have been involved in drawing up and have a copy of, focused on better meeting an individual's needs and increasing their quality of life in a way that reduces the likelihood of behaviour that challenges occurring in the future
- Information and advice relevant to the individual with the learning disability and/or autism in a format that they can understand
- Any support required to assist people with learning disabilities and/or autism to communicate
- The offer of a personal budget, personal health budget or integrated personal budget with the information, advice and support about how to manage one
- As well as the legal right to statutory advocacy, people with a learning disability and/or autism who have a mental health condition or display behaviour that challenges, would be offered advocacy support, tailored to meet their needs at key transition points in their lives

## **Coordinated and Integrated Care**

- A local care coordinator will be offered to everyone to coordinate and ensure timely delivery of a wide range of services in the plan, working closely with the person and their family
- Commissioners in Nottinghamshire will work more collaboratively across boundaries to ensure collaborative commissioning and risk sharing
- There will be pooled or aligned budgets in place for funding associated with the care and support for those with a learning disability and/or autism

#### Access to Mainstream Services

- Mainstream services will be available to people with learning disabilities and/or autism can access them with the necessary reasonable adjustments
- Hospital passports will be used to help ensure that staff in mainstream NHS services can make reasonable adjustments for someone with a learning disability and/or autism, including accommodating behaviour that challenges
- Clearly identified and readily accessible liaison staff in universal NHS services, with the specific skills in working with people with a learning disability and/or autism will be available and able to advise on reasonable adjustments
- Reliable methods to check on service quality and ensure that mainstream services serve people with learning disabilities and/or autism appropriately
- Regular audits in mainstream mental health services in relation to how the mainstream services serve people with a learning disability and/or autism and make improvements as a result, using the Green Light Toolkit

#### Minimising the Use of Hospital Services

• All planned or unplanned admissions will require a pre admission care and treatment review or blue light review to ensure that hospital based services are the most appropriate setting for individuals

# 5 Delivering our Vision

Our future model of care and support in Nottinghamshire will be focused on enabling access to mainstream universal and community support with enhanced specialist, specialist and targeted community based support only provided when 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 will only be used to complement community services e.g. short breaks, crisis, or where inpatient settings are mandated.

Commissioning these new-style services will reduce the demand on hospital placements which are disempowering and unsettling for individuals and their families. This will allow the amount of in- patient beds to be reduced over time.

Support and care in Nottinghamshire will be orientated around the person and their family, friends and informal support networks. It will have six levels of services around the person as illustrated in the diagram below:

	Level	Example services
<ul> <li>1. The person</li> <li>2. Family, friends and informal supporters</li> <li>3. Mainstream services and community petworks</li> </ul>	4. Targeted community provision	<ul> <li>Special schools and colleges</li> <li>Leisure groups</li> <li>Home care</li> <li>Day opportunities,</li> <li>Work schemes,</li> <li>Short breaks (planned)</li> <li>Services for Looked after children, special education needs, children in need</li> <li>CAMHS Tier 1&amp;2</li> </ul>
4. Targeted community provision 5. Specialist support 6. Enhanced specialist support 7. Inpatient care	5. Specialist support	<ul> <li>Residential care</li> <li>Supported living</li> <li>CLDTs</li> <li>CAMHS Tier 3</li> </ul>
Key Person subject to CPA and forensic	6. Enhanced specialist support	<ul> <li>ICATT</li> <li>Crisis Support Breaks (unplanned)</li> <li>CAMHS Tier 4 &amp; CAMHS Crisis</li> </ul>
Person not necessarily subject to CPA or forensic	7. Inpatient care	<ul> <li>Locked rehab</li> <li>Assessment and treatment units</li> <li>Low and medium forensic</li> <li>CAMHS inpatient</li> </ul>

Figure 1: future model of care in Nottinghamshire

Terminology: CAMHS: Child and Adolescent Mental Health Services, ICATT: Intensive Community Assessment and Treatment Team, CPA: Care Programme Approach, CLDT: Community Learning Disability Team.

In Nottinghamshire we want to ensure that each person's support is coordinated across and between the different levels to provide a seamless pathway focused around the person and their family and carers to enable them to be as independent of public services as possible and maximise their potential. The emphasis will be on supporting the person with a learning disability and/or autism, whether as an adult or child in having as similar a life and access to public services and others as the general population, recognising that in some cases those with autism may choose to play less high profile roles in their communities.

# 5.1 Key Pillars of the New Model of Care

## a) Care Coordination

We feel that one of the keys to our success will be the strengthening of co-ordination of care and support for those with a learning disability and/or autism across the different levels of support. In our model, who provides 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 CLDT and/or ICATT teams, or for children from the CAMHS and other children's services teams, it is envisaged that a clinician will coordinate care and support. This is in line with statutory regulations requiring a health or social care practitioner to coordinate if the person is on 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 may be best taken by the family or carers of the person concerned, particularly if there is a personal budget or personal health budget involved. For children the design of care co-ordination will be in line with what is designed through our 'Future in Mind' plans.

Whoever the person coordinating the care and support for the individual is, the opinion of the person with the learning disability and/or autism will be listened to and respected in deciding who co-ordinates their care, and changing this person if the complexity of needs change, or if it is felt that their relationship is not as productive as it could be in helping making sure the person's needs and outcomes are met. The person who coordinates the care will be a constant positive force in the person's life, and they need to have an excellent working relationship. Independent advocates have a valuable part to play here in ensuring that the person's wishes are communicated and understood.

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, because of the different skill sets. However this handover will be done seamlessly and at the right point in time for the person concerned, and will make use of the continuity provided by the family and carers to achieve this.

#### b) Training and Education

All staff will be trained and experienced in supporting people with behaviours that challenge, and have an appropriate, evidence-based, range of responses to meeting people's needs and addressing challenging behaviours to ensure seamless care and support. In particular staff will be able to deliver proactive strategies to reduce the severity and frequency of behaviour that challenges, such as positive behavioural support (PBS) including personcentred 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.

## c) Mainstream Services and Community Networks

People with a learning disability and/or autism will experience similar access to services as the general population. The CLDT and ICATT teams will facilitate this access by supporting staff 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:

- Education, training and employment services
- Primary care
- Physical healthcare services and mental health services, including primary care
- Services that prevent or reduce anti-social or offending behaviour
- 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
- Mainstream forensic services
- Dental care
- Generic housing services
- Settled accommodation options including home ownership or security of tenure
- Substance (drugs and alcohol) misuse services

In the new model there will be a stronger emphasis on the support available from communities and networks, both community networks that are of interest to the whole population, and peer support networks around those with a learning disability and/or autism and their family carers. There will also be an emphasis on the person making their own contribution to communities. There will be much more of a systematic approach to supporting peer networks, recognising the organic nature in which they evolve and develop. Our feedback from people with a learning disability and/or autism and their families illustrates that where peer networks exist, they are really valued in the most part with the exception of people with autism who might choose to be less involved in social networks. Formal support providers and residential care settings will be commissioned to support these peer support networks as and when possible or necessary.

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

There will be 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 focus on 'whole life' support, providing seamless care and support as children progress into adulthood and beyond into old age.

The specialist and targeted community-based support includes:

- 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

Central to the operation of this support will be a register of those at risk of admission to inpatient services, developed to include children, those with autism, and forensic cases as well. This will provide direction as to which adults and children need to be the priority for their services. Where 'unknown' children and adults present to services, this information will be used to refine the register, so that as far as possible all children and adults whose needs remain high risk, are already known through the register. Staff across teams will provide proactive care and support, intervening early to help the person reduce the severity and frequency of their challenging behaviour.

This support will be offered through the following services, with the person coordinating the care and support ensuring that the right input is provided at the right time for the person, integrated seamlessly in a continuum of care for the individual. A multi-organisational steering group will underpin this seamless care and support providing a consistent vision across teams, establishing responsibilities for care and support where there are 'grey' areas, and smoothing the pathway as children transition to be adults.

We want people with forensic needs to be better supported in the community. Although the skills development to provide this will focus primarily on the ICATT and CAMHS teams, all teams will have an understanding of how to manage and address the needs of 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.

Team	Description	New/enhanced responsibilities and skills as a result of the model
CLDT teams	<ul> <li>Supporting adults 18+ with a learning disability and/or autism who display challenging behaviour or have a mental illness for long period of time</li> </ul>	<ul> <li>Promoting the capabilities of families and providers</li> <li>Trained and experienced in supporting people with behaviours that challenge</li> <li>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</li> <li>More integrated working between health and social care teams</li> </ul>
ICATT	<ul> <li>For people 18+ who have a learning disability and either show severely challenging behaviour or have an additional mental illness and without ICATT intervention the person would require inpatient admission</li> <li>Provide the enhanced support interventions - rapid response, short term advice and health interventions to those who are experiencing an increase in emotional and/or behavioural difficulties in community settings</li> </ul>	<ul> <li>Better liaison with the County and City CLDTs than currently</li> <li>24/7 crisis support with closer liaison with the Mental Health crisis team through joint working to enable the Mental Health crisis team to support those with a learning disability, and the ICATT team to better support those with mental health issues</li> <li>Community forensic skills integrated within the ICATT teams 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</li> <li>To provide assessment advice and support to police custody areas and magistrates courts about assessing and managing high risk or complex behaviours.</li> <li>To support the offender pathway service to ensure access and egress from the offender pathway is a key priority</li> <li>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</li> <li>Trained and experienced in applied behavioural analysis and the proactive support of people with behaviours that challenge</li> </ul>
County and City Emergency Duty Team (children and adults).	<ul> <li>Out of hours support and signposting to services for those with eligible needs, including those with a learning disability and/or autism</li> </ul>	<ul> <li>High level understanding of the support needs of people with behaviours that challenge</li> <li>Ability to respond to the needs of those who have come into contact with criminal justice system</li> </ul>

Team	Description	New/enhanced responsibilities and skills as a result of the model
Community CAMHS (City and County).	<ul> <li>CAMHS Tier 3 and Tier 4support in the community, including for Learning Disabilities and/or those with autism, providing enhanced support interventions and crisis management</li> </ul>	<ul> <li>Linking into the 'Future in Mind' programme</li> <li>Greater understanding of the growing population of children with autism, and addressing their needs, including aligning eligibility for support</li> <li>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</li> <li>Trained and experienced in proactively supporting people with behaviours that challenge</li> <li>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</li> </ul>
County and City Children's teams	<ul> <li>Providing support for Looked After Children, Children in Need, and those with Special Educational Needs</li> </ul>	<ul> <li>Support for all parents caring for children of whatever age who have LD and/or autism and who are at risk of developing or are beginning to develop a MH condition or behaviour that challenges, as well as evidence-based parenting training, and practical and emotional support</li> <li>Greater understanding of the growing population of children with autism, and addressing their needs, including aligning eligibility for support</li> <li>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</li> <li>Trained and experienced in supporting children and young people with behaviours that challenge.</li> <li>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</li> </ul>

Team	Description	New/enhanced responsibilities and skills as a result of the model
County and City Transition Teams.	<ul> <li>Providing transitional support for children into the adult world, and the care and support that they need</li> </ul>	<ul> <li>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</li> <li>Trained and experienced in supporting children and young people with behaviours that challenge</li> <li>Greater understanding of the growing population of children with autism, and addressing their needs, including aligning eligibility for support</li> <li>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</li> </ul>
Asperger's teams	<ul> <li>Multidisciplinary team for City without social care</li> <li>Social care team for County</li> </ul>	<ul> <li>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</li> <li>Have a strong link with ICATT to ensure appropriate levels of support for those with forensic needs</li> <li>Trained and experienced in supporting people with behaviours that challenges</li> </ul>
Residential care providers, Supported Living providers and Shared Lives carers	<ul> <li>Providing supportive accommodation options for adults with a learning disability and/or autism</li> </ul>	<ul> <li>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 local Forensic services and justice partners who will manage the risk of offending</li> <li>Trained and experienced in the proactive support of people with behaviours that challenge</li> </ul>

Team	Description	New/enhanced responsibilities and skills as a result of the model
County and City Community Forensic teams	<ul> <li>Providing support to those living with a mental illness and/or personality disorder in the community</li> </ul>	<ul> <li>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 local Forensic and intellectual disability services and justice partners who will manage the risk of offending</li> <li>Trained and experienced in the proactive support of people with behaviours that challenge</li> <li>Increased ability to manage the needs of people with Asperger's</li> </ul>
Criminal Justice Liaison team	<ul> <li>A liaison and specialist liaison, assessment and diversion service provided into police custody suites the courts and community policing to identify a range of vulnerabilities inclusive of mental illness, personality disorder and intellectual disability. To offer support through the justice system and refer onto main stream services.</li> </ul>	<ul> <li>Increased ability to assess and 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 local Forensic and intellectual disability services and justice partners who will manage the risk of offending</li> <li>Trained and experienced in the proactive support of people with behaviours that challenge</li> </ul>

#### e) Inpatient Settings

Inpatient settings will be integrated into a broader care pathway, working closely with community based mental health and learning disability services. 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 person coordinating a person's care and support and ICATT staff will work with hospital staff from before the day of admission, to ensure an estimated day of discharge is determined with a clear assessment and treatment plan from when the person is admitted with measureable outcomes-based milestones so that discharge planning and preparations for they stay begin before the admission.

With the support of the person coordinating the care and support for an individual and ICATT staff, hospital staff will ensure that people will be constantly monitored for being fit for discharge to ensure they do not remain an inpatient beyond this point.

A clear offender pathway (previously referred to as high, medium or low secure services) will be available for Nottinghamshire residents. Secure Hospital inpatient care will be restricted to forensic services and those who present with significant harm to others but are not fit to plead in court and are diverted from the Criminal Justice System. The criteria for admission will follow the following principles: - An admission of a person with a learning disability detained under Part II of the Mental Health Act 1983 (Compulsory Admission to Hospital and Guardianship) will only occur if the referral for an admission is via the courts as part of the diverting offenders with mental health problems and/or learning disabilities within the National Conditional Cautioning Framework.

At this stage it is anticipated that there will be no out of area placements required for people in Nottinghamshire but this will need to be confirmed on further analysis of the accommodation options within Nottinghamshire.

Hospital-based support will include both secure and non-secure, as follows:

Type of accommodation	Sept 2015 No. of beds commissioned for Notts residents	2020 No. of beds commissioned for Notts residents	Assumed length of stay	New/enhanced provision as a result of the model
Crisis support or beds	Does not exist	To be determined on further planning	Length of intervention or stay to be up to a month.	<ul> <li>A range of options are required from providing assertive support where the person lives or staying with families through to robust accommodation units for people with destructive behaviour</li> <li>The objective is to learn from Nottingham's Mental Health Crisis House - Haven House</li> <li>ICATT team supporting staff in units and families and carers in other accommodation options</li> </ul>
Short break beds	27 units available	To be determined on further planning	Length of stay to be up to a month.	<ul> <li>Will expand from current 27 units to cater for extra numbers in the community</li> <li>A range of options required from staying with families to robust accommodation units for people with very challenging behaviour</li> <li>ICATT and CLDT teams supporting staff in units and families and carers in other accommodation options</li> </ul>
Low and medium secure	18 LD/autism beds in area, 3 non-specific beds, and 16 out of area beds	17 beds	Length of stay – 2-3 years (low) and 4-5 years (medium)	<ul> <li>Fewer beds commissioned for people from Nottinghamshire</li> <li>Trained and experienced in supporting people with behaviours that challenge</li> </ul>
Intensive Community Inpatient Support Services (previously Locked Rehabilitation services)	11 beds in area and 12 out of area	8 beds	Length of stay to be up to 12 months	<ul> <li>Fewer beds commissioned for people from Nottinghamshire</li> <li>Trained and experienced in supporting people with behaviours that challenge</li> <li>Admission into this part of the pathway will be determined by each individual's level of clinical &amp; treatment needs. The aim of this provision of care is to support people who may require a longer period of support due to the behaviours that they are exhibiting that others find challenging. This extended period of support will allow</li> </ul>

Type of accommodation	Sept 2015 No. of beds commissioned for Notts residents	2020 No. of beds commissioned for Notts residents	Assumed length of stay	New/enhanced provision as a result of the model
				for the further development and testing out of proactive and reactive strategies.
Assessment and Treatment	18 beds (block contract) with 13 currently used	8 beds	Length of stay to be between 3 to 6 months	<ul> <li>Fewer beds commissioned for people from Nottinghamshire</li> <li>Trained and experienced in supporting people with behaviours that challenge</li> <li>All admissions into this part of the pathway will be as a consequence of the person's behaviour changing significantly resulting in the need for their positive behavioural support plan to be reviewed, modified, and adjusted. It is anticipated that all individuals accessing the assessment and treatment service will be detained under Part II of the MHA 1983. L</li> </ul>
CAMHS Adolescent beds – Learning disability only	1 bed	1 bed 13 beds* ( Local, regional and national resource – function and funding pathways need further exploration via national procurement work streams for CAMHS)	Length of stay on a case by case basis	<ul> <li>Fewer beds commissioned for people from Nottinghamshire for those with a learning disability and/or autism</li> <li>Trained and experienced in supporting people with behaviours that challenge</li> </ul>

# 5.2 How is our New Model Different?

The emphasis on community provision over inpatient settings will mean that the size and extent of community provision relative to inpatient provision will be much more extensive than currently. In particular there will be an enhanced support and crisis team in place – this is currently not provided. The community provision will be focused on three cohorts:

## • The current in-patient cohort, including those in forensic settings

The community provision will need to accommodate those previously served by inpatient settings, so people can improve their quality of life, be safe and improve the quality of their care and support so that where possible they can stay in their own home and any in-patient admissions are minimised.

## • The current community cohort

The 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 to when they are the best option.

## • The wider learning disability and autism population

This is the cohort that is currently unknown 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 for those with learning disabilities and/or autism where at all possible.

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

The role of mainstream services and community networks are an important partner in achieving this. There will need to be much more of a focus, on making sure that people with learning disabilities and/or autism can access all the relevant mainstream services, and have the ability to be supported by their peers, and to contribute to the support of others in this way as well.

In addition, there will be a consistent approach to challenging behaviours across all teams so that the right interventions are delivered to change behaviours, and therefore reduce the severity and frequency of challenging behaviour and consequently the needs that need to be addressed. The UK Positive Behavioural Support Competence Framework lists the competencies that define best practice, and this framework will be used to create this consistent approach to challenging behaviour across the system.

The framework has a number of key themes:

- Creating high quality care and support environments
- Functional, contextual and skills based assessment

• Developing and implementing a Behaviour Support Plan (BSP)

There are also specific enhancements required to key teams delivering community provision, as detailed above e.g. ICATT teams delivering 24/7 care and support, accommodation options to address crises, improved recognition and effectiveness of those co-ordinating care and support for an individual.

# 5.3 How will Care Settings Change?

Care settings will shift from in-patient provision to community settings and will be able to cater for those who have come into contact with the Criminal Justice system. Community settings will be enhanced through improved community services, and expanded capacity as well as the addition of crisis accommodation provision for those with learning disabilities and/or autism. Short term care settings such as crisis accommodation and short breaks, as well as long term care settings through e.g. Shared Lives and Supported Living.

## 5.4 What will be Commissioned that is Different?

#### **Advocacy Services**

Advocacy services are a key enabler for the new model to help those with a learning disability and/or autism exercise choice and control over their care and support over the long term. Currently advocacy services in Nottinghamshire are being re-commissioned. They are currently provided. through a single gateway 'Your Voice Your choice' providing a single point of access for all advocacy services and to provide capacity during the resolution of particular issues as they arise, rather than long term support. 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 so the commissioning of advocacy for them needs to reflect this. Consideration should also be given as to how ongoing support can be offered that does not meet the criteria for advocacy.

#### **CLDT teams**

These teams are currently provided and managed by the City and County local authorities with NHT staff co-located within them. They will need to be commissioned to cater for a greater volume of cases and to cater for more people who have come into contact with the Criminal Justice system. As for ICATT teams the commissioning of CLDTs will also need to encourage a culture in the ICATT teams, that promotes a proactive approach to challenging behaviour that seeks to reduce the severity and frequency of challenging behaviour, preventing the escalation of needs and intervening early to reduce their impact.

#### **Crisis and Short Breaks Support**

Learning from the mental health crisis house that has been opened in Nottingham City, Nottinghamshire will look at commissioning a range of options for crisis to support individuals and their families. Short break provision will be expanded to ensure that this is another option for people to prevent hospital admissions.

#### **Supported Living Services**

Nottinghamshire already has a history of developing accommodation options to support the transfer of in-patients into community settings from long stay NHS and private hospital

placements. Some of these offer a core and cluster model providing private space as well as shared support and a community, with 6-7 schemes built delivering this model, providing up to 33 individual flats. With the new model Supported Living services will be commissioned to support people with more complex behaviours including those who have been in contact with the Criminal Justice system, and also for a greater number of people. There will need to be market development activity to create a market of small niche providers in Nottinghamshire to manage people with extremely challenging behaviour, since this support is not consistently readily available across the whole of Nottinghamshire, particularly in the City. Where it does exist there is a need to support our existing core providers to develop greater capability and reliability in meeting the needs of people with challenging behaviour.

#### **Residential Services**

Consideration will need to be given to strengthening the commissioning of residential services in order to ensure that they recruit and train staff to meet the requirements of this cohort.

#### **ICATT teams**

The role of these existing teams, currently commissioned from NHT will expand to provide a 24/7 response, closer liaison with the Mental Health crisis team, closer working with CLDTs, as well as inclusion of community forensic skills and capabilities. The increased capacity of the team will cater for the greater volume of cases. Commissioning will also need to encourage a culture in the ICATT teams that promotes a proactive approach to challenging behaviour that seeks to reduce the severity and frequency of challenging behaviour, preventing the escalation of needs and intervenes early to reduce their impact.

# 5.5 How will it be Commissioned Differently?

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 integrator model to support alignment and fit of people's needs with a range of providers.

Whilst we have some excellent examples of supported living in Nottinghamshire that is meeting people's needs, it is anticipated that there will need to be significant market development activity to create a sustainable market of providers in Nottinghamshire which can deliver some of the new or enhanced commissioning intentions. This will require close and trusting relationships with providers, listening to their input to create Market Position Statements, and then working closely with them to build capacity in the marketplace.

An example area which will need market development is that of small niche providers who are able to provide accommodation options for those with very challenging behaviours. This need for small niche providers will also require commissioning mechanisms, as well as market development activities, to encourage a much smaller type of provider. Procurement and contracting mechanisms must not to be too time-consuming or to naturally 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, commissioning for outcomes. There may also be a need to encourage social enterprises as a good way to deliver services. This will require additional market development effort to ensure suitable social enterprises are developed that can take on such services.

At the other end of the scale in some cases it will need to be recognised that to achieve cost effective services commissioning may need to happen on a more regional basis than just Nottinghamshire.

Since the approach and culture of providers is critical to delivering effective community services for those with a learning disability and/or autism, commissioners will need to investigate options for commissioning services for outcomes. The outcomes concerned are likely to 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.

Decommissioning of in-patient beds needs to be carefully considered and close working relationships between commissioners and providers will be required to deliver this successfully.

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 through strengthening the services that support this group.

We would want to ensure that there is collaborative commissioning and linked risk-sharing between CCGs and NHS England in commissioning of beds in Nottinghamshire. This will require the support of NHS England in the negotiations to ensure that CCGs and other specialised commissioning teams have a plan to reduce the numbers of beds they commission in Nottinghamshire.

We will link this plan in with existing plans in Nottinghamshire for example our Crisis Concordat action plan, strategic priorities and national outcome measure reporting. We will also ensure that there is alignment to both the Nottingham City and Nottinghamshire County 'Future in Mind' plan which is due for submission in October 2015 by having a consistency of personnel involved in the creation of both plans.

# 5.6 What Enablers need to be in Place for our System to Operate?

#### **Proactive Care and Support**

- A register to provide adults and children most at risk of admission to hospital with proactive, preventative support, supported by risk stratification. These risks will include the development and identification of behaviour that challenges, as well as the development of psychiatric disorders. Nottinghamshire already has a register in place, but it will need to be extended to include children, those with autism without having a learning disability and also those with a forensic history.
- Everyone with a learning disability over the age of 14, or those required to do so through having an Education Health and Support Plan, will have an Annual Health Check, resulting in a Health Action Plan which will be integrated into their person-centred care and support plan. Whilst Annual Health Checks are in place across GP practices in Nottinghamshire, practice is variable in a large part due to a lack of skills in helping to

diagnose a learning disability. The extension of health checks down to the age of 14 will increase the existing capacity issue in delivering these. Work will be undertaken with primary care which CCG;s are best placed to support with to understand how best they GPs can deliver a consistent approach to Annual Health Checks from the age of 14 for those with a learning disability.

- The impact on families and carers can be especially severe for those with a learning disability and/or autism, particularly if they display challenging behaviour. Support for families to lead a full family life and to maintain their physical and emotional resilience, is particularly important. Information and advice to manage challenging behaviours and to operate personal budgets and personal health budgets, and the availability of peer networks will be particularly important. The recently enhanced duties and responsibilities towards carers provides a clear statutory framework for this, and those working with people with a learning disability and/or autism, will prioritise support to help families and carers improve their quality of life, and to sustain the caring relationship.
- The enhanced responsibilities of health and social care organisations in relation to safeguarding will be particularly important for teams working with people with a learning disability and / or autism, considering what happened at Winterbourne View. There will be stringent policies and procedures in place to support whistleblowing and teams will work quickly to act on any early detection of abuse or inappropriate treatment.

#### **Choice and Control**

- Person centred plan (PCP). 'My plan', will be a person centred care and support plan which people and their carers have been involved in drawing up and have a copy of, focused on better meeting an individual's needs and increasing their guality of life in a way that reduces the likelihood of behaviour that challenges occurring in the future. The use of Person Centred Plans in Nottinghamshire starts from an understanding that people using services, and their carers and communities, are experts in their own lives and are therefore essential partners in the design and development of services. PCPs were initially implemented for a cohort of those with a learning disability and/or autism a couple of years ago, and through the Transforming Care programme they will be extended out to all those with a learning disability and/or autism. The PCP will provide all those involved in working with the person with a learning disability and/or autism, with a sense of the life journey of the person concerned, and what really matters to them in terms of how they lead their lives. The PCP will be supported by an underlying 'service plan'. 'My plan' will also address physical health, mental health and additional needs such as sleep difficulties, sensory impairments and ADHD need to be identified and addressed in the plan.
- The County and City Councils have new duties in the Care Act in relation to the provision of information and advice both to those receiving Council funded and those receiving self-funded care and support. There will be a particular emphasis on offering information and advice is in a format that the person with a learning disability and/or autism can understand and offering information and advice is in a format that the person or may be able to understand, and also on providing information and support around managing challenging behaviours and how to operation personal budgets and personal health budgets. This will support people with learning disabilities and their families to make choices directly and to be better informed about universal, targeted and specialist services. Teams, particularly the person co-ordinating care and support for an individual will make good use of the enhanced approaches to

information and advice to make sure that both the person with a learning disability and/or autism, receives the right information and advice at the right time in their care and support journey, relevant to the individual with the learning disability and/or autism in a format which they may be able to understand, and which helps them influence decisions around their care and support.

- Through the Care Act there is a new duty for the City and County Councils to provide independent advocacy at any point if it is felt a person would have substantial difficulty in being involved in the social care process and have no family or friends who can support their involvement. For those with a learning disability and/or autism, the model will move beyond this to a much more regular use of advocates around key life decisions. As a result the intention is that using an advocate will become the norm for those with a learning disability and/or autism and challenging behaviour or mental health needs. Care and Treatment reviews (CTRs) in Nottinghamshire show that currently only 30-40% of people had accessed advocacy this needs to change. This will require a refocused approach to commissioning the single point of access to advocacy services, Your Voice Your choice', and we will commission an immediate interim increase in advocacy services for CTRs before the retendered contract starts in September 2016.
- New duties for health and social care organisations around offering and aligning personal budgets and personal health budgets, are particularly important for people with a learning disability and/or autism. By the end of the programme all people who are eligible for services will have the option of a personal budget and/or personal health budget so that people and their families and carers can exert their influence effectively in how care and support is provided. They will also receive the right information and advice at the right time to make informed choices around their personal budget and/or personal health budget. The funding in these personal budgets or personal health budgets will either be managed by the person, their family and carer, a third sector organisation or health and social care provider. In line with the move to pooled or aligned budgets, there will be a move to integrated personal budgets for people with a learning disability and/or autism, combining health and social care funding.

#### **Co-ordinated and Integrated care**

- To help deliver whole system care, there will be a move to pooling budgets across CCGs, Local Authorities and Specialised Commissioning, for low and medium secure to support those with a learning disability and/or autism and those who may/have come in contact with the Criminal Justice System. The ability to move to truly pooled budgets for specialised commissioning will require national changes to NHS funding. Even where pooled budgets prove not to be possible or practical, budgets will be aligned to gain as much of the benefits of pooling funds as possible. The monies released from in-patient services to be re-invested in community services, will need to be pooled, so that replacement care and support commissioned is truly focused on the person and not constrained by the organisation it belongs to.
- It is envisaged that through the Transforming Care programme a single overview plan (both 'My plan' and the underpinning service plan) will be delivered across health and social care, whether the person is on CPA or not. This will require a single ICT system to support these single overview plans, accessible to all those working with a person with a learning disability and/or autism, and potentially to the person and their carers and families. The single overview plan will be supported by more specific plans around

specific needs, which are also likely to be shared and available across organisational boundaries.

#### Accessing Mainstream Services

- The Hospital Passport will be consistently available within Health Action Plans to help staff in mainstream NHS services make reasonable adjustments for someone with a learning disability and/or autism, including accommodating behaviour that challenges.
- A scheme for quality checking mainstream services will be put in place to ensure that mainstream services serve people with learning disabilities and/or autism appropriately, and that action is taken to address any identified issues.
- There will be regular audits in mainstream mental health services in relation to how the mainstream mental health services serve people with a learning disability and/or autism and make improvements as a result, using the Green Light Toolkit.

## Minimising the Use of Hospital Services

- Care and Treatment Review (CTRs) or 'Blue Light' reviews are already in place in Nottinghamshire prior to any admissions (planned or unplanned) to ensure that hospital based services are the most appropriate setting. They are providing valuable data that is already influencing how services are delivered.
- National Specialised Commissioning Secure Services Access Assessments Guidance is in place across all user groups to access secure hospitals, it is a clinical process to determine that a person meets the criteria for admission into secure hospitals and level of security (medium or low secure) as high secure has a different criteria for admission. This process needs to stand alongside the pre admission CTR and blue light processes to ensure appropriate admissions to secure settings

#### Workforce

- The model requires a workforce with the relevant skills, knowledge and values needed to deliver high quality care and support within a culture of fairness, accountability and reflection, learning from experience both within Nottinghamshire and externally. Recruitment processes need to reflect the skills and values required. There will be a consistent approach to addressing challenging behaviour, using techniques such as positive behavioural support, with a deep and shared understanding of the reasons why each person displays challenging behaviour. A competency framework for positive behavioural support will be chosen which will be implemented to provide this consistency of approach across different health and social care organisations. There will also be much greater skills and awareness in the workforce as to how to manage those who have been in contact with the Criminal Justice system.
- The workforce will also routinely use data and intelligence to challenge and improve how it improves services. Data from CTRs is already starting to inform and shape services, and Nottinghamshire will build on this to shape service based on a better understanding of needs, particularly around children and autism, the experience of people who use the services, and information relating to how services are delivering to meet people's needs and desired outcomes.

## 5.7 How will this be Different for Patients and their Families

Cases Studies provided by Marcus Callaghan, Supplier Manager Mental Health and Learning Disabilities, Specialised Commissioning

#### Person A

"This person was placed in a locked rehabilitation hospital. Her mental wellbeing deteriorated and as such she was referred for an adult access assessment with a view that she may require treatment in a low secure hospital. This assessment was undertaken and it indicated that she met the criteria for admission to low secure care. As there are no low secure services within Nottinghamshire for women with a learning disability and or ASD but there was a degree of urgency a discussion took place between the CCG and NHS England to work out a plan to meet her needs.

Due to the crisis this person was in it was agreed that urgent action was required. It was agreed that she would be placed in a Psychiatric Intensive Care (PICU) bed (funded by the CCG) for her and others safety. Once assessed and accepted by a low secure provider she would then transfer to that service. A few days later she transferred to the low secure provider (funded by NHS England). As this was out of area the NHS England case manager for that area was involved in the decision making plus it was agreed that this was a "blue light" scenario due to the crisis and that a CTR would be undertaken soon after admission.

This case demonstrates positive integrated commissioning of services to meet a person's needs and risk whilst maintaining their and the public's safety as they were going through a crisis."

#### Person B

"This person has a complicated presentation with a range of diagnoses and has been in hospital both secure and non-secure for several years. An attempt was made to place this person in the community recently but they committed a serious assault that led them to return to hospital. The person's presentation deteriorated earlier this year that led to a request for an access assessment for secure care. This was undertaken and it indicated that he required treatment in a medium secure environment. A provider was sought and a placement offered. However, this transfer did not take place as there were no beds available at the provider, a situation that continues. NHS England have referred him to all of the medium secure providers, unfortunately none of them have been prepared to accept him for admission. Indeed some providers have indicated that they believe that a low secure environment would be more suitable. This has been heard and a further access assessment to support that has been commissioned. A CTR was held that supports admission to a hospital bed. Low secure providers have also been contacted but no placement has been offered. The CCG involved are also stuck in that no alternative locked rehabilitation provider will consider his case whilst he has been assessed as requiring secure care. Consequently this person continues to be placed in a provider that does not believe that they can meet his current needs.

An integrated approach under the proposed model may have helped this case. A CTR being held prior to the referral for an access assessment would have encouraged discussion and

consideration of alternative approaches. That is not to say that this consideration did not take place but the model would have provided a clearer structure for the decision making process".

#### Cally Ward, Carer and Challenging Behaviour Foundation

"Families will be supported and valued as partners and will be engaged on an individual, service and strategic level as part of this plan. Children and adults will receive more timely, responsive, flexible and joined up support and care in the community, across education, health and social care. A focus on early identification of children at risk will target support into early preventative intervention. Families will receive specialist information, advice and a range of practical support in a timely and appropriate way across the lifecycle with a particular emphasis on key transition points and early intervention to prevent crises. Support and care will be co-ordinated across settings to ensure a consistent and holistic approach. Mainstream services will meet their duties under the Equality Act to make reasonable adjustments to the way they work with children and adults with learning disabilities/ autism who have a mental health condition or display behaviour that challenges. Staff will be trained to be competent and confident to include them. Children and adults and their families will be supported by robust specialist services in the family home and community. Intensive, flexible and person-centred support will be available in a crisis to support the child/adult and their families or carers. As for the general population, if admission for inpatient assessment and treatment is necessary the service will be local, short term and outcome orientated."

#### 5.8 Staff and Providers

#### Dr Richard Welfare, Clinical Director for Specialist Services, LD and CAMHS, NHT

"In the future we will have greater choice and opportunities for people who challenge services. Most people will be well supported in their communities both within their families or in support services. Carers will have a greater voice in services and will be more able to shape the support their person receives. Much fewer people will be admitted to hospital and in a crisis will be able to call on a much wider set of support services for the individual. The risks and challenges the people in distress can pose will be met with a more comprehensive service response."

#### Clare Gilbert, Lead Commissioning Manager, Nottingham City Council

"The model of care provides a significant opportunity for the CCGs and local authority to work jointly to commission a range of targeted and specialist provision centred around the Care Co-ordinator model. The proposals align strongly with the finding of the City Council's Learning Disability Strategic Commissioning Review which has taken place over the last year. The approach not only focuses on those at highest needs, but enhances provision for all individuals with learning disability by strengthening the utilisation of early intervention.

The reduction of inpatient beds will support significant new investment in the provision of high quality supported living and residential services. This will enhance the range of accommodation provision being provided which should reduce escalation of need and provide effective pathways out of inpatient support. The model emphasises the need for a skilled and well trained workforce to ensure that these outcomes are achieved."

#### Jayne Lingard, Commissioning Officer, Nottinghamshire County Council

"As a social care commissioner for younger adults, this new system model will lead to significant strides in the commissioning landscape. The development of a shared culture of and competence in positive behavioural support across all layers of support (including their families) for people with learning disabilities and or autism has the potential to reduce support costs whilst delivering much improved individual outcomes

- The greater competence and increased flexibility of health and social care services will enable us to commission more robust and more appropriate (home care) support and residential care provision for people with complex needs.
- The pooling of budgets would enable us to spend less time debating who should bear the cost of responding to crises, focussing instead on creative and person-centred solutions between partners and understanding what led to the crises and how to avert them in future.
- The empowerment of families and informal supports has the potential to increase the social inclusion of people with a learning disability and / or autism, greatly increasing my job satisfaction"

#### Gary Watt, LD Nurse Specialist, Bassetlaw CCG

- "Staff and providers are able to meet people's needs closer to home, thus having good insight and oversight into local care provision and knowledge of local dedicated pathways in meeting requirements. This will be achieved by the sharing of information within the geographical area the prompting of quality care at the right time and in the right place.
- 2. The foundation of robust community services will be based upon the building blocks of the care programme approach resulting in an allocated and dedicated care coordinator to support an individual well into recovery and beyond. Thereafter care oversight will be delegated to a capable and caring other as more focussed support in adverse behavioural presentations is necessarily lessoned.
- 3. Care will be delivered within a framework of community services by teams that have clear lines of responsibility within a seamless service."

#### 5.9 Key Enablers for Success

#### **Trusting Cross Organisational Relationships**

Trusting relationships are required across all organisations in Nottinghamshire involved in commissioning care and support to address the needs of those with learning disability and/or autism and those who have/may come into contact with the Criminal Justice System. The well attended Transformation Board and Working Groups and constructive conversations that have taken place at the Board and Working Groups, have proved that the foundations are in place for these trusting relationships to be established that will support the successful delivery of the programme.

#### Single Shared Vision across all Stakeholders

All organisations must have the same aims and vision in relation to the care and support of people with learning disabilities and/or autism and those who have/may come into contact with the Criminal Justice System. This will help them to work effectively together, focused on the same goals. We have already started the process of developing a shared vision and aims and will continue to explore the evidence base and innovative developments of other areas together.

#### Support for the Programme

Since this is a major change for the way services will be provided in Nottinghamshire, then there needs to be considerable engagement on these plans and we intend to formally consult on the new service model.

Giving individuals currently using services and those with potential/future interest in service change the opportunity to share their experiences, co-design new ways of working and service models and be involved throughout the transformation process will ensure that we establish community and support services that are respond to the needs of individuals and are fit for purpose now and for the future.

The public communications and engagement objectives for the programme have been identified as follows:

- Increase awareness of the Transforming Care agenda and local plans to improve care
- Increase awareness with key target audiences and stakeholders of the establishment of the Transforming Care Fast track programme and the joint ambition and vision
- Communicate the need and drivers for change across the health and care system, national and local, for people with a learning disability and/or autism
- Support change in working practice, improved quality of life and patient / carer experience across services for people with a learning disability and/or autism in Nottinghamshire
- Involve patients, carers and families in transformation, using their experiences and feedback to identify and respond to their needs and facilitate an ongoing two-way dialogue to inform local planning and implementation
- Provide effective and meaningful opportunities for public and stakeholder involvement and/or consultation with clearly defined objectives and embedded mechanisms to provide feedback on how engagement has informed plans and implementation
- Promote service change and new community services to support people with a learning disability and/or autism as a safe alternative to inpatient care that improves quality of life and independence
- Reposition inpatient hospital care for those with learning disabilities and autism as a long-term solution only for those whose needs cannot be met in the community
- Support and dovetail with communications for the national Transforming Care agenda to ensure constituency of messaging and narrative to support service change
- Communicate service change to key stakeholders and the wider public across Nottinghamshire through timely, clear and concise messaging and simple, inclusive language, avoiding the use of acronyms, clinical and technical terms

Moving forwards, engagement activity will focus on involving individuals with a learning disability and/or autism who have the potential to develop challenging behaviours, alongside their families and carers, to test the efficacy, equity and validity of new community support services as they are established.

In order to achieve full involvement the programme is committed to providing feedback to those who share their experiences and recommendations with us regarding how their input has helped shape future care provision. Internal communications between commissioning and provider organisations, both NHS and Local Authority, will focus on a consistent flow of information between the partners involved in transforming care, ensuring all those who have a part to play in implementing new models of care are up to date with transformation progress and are sighted on next steps and actions required. Workforce specific communications will aim to explain the national context and drivers, sell and embed the local vision and help staff commissioning or delivering care understand their specific role within transformation.

#### **Sufficient Funding**

Particularly to pump-prime the investment in community services to allow these to be built up before they are able to prevent hospital admissions. The savings from using fewer medium and low secure beds (currently commissioned by NHS England) will need to be used to fund community services. This will require a national policy decision to implement whole care pathway commissioning for this group of patients and the pooling of specialist and CCG budgets. If this is not possible then the financing of the plan is in jeopardy

## 6 Supporting Information

## 6.1. **Population Data and Trends Expected to 2025**

This data has been presented by Nottinghamshire County and Nottingham City as there are differences in populations due to demography between the populations of the two areas.

#### Learning Disability – All Types

#### **Nottingham City**

Age Band – Predicted Population	2014	2015	2020	2025
18-24	1,684	1,678	1,602	1,603
25-34	1,223	1,223	1,252	1,245
35-44	920	926	938	983
45-54	841	847	834	793
55-64	606	618	694	750
65 -74	409	417	466	490
75-84	250	248	254	294
Over 85	103	103	114	125
Total population aged 18-64 predicted to have a Learning Disability	6,035	6,059	6,153	6,284

#### **Nottinghamshire County**

Age Band – Predicted Population	2014	2015	2020	2025
18-24	1,714	1,711	1,566	1,526
25-34	2,306	2,331	2,465	2,445
35-44	2,469	2,439	2,367	2,518
45-54	2,831	2,835	2,677	2,393
55-64	2,266	2,290	2,546	2,704
65 -74	1,884	1,934	2,048	2,037
75-84	1,009	1,030	1,199	1,466
Over 85	378	391	472	584
Total population aged 18-64 predicted to have a Learning Disability	14,857	14,960	15,341	15,673

## Learning Disability – Moderate or Severe

#### **Nottingham City**

Age Band – Predicted % Change from 2014	2015	2020	2025
18-24	0%	-4%	-3%
25-34	0%	2%	2%
35-44	1%	2%	7%
45-54	1%	-1%	-5%
55-64	2%	15%	23%
65 -74	2%	13%	19%
75-84	-1%	1%	17%

Over 85	0%	9%	19%
% change in population predicted to have a moderate or severe Learning Disability	0%	2%	4%

## Nottinghamshire County

Age Band – Predicted % Change from 2014	2015	2020	2025
18-24	0%	-8%	-9%
25-34	1%	7%	6%
35-44	-1%	-4%	2%
45-54	0%	-6%	-15%
55-64	1%	13%	19%
65 -74	2%	7%	7%
75-84	2%	18%	44%
Over 85	3%	23%	51%
% change in population predicted to have a moderate or severe Learning Disability	0%	2%	3%

## Autism Spectrum Disorders

## Nottingham City

Age Band – Predicted Population	2014	2015	2020	2025
18-24	619	617	587	591
25-34	511	508	521	519
35-44	389	394	399	416
45-54	362	365	359	347
55-64	271	273	307	332
65 -74	187	192	216	226
75 and over	151	151	158	191
Total population predicted to have an Autism Spectrum Disorder	2,490	2,500	2,547	2,662

#### Nottinghamshire County

Age Band – Predicted Population	2014	2015	2020	2025
18-24	648	645	591	577
25-34	921	933	996	993
35-44	993	978	950	1,015
45-54	1,204	1,206	1,127	1,003
55-64	997	1,003	1,109	1,179
65 -74	854	876	921	923
75 and over	614	630	750	931
Total population predicted to have an Autism Spectrum Disorder	6,231	6,271	6,444	6,621

## **Behaviour that Challenges**

#### Nottingham City

Age Band – Predicted Population	2014	2015	2020	2025
18-24	28	28	27	27
25-34	22	22	23	23
35-44	17	17	17	18
45-54	16	16	16	15
55-64	12	12	14	15
Total population aged 18-64 with a learning disability, predicted to display challenging behaviour	95	96	96	97

## Nottinghamshire County

Age Band – Predicted Population	2014	2015	2020	2025
18-24	28	28	26	26
25-34	42	42	45	44
35-44	45	45	43	46
45-54	55	55	51	46
55-64	45	45	50	54
Total population aged 18-64 with a learning disability, predicted to display challenging behaviour	215	215	216	215

Source: Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information System (POPPI)

Strategic ObjectiveCare Outcomes Framework 2014/15NHS Outcomes Framework 2014/15Outcomes Framework 2014/15	lic Health
	utcomes work 2014/15
jointly owned pathway / model of care that reflects best practice and maintains people in their 	ng the wider nation of Aults with a arning sability / in ntact with condary ental health rvices who e in stable and propriate commodation nployment for ose with long m health nditions ocial isolation

## 6.2. National Outcome Measures which relate to this Plan

## 6.3. Public Health England Statistics (2013/14 data)

Compared with benchmark

Better	Similar	Worse
Lower	Similar	Higher

Indicator	England	Nottingham	Nottinghamshire
		City	County
Population			
Learning Disability QOF Prevalence (18+)	0.5	0.5	0.6
Adults (18 to 64) with learning disability known to local	4.3	4.3	5.3
authorities			
Children with Moderate learning difficulties known to	15.6	8.2	6.3
schools			
Children with Severe Learning Difficulties known to	3.73	3.66	2.38
schools per 1,000 pupils			
Children with Profound & Multiple Learning Difficulty	1.27	-	1.00
known to schools per 1,000 pupils			
Children with autism known to schools per 1,000 pupils	9.1	13.5	10.5
Health	•		
Proportion (%) of eligible adults with learning disability	44.2	41.2	52.0
having a GP health check			
Accommodation and social care	•		•
Adults with learning disabilities in settled accommodation	74.9	64.8	73.0
Adults with learning disabilities in non-settled	21.7	34.6	24.4
accommodation (%)			
Adults with learning disabilities living in accommodation	3.38	0.55	2.54
whose status is unknown to LA (%)			
Adults with learning disabilities living in severely	0.25	0.00	0.20
unsatisfactory accommodation (%)			
Adults with learning disabilities in employment	6.7	1.6	7.2
Adults with learning disabilities receiving direct payments	30.5	28.6	38.9
(%)			
Rates of referral for abuse of vulnerable person per 1,000	109.3	40.2	74.5
Co-ordination and local planning			
Comparison of LA and QOF prevalence estimates	-0.1	-0.2	-0.1
Comparison of pupils with learning difficulties and LA	80.2	-	46.2
prevalence estimates			
Comparison of pupils with severe and profound and	13.5	-	-0.4
multiple LD and LA prevalence estimates			
Adults using day care services supported by the LA (per	323.7	329.7	380.9
1,000 people)			
Adults receiving community services supported by local	754	654	652
authorities (per 1,000 people with learning disabilities)			
Children with learning disabilities known to schools per	20.6	-	9.6
1,000 pupils			
LA gross current expenditure relating to residential	£22,165	£16,507	£25,844
personal and social services for adults	,	,	,
		1	I

Source: Public Health England, Learning Disabilities Profiles

http://fingertips.phe.org.uk/profile/learning-disabilities

## **Survey for Individuals and Family Carers**

## **Nottinghamshire Fast Track Area**

Susan Clifford Registered Nurse BSc Sarah Wakeling Board Certified Behaviour Analyst

Positive Behaviour Support Consultancy

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#### **Nottinghamshire Fast Track Project**

#### Purpose

The purpose of the project is to identify the needs, current provision and changes that need to be made to ensure individuals in Nottinghamshire with Learning disabilities and / or autism are supported within their local community. Views are needed from family carers of those who use the services to influence and develop the services and shape the future. Alongside this project, we will look at the individuals who use the services with Learning Disability and Autism.

#### Scope

Project to undertake the views of family carers' and individuals with Learning disabilities and / or autism who are or have been in inpatient services between April – July 2015 funded by Nottingham City or County CCG's.

#### Process

A survey to be developed and information collected by phone from family carers of individuals who have been in inpatient services between April – July 2015 and who have undergone a Care and Treatment Review. Information was taken from individuals directly during the review process.

#### **Time Scale**

Data will be collected and analysed for particular themes and this information sent to the Fast Track Program Board by the 4<sup>th</sup> September 2015 ready for submission of the bid on the 7<sup>th</sup> September 2015.

## Project 1: Family Carers

In regard to family carers, key lines of enquiry were followed around the following headings:

- Community support
- Training needs
- Alternatives to admission
- Communication
- Care and Treatment
- Discharge Planning

#### Community support

1. Prior to admission to hospital do you feel there was adequate support in the community?

## E.g. ICAT team, Social work input, Support from GP / Psychiatry

All of those that mentioned the ICAT team said they were a good support but all also felt that the out of hours support was poor, this included residential care. One family carer said, "The social worker only works part-time. The home doesn't have anyone available at weekends and untrained staff have to get on with it. If I could sue the Home/company I would. They said they could take care of my son but they employ carers, a cheaper rate than support workers."

No one highlighted either GP or psychiatry support.

2. Do you feel there is a nominated person that you can always go to should you need help?

#### E.g. Social worker who keeps the case / Community care officer/ Care coordinator

There was a mixed response, some individuals stating yes others no. Some highlighted their Social Worker as the first port of call, others the Manager of the service. One individual refused to respond.

Training Needs

3. Is training offered to you to meet the needs of the person you care for? *E.g. Training in positive behaviour support* 

One individual refused to respond. All others stated they had never been offered any training. They were just "left to get on with it."

## 4. Was there any offer of support groups or similar?

One individual refused to respond. All the others stated they had never been offered any support groups or similar. The majority thought it would be useful to share their experiences with families in similar situations.

Alternatives to admission

5. If there was a service / crisis bed available (not hospital) instead of hospital admission would this have been more appropriate?

# Was a change of environment needed? Was an increase in the support package required?

Most of the individuals thought that a crisis / respite bed would have been a better alternative. One refused to answer and two felt there was no option other than hospital.

6. Did you have a quick response when you felt that the situation was changing which led to the admission? Community nurse visit / GP visit Though the ICAT team were spoken of in a very positive way the consensus was that the response to the deteriorating situation was poor.

Communication

7. Did you feel that throughout the admission process and when an inpatient that you were communicated with effectively?

## If there was information that was sought was it given in a timely manner and in a way that you could understand?

There was a mixed response in regard to communication from very good to very poor. Those that had good communication asked questions and requested necessary information.

## 8. Do you feel your voice is heard?

## Would you be interested in being part of a Focus Group?

There was a mixed response with half the group saying they felt listened to and the other half not. Most carers responded positively to the idea of a support group with the focus on future services. One did not respond and one said they needed to put pen to paper to get their voice heard. One individual stated that their social worker did not listen to them and the only time their voice was heard was at a MDT (Multi-disciplinary meeting) or a CTR (Care and Treatment Review).

## 9. Would you know where to go and how to raise concerns

# During the hospital stay were they made aware of complaints procedure?

One individual stated they would not know who to complain to, though everyone else said they did. These did vary though from the Manager, CQC to the Social worker. One individual stated that they had made a complaint but when she spoke to the manager two weeks later the manager stated she was not aware of the complaint. Care and Treatment

## **10. How did you rate the care and treatment while an inpatient**

## Any concerns or worries over restrictions placed on the individual?

One individual stated that they did "not know what was done in these places" and a leaflet would be useful. Two did not comment. One individual commented that she only saw her relative in the visitor room so did not know what the environment was like. Another individual rated the service as 6 out of 10 as there were some poor practices namely wearing other people's clothes and staff did not treat the patients as individuals.

A further carer said, "I would rate the care and treatment between 5-6 out of 10 when the patient was first admitted, they did nothing and she might as well have been at home. The patient wasn't eating and I had to come and feed her"

## 11 Did you feel that as an inpatient it was a Safe Environment? Any problems with other individuals?

One individual said that her sister was attacked. One said that the doors were locked. All others felt they were safe.

## Discharge Planning

## 11. Were you involved in the whole process?

## Were your views listened to?

There was a mixed response, some felt their voices were heard others that decisions were made without taking their views into account. One individual stated "There is one choice, nothing else. That's no choice at all".

12. Did you have opportunity to give your views on what sort of service or support you felt was needed if appropriate?

## E.g. All male service / in a group setting

Though a few stated that they did feel listened to one individual stated "Going into hospital was traumatic for the patient and did not help her recovery. There's nothing else and things have not changed much post-Winterbourne and it's a long way off being right".

## Conclusion

**Community support:** An analysis of the information indicated that out of hours seemed to be where most of the problems occur. The staff teams are less skilled and generally weaker with poor support from managers.

**Training needs:** One of the main conclusions that can be drawn from this piece of work is that some families do not feel supported or at times equipped to carry out their role as a carer. They have been offered no training in supporting those they care for and at times struggle with the enormity of it all.

**Alternatives to admission:** There was a positive response to the concept of a crisis / respite bed. It has been recognised that changing the environment can often lead to a change in behaviour and this may allow family carers time to reflect and recharge their batteries, especially after a crisis.

**Communication:** The services which those surveyed have experienced have fallen short of the family carers expectations with communication being one of the biggest issues. It appears that those who ask questions and make themselves heard do well whilst those who rely on the professionals to inform them of changes and decisions being made fall short. As all the individuals were not sure whom complaints should be addressed to, is a concern, and that a complaint was not responded to, was even more so. The area of discharge planning was also inconsistent.

**Care and Treatment**: Whilst appreciating that many of the inpatient environments may not be suitable for visitors there does need to be more openness in what happens in the service, whether this be information in writing along with staff spending time with relatives. As stated earlier there are differences in experiences, which should be consistent for all.

## **Project 2: Individuals**

In regard to individuals, they were asked the following questions:

#### 1. What's important to me now?

Family: Those with a family highlighted very firmly that they were important to them and that they liked to have regular contact. This meant living in a place that enabled visiting their family and their family visiting them.

Possessions: The majority of patient's felt that their possessions were important to them. They took into consideration their possessions in regard to where they might live and expressed a wish for them to be also accommodated. Though most patient's had few possessions beyond CD player, TV etc. they specifically enjoyed talking about how important their possessions were.

Activities: The majority of individuals mentioned enjoying music and most activities that were suggested involved their possessions, e.g. CD collection. Few community activities were reported, possibly due to a lack of access in inpatient facilities.

#### 2. What's important to me in the future?

All individuals who had a family said that contact was important and being close by was preferred. Many patient's talked of going to college or finding work. One individual stated they would like "to do voluntary work and help other people". Meaningful activity that gave people a sense of worth seemed very important along with structure and a sense of safety.

## 3. What staff support would be needed? Type of person, age, sex.

The analysis showed a mixed response. Some individuals wanted staff of the same sex and age and others not specifying any preference. Some individuals reported that they would particularly look for staff with similar interests to themselves. There was a sense that individuals were looking for people to spend their time with who would enjoy the same things, possibly fulfilling the role of a friend/peer in the absence of this network.

There was also comment in regard to the staff being well trained and understanding their needs, as well as being patient and caring. Some individuals reported that they would like regular staff and staff that would stay for the long term. One individual said, "staff must be well trained in supporting me having my angry behaviour."

#### 4. Who would I like to live with?

There was a mixed response, some patient's wanting to live alone and others with groups of people. No one said they would like to live with large groups of people. Of the individuals that stated that they would like to live with others, they all said that they would need their own space and their own staff.

## 5. My home. What would it look like? What would be important?

The first two questions concerning what is important now and in the future very much shaped the answer to this question in regard to space and vicinity to amenities. No one said that they would like to move away from the area that either their family lived, or an area that they were familiar with. There was a range of answers though, some described a house with a garden, others a flat, others in shared living facilities. There was a strong feeling that a "normal" house in a "normal" community was important.

## 6. What barriers might there be to stop this happening?

There was some understanding that the individuals themselves could be a barrier preventing discharge, and there was insight to understand that they were working towards goals to make discharge happen. There was some fear around change and individuals were given coping strategies in dealing with these changes. There were

a couple of individuals on a section 37/41 so the Ministry of Justice needed to be satisfied that the discharge was safe.

### Conclusion

**Person centred:** The analysis of the information confirms our thinking that support in the community for individuals with Learning Disabilities and Autism needs to be Person Centred, helping individuals create a life that is specific to them.

**Quality of life:** Quality of life should be seen as a goal for individual support but also as a strategy to support individuals to live meaningful and purposeful lives. A Positive Behaviour Support Plan would focus services on this aim.

**Ordinary life:** There is no one model of accommodation that fits all. There needs to be a range of services commissioned but all within "normal" community settings to allow for integration and social inclusion in the wider community, especially to facilitate family life.

**Specialism:** Many individuals recognise their role in achieving discharge and successful community living, however clearly services need to have the right expertise to support a diverse range of people and needs. In particular any shared accommodation needs consideration as to whether the group will live well together. This is especially if there are any shared staff. Many individuals find sharing attention difficult.

Many of the individuals surveyed have very complex needs with risky / challenging behaviours. The staff group supporting them will require a different skill set for different individuals according to that need.

The training and support of staff should be viewed as the responsibility of all involved and multi-layered, focusing on key skills in each layer. Positive Behaviour Support training would be the model of choice for this client group. The training should include therefore Commissioners (Local authority and Health), voluntary organisations, providers, clinicians, direct care staff and family supports. This should up skill the community staff (knowledge and skills) to provide robust packages of support with additional expertise brought in as required. This may go some way to reduce the staff turnover that many providers face and that the individual's themselves report as a challenge to maintaining positive and productive lives.