

‘Live Well, Live Longer’: Joint Strategy for Learning Disabilities for North Yorkshire 2016 – 2021

18th January 2017

Presented by: Kathy Clark (Assistant Director Health and Adult Services) and Victoria Pilkington (Head of Partnership Commissioning Unit)

Summary:

The draft Joint Strategy was considered by the Health and Wellbeing Board at its meeting on 15th July 2016. A number of comments by the Board were made and these have been incorporated in the revised draft.

The draft Joint Strategy has also been informed by:-

- feedback from an on-line questionnaire;
- a wide ranging engagement with stakeholders (particularly users and carers);
- analysis of data from the Joint Strategic Needs Assessment;
- national demographic projections; and;
- statutory requirements

The County Council and the NHS have made significant improvements to the lives of people with learning disabilities from North Yorkshire over the years. We want to build on this by continuing to support people to become more independent, lead healthier lives, be part of their communities, have more choice and control, feel ready for adulthood, gain meaningful employment, and also to support carers and families. These are the things that people have told us matter most to them and which will enable them to ‘live well and longer’.

Which of the themes and/or enablers in the North Yorkshire Joint Health & Wellbeing Strategy are addressed in this paper?

Themes	✓
Connected Communities	✓
Start Well	✓
Live Well	✓
Age Well	✓
Dying Well	✓
Enablers	
A new relationship with people using services	✓
Workforce	✓
Technology	✓
Economic Prosperity	

How does this paper fit with other strategies and plans in place in North Yorkshire?

- Mental Health Strategy 2015-2020 'Hope, Control and Choice.'
- Autism Strategy
- Dementia Strategy (in development)
- Care and Support Where I Live strategy 2014.

What do you want the Health & Wellbeing Board to do as a result of this paper?

- To agree and endorse the Strategy.

Authors: Kathy Clark and Victoria Pilkington
Date: 6th January 2017

Copy for approval – Dec 2016



Partnership Commissioning Unit
Commissioning services on behalf of:
NHS Hambleton, Richmondshire and Whitby CCG
NHS Harrogate and Rural District CCG
NHS Scarborough and Ryedale CCG
NHS Vale of York CCG



*Airedale, Wharfedale and Craven
Clinical Commissioning Group*



North Yorkshire
County Council

‘Live Well, Live Longer’

Learning Disabilities:

Joint Strategy for North Yorkshire

2016 – 2021

CONTENTS

Page

- Introduction 3
- Our shared vision for people with LD 4
- What we know about Learning Disabilities in North Yorkshire 5
- Services and Choices in North Yorkshire 8
- What people have told us 14
- What else we know 17
 - National Picture 17
 - Cost Quality and budgets 19
 - Local Strategies 20
- Our Priorities and Principles 22
- Where do we want to be 23
- How do we get there 26
- Summary of Living Well Living Longer 32
- Next Steps 34

For final design: check page numbers match sub-headings will need to be removed before submission

Introduction

Over the last thirty years there has been significant progress which has enabled people with a learning disability to lead fulfilling lives as citizens in the community, with the same rights as anyone else. With the introduction of personalisation and personal budgets, individuals now have greater choice and control over how they are supported to live their lives and be more independent.

There is much to be proud of in the progress made in North Yorkshire, with many people with a Learning Disability achieving greater choice and control; by having their own tenancies; gaining employment; and being part of the wider community. We want to build upon the success to date and continue to respond to what people are telling us they want: to become more independent, lead healthier lives, be part of their communities, have more choice and control, feel ready for adulthood, gain meaningful employment, and also to support carers and families, which will enable them to *'live well, live longer'*.

We recognise that achieving this will mean further changes and at a time when we are facing some of the most significant challenges in the history of the public sector. Demand for services is increasing, people are living longer with more complex needs, legislation and service user expectations are changing and this is against a backdrop of reducing public sector budgets. If we are to continue to meet people's aspirations and needs, we cannot do what we have always done and must challenge traditional service models, create new solutions, harness community resources and develop services that will provide for people now and for future generations. We recognise that for some people, change will be difficult and we cannot promise that everyone will get exactly what they want, however, we will support individuals and work together to find local solutions that can meet individual needs.

This strategy concentrates on what matters most to people with a learning disability in North Yorkshire, commencing from young adulthood. Our strategic approach is centred on promoting people's health and wellbeing, preventing, delaying or reducing the need for services, and protecting people from abuse. We see this as a foundation for continuous improvement in learning disability services and better lives for the people who use them. We want to make the most of the strengths that people have and the support and opportunities available within their local communities.

The Health and Wellbeing Board partners are committed to delivering this strategy and finding creative and innovative new ways of delivering services and solutions.

Our shared vision for people with a Learning Disability

'Live Well, Live Longer with a Learning Disability in North Yorkshire'

The North Yorkshire Health and Wellbeing Strategy was refreshed in 2015. The overarching vision of the strategy is:

"People in all communities in North Yorkshire have equal opportunities to live long healthy lives "

In North Yorkshire, our aspiration is for all people with a learning disability to '**Live Well, Live Longer**'. This means that people with a learning disability will

- Have the right to choose, and be in control, of their daily life (where possible)
- Enjoy the best health and well-being possible
- Lead a fulfilling and active life
- Feel safe and supported
- Be respected and treated with dignity
- Possess positive self-esteem

What do we know about learning Disability in North Yorkshire?

Learning disability is defined as the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence, often defined as an IQ level of 70 or less), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.¹

Co-existing health conditions

National research shows that people with learning disabilities are more at risk of developing health problems when compared with the general population.

Respiratory and heart disease are the leading causes of death for this group, and they are more likely to have diabetes, sensory impairments, mental health problems or epilepsy. Additionally, as they age those with Downs Syndrome have a greater risk of developing a type of dementia that's either the same as or very similar to Alzheimer's disease.

- 40% of people with learning disabilities also have physical and/or sensory impairments
- 25-45% of people with learning disabilities also have a mental health condition
- 36% of children and adolescents with learning disabilities also have a diagnosable psychiatric disorder and are 33 times more likely to be on the autism spectrum²

Health inequalities

We know that people with a learning disability are no different from anyone else when responding to their ill health concerns. However, national evidence shows they are 58 times more likely to die before the age of 50 than those who do not have a learning disability. Findings from the 2013 Confidential Inquiry into premature deaths of people with learning disabilities found that men and women die 13 and 20 years sooner, respectively, than those without. Furthermore, Mencap estimates that 1,200 people still die avoidably every year.

The recent reports by Mazars, into unexplained deaths in Southern Healthcare services in the South of England, and by CQC on the national picture, highlight that there are lessons to be learned from many early deaths, with too many people not getting the health care they need in a timely way. Currently these deaths are not consistently being reviewed to identify the lessons to be learned.

¹ Valuing People White Paper 2003

² Mental health in people with learning disabilities – Alison Giraud Saunders, Aug 2011

There have been several reports on the health care of people with learning disabilities. Emerson and Baines, in their research report 'Health Inequalities & People with Learning Disabilities in the UK: 2010' state that;

"The health inequalities faced by people with learning disabilities in the UK start early in life, and result, to an extent, from barriers they face in accessing timely, appropriate and effective health care. The inequalities evident in access to health care are likely to place many NHS Trusts in England in contravention of their legal responsibilities defined in the Disability Discrimination Acts 1995 and 2005 and the Mental Capacity Act 2005".

Local Picture

Current statistics are detailed in our Joint Strategic Needs Assessment (JSNA) and Market Position Statement (MPS)

<http://www.northyorks.gov.uk/article/25078/Joint-strategic-needs-assessment>

<http://www.northyorks.gov.uk/article/27589/Market-position-statement>

. Some of the key statistics are highlighted below.

- The total number of adults in North Yorkshire aged 18-85 and over with a learning disability is predicted to be **11,338**; rising to 11,870 by 2030.³
- The total number of adults locally aged 18-85 with a **moderate to severe** learning disability, and hence likely to be in receipt of services, is predicted to be in the region of **2,300**.⁴
- **1,883** adults aged 16–64 are funded by and known to North Yorkshire Health and Adult Social Care. Of these, 1,590 are currently in receipt of services. (This does not account for those people who fund their own care.)
- There are a total of **2,300** people with a learning disability **registered with GP practices** across North Yorkshire. The accurate identification of people with a learning disability is complicated by a reliance on 'read code' searches on GP practice systems and can result in underestimation of the true number.
- The total population for young people with a learning disability **aged 14-18** in North Yorkshire is approximately **550**.
- On average annually, just over **100** young people will 'move' from Children's Services to Adult Social Care, of whom over a third will have an array of complex needs and will require support with their health needs also.
- There are **310** people with learning disabilities who **also have autism** known to the local authority. The largest cohort of 162 is age 18 – 34 (<http://www.nypartnerships.org.uk/CHttpHandler.ashx?id=32990&p=0>)

Although we know there are still health inequalities, the good news is that within North Yorkshire people with a learning disability are living longer as healthcare

³ PANSI 2015 data

⁴ As above

improves. This means an increase in demand for support services over a longer period of time, particularly those services associated with young people with complex needs and those related to old age – e.g. dementia and physical frailty.

Some people have a range of complex health and support needs. This diverse group includes people with profound and multiple disabilities who often have physical and sensory disabilities. These individuals have long term complex health and care needs that require carefully managed support packages.

There are also some people who have complex needs and behaviours that can be challenging, and we know we currently have 38 local people in secure accommodation with highly complex learning disability and/or autism who display self-injurious, or aggressive or risky behaviours which may put themselves or others at risk. People may have a range of needs in addition to their learning disability, either due to substance misuse, mental health, autism, ADHD or a personality disorder.

Based on current experience, and because they are well enough to do so, around two to three people with a learning disability leave secure accommodation each year, and require support to re-integrate into the community. People move out of secure accommodation on the basis of their individual needs, rather than via a stepped approach. For example, people currently in medium secure accommodation may be ready to move into residential or nursing home placements on discharge.

DRAFT

Services and Choice in North Yorkshire

Within North Yorkshire, similar to the National picture, we have a good market place of services for people with learning disability.

Note for designer to add: Annual Health Checks in Primary Care (next to Preventative/Early Help bubble). Move respite and short breaks from carers section to community services section



Adult Social Care is provided by North Yorkshire County Council.

Health services are provided through GP surgeries and through the community and secondary mental health providers:

Tees Esk and Wear Valley work in Hambleton Richmondshire and Whitby; Scarborough and Ryedale; Vale of York and Harrogate and Rural District Bradford Care Trust works in Craven.

North Yorkshire benefits from a widespread and diverse group of voluntary sector and private providers organisations that deliver support across the county. These groups play an invaluable role in providing services that support people to live in their own homes, to have an active life and to get involved in community life.

We know there workforce issues in terms of recruitment and retention which can sometimes make it difficult for providers to maintain high quality services. This is not

just a local issue, but we will work with providers locally to explore what can be achieved collaboratively to address these problems

We also need to ensure a more equitable provision across the different localities in the county. This will mean reviewing our current services and might challenge some traditional service models in some places.

We know that people with a learning disability and their carers in North Yorkshire rightly expect high quality services, and our younger people have different expectations about the support they require than their older counterparts.

Addressing all of these issues, means that we need to ensure there is a greater range of support options available which can be tailored to individual need. We are working with the market to develop a full range of care and support services at an individual and local level to assist people with learning disabilities to make choices and decisions.

Moving forward, health and social care will take a joint strategic approach to developing the market where possible to ensure a consistent and a coherent approach across North Yorkshire also encouraging efficiencies. Together, the commissioning teams will review current service provision across the county and develop or modify future commissioning activity.

Advocacy

Formal advocacy support is commissioned by health and social care, with the current provider Cloverleaf working with other organisations to ensure people can have a voice in formal processes, such as Care Act Assessments and Mental Health and Deprivation of Liberty processes. There are also other advocacy groups active and thriving in the county who offer alternatives to the formal service, including Keyring which supports self advocates.

Carers

Those caring for family members and loved ones play a vital role in maintaining the health and wellbeing of those who need help. We understand that unpaid carers want to support their loved ones to live an independent life, but the caring role can often take a toll on their own health and wellbeing.

Carers are at greater risk of poor health than the general population, and are particularly likely to develop depression. All carers now have the statutory right to an assessment whether their cared for person has eligible needs or not. The carers' assessment will look at carers' well-being, mental and physical health and if the carer has eligible needs, a support plan will be developed to meet the carer's needs. This might require replacement care to be provided for the cared for person to allow the care to take a break.

As people with learning disabilities are living longer, their carers are getting older. Locally, there are **432** people **living with a parent or carer over the age of 65**⁵. Some of these may not be known to Adult Health and Social Care currently but they are likely to require care and support at some point in the future as they become older themselves. Importantly, they will also need support and reassurance about future planning and what can be put in place when they are no longer able to support for their adult children.

Carers in North Yorkshire can access support through the local Carers Resource Centres commissioned by the County Council and the Clinical Commissioning Groups

Preparing for Adulthood

We know from earlier consultation with young people that our planning has in the past started too late, is short term and lacks clear outcomes for individuals.

We have responded to this, by establishing a Transition Steering Group of senior officers from Children and Young People's Services (CYPS), Health and Adult Social Care (HAS) and the CCGs and local transition groups. These are multi-agency forums in each area of the county, which share information, coordinate assessments and identify suitable pathways into adulthood for young people with complex special educational needs and disabilities (SEND). We are also continuing to develop a greater range of pathways into adulthood, including local personalised learning for young people aged 19+ with the most complex needs whom would previously have been placed out of county. Importantly, from the age of 14 onwards all Education, Health and Care Plans (EHCP) must include a focus on preparing for adulthood.

A new 'Preparing for Adulthood' team has been established with the service able to support between 60 – 80 people per year. This team will build on good practice so that a larger group of young people will not need to move out of county to have their needs met, can return at an earlier stage and can ensure that the move from transition as a child to becoming an adult is smoother and easier for both the young person and the family. This model will ensure the integration of the work and responsibilities of CYPS and HAS for young disabled adults. Further work will be undertaken to integrate services from health, housing and leisure, and other relevant agencies. The enhanced support that this model provides will contribute to more efficient planning, reduced costs and improved outcomes for young people.

Safeguarding

There were 185 safeguarding concerns reported about people with a learning disability in 2015-16. This is from a total of 4744 concerns raised in North Yorkshire.

⁵ NYCC Market Position Statement

The importance of keeping service-users safe and protected from avoidable harm, outlining clearly what is not acceptable practice, is intrinsic when planning and delivering services for people with a learning disability.

Regionally, NHS England lead a monthly Quality Surveillance Group that include a broad number of partners including the Care Quality Commission, Healthwatch and Public Health England. Within North Yorkshire itself, we have established our statutory safeguarding board and a multi-agency approach to safeguarding with the Police, Police and Crime Commissioner, Safer and Stronger Communities, Children and Young People's Services, Community Safer Partnerships, the Fire Service and Health to ensure that our approach to safeguarding is consistent and robust. We know that a particular issue for people with a learning disability is hate crime and have established hate crime reporting centres in libraries and police stations.

The LD Partnership Board has sponsored the development of **Safe Places**. These are designated places within the community where staff have been trained to be able to offer vulnerable people, including those with a learning disability the support they need if they are anxious or feel unsafe. The scheme launched on 5th May 2016 and there are already 142 recognised Safe Places.



Meeting Health Needs

We know from the annual self-assessments we undertake, and the feedback from people with a learning disability and their carers, that we need to improve some areas of health provision e.g. increasing the uptake of annual health checks at GP practices (and subsequent use of health action plans and where appropriate 'Hospital Passports'), cancer screening and eye enhanced tests. Our ambition is for 70% of people with a learning disability to receive an annual health check. When embedded within primary care practice, the annual health check is an effective tool for identifying and treating any health concerns or issues at an early stage to prevent problems from escalating into bigger health worries requiring more specialist intervention.

Employment

The current government policy is ambitious with its target of 48% of people with learning disabilities to be in paid work by 2025, (Valuing Employment Now – Department of Health 2009). At present, the national average is 6.1% of people with learning disabilities are in paid employment. Records indicate that approx 162 people who are known to North Yorkshire County Council who have a learning disability are in paid employment, which, although is better than the national average, illustrates we still have much to do.

Case Study

Tamsin is a young lady with Autism and a learning Difficulty, she was referred to the Supported Employment service in 2015 for support in identifying voluntary or paid opportunities. Tamsin had completed an equine studies course, but had decided not to complete another term.

Tamsin expressed a keen interest in working with animals; regularly walking the dogs of neighbours for which she was paid a small amount. The Employment Support Service contacted Pets at Home who were able to offer Tamsin a six week work placement, Tamsin thoroughly enjoyed her time there and the placement was extended. Tamsin received positive feedback and Tamsin would have liked to apply for paid work but unfortunately there were no vacancies available.

Tamsin completed the Princes Trust course in 2015 and her confidence grew immensely, she was involved in the community project something she really enjoyed. Following this work, Tamsin was successful in her application for a paid work placement at Marks & Spencer (Remploy) and she was able to put into practice customer service skills she had learned at Pets at Home.

Tamsin wasn't confident using the till, the concept of handling money and giving change was confusing and it was evident that Tamsin would need further training/time to enable the effective use of the till. In August 2016 the Martin House charity shop manager met with Tamsin and offered her an opportunity to volunteer and gain experience of handling money/using the till. Tamsin is still volunteering half a day week and received positive feedback on her till progress and excellent customer service skills. Tamsin was offered another temporary contract with M&S Nov-Dec 2016 and with a few mentoring sessions is serving customers with confidence. Tamsin has been offered and accepted another contract starting Jan until March 2017, this may well be extended further.

Gaining paid employment has made a great deal of difference to Tamsin's self-esteem, self-worth and financial gain. It was important to Tamsin that she was able to gain employment as she felt it put her on equal footing with her peers.

Encouragingly, a new NHS initiative has been announced whereby NHS England and NHS Employers are developing practical support to make progress in this area⁶. There is also the 'Valued in Public' guidance issued by the Department of Health in 2009 which offers guidance to Local Authorities and other public organisations on actively employing people with a learning disability within their own organisations.

⁶ NHS jobs pledge for people with learning disabilities – NHS England 2015

Accommodation and Housing

We want more people with learning disabilities to be supported to live locally in housing, either with others or by themselves, so that they receive the same opportunities as everybody else to have their own home and become more independent. The number of people currently in 'settled accommodation' (by which we mean in their own home or living with family) is 1,405. A further 172 live in residential nursing care. The use of residential and nursing registered care is expected to decrease, but there is always likely to be a need for specialist care home services, for the minority who have particularly complex and specialised needs, although even in these circumstances we will look for opportunities to use it as a way to help people transition to more independent living

DRAFT

What have people and their carers told us?

This strategy has been shaped by the views of people with a learning disability and their carers. We have been able to hear these views through our joint working with the North Yorkshire Learning Disability Partnership Board and Local Area Groups. We have also held engagement sessions over the last two years.

The following are the themes we have been told by people with a learning disability and their families in North Yorkshire that they want to see:

More choice and control over my life:

- People want to be given real choices
- People don't always know what is possible or what is on offer
- People need support to help them make decisions, and want more independent advice and advocacy
- Personal budgets and Direct payments do not in themselves provide choice and control if the support they want is not available

"More education and support is required for individuals to make wise choices and understand the difference between the two and the consequences of making a wise or an unwise choice. This may then assist in empowering individuals to progress."

"Do not want personal budget, cannot buy any care in my local area. Need personalised services which means providing services which meet our needs in our area."

"More services able to meet very complex needs. There is little choice at the moment."

"Listen to us then act on what we need instead of providing a service which does not meet our needs or expecting us to fit into a local pigeon hole or have to travel miles for a service."

"I think that People need to listen and take seriously feelings as well as physical needs, and how they would like to be helped, not told that you can't help with this or that and referring to others when we have to go through the whole story all over again with each new worker. You make life more complicated than it needs to be."

Better health care for people with learning disability

- Healthcare professionals in mainstream health services need better training in learning disabilities,
- More support and extra time is needed for routine health appointments,
- People don't always know what they should expect or ask for be able to help them with health problems

"More needs to be done on access to services which I cannot access because i need special treatment and it takes a long time to happen and i am in pain whilst i wait "

"Explain in words (people) understand and the implications of what any treatment or refusal of treatment are"

"People with LD are not always comfortable with an annual health check and more work needs to be done. A&E /Walk-in Centre are one and the same in our area and involve long

waiting times which involves more anxiety than usual if waiting for hours. On the rare occasions this has happened to us we have requested a home visit. Dental provision is poor with no emergency treatment (usually months) as sedation or intubated GA is required for many needing treatment. People with LD can be treated with drugs for 'behaviour issues' when they have toothache"

"More training and courses for nurses and other health professionals on how to interact better with those people who have learning disabilities"

To be able to play an active role in society,

- People want to see communities valuing and celebrating the contribution people with a learning disability make.
- People want to be helped to do more for themselves
- More people want the change to find employment
- People want to feel safe in their local areas

"Independence sometimes makes us isolated."

"Transport is a difficulty in some of the rural areas in NYCC which can be a barrier for involvement"

"The community (needs to be) safer"

"Ensuring that social inclusion is meaningful and not just specialised groups - i:e disability swim etc"

"Raise awareness and eradicate ignorance shown towards people with Learning disabilities - much of which I have witnessed"

"There needs to be a focus on how to help people with learning disabilities be more active in their community - for example accessible gyms, swimming pools and learning disability exercise group sessions."

Support to live in a home I can call mine

- People with complex needs require more intensive support
- Where people have specialised need local services need to be as good as or better than an out of area service - don't move people back to a poorer service

"Ensure there are houses/accommodation to ensure they can live in their community with all the appropriate adaptations"

In my experience housing is difficult to access for the people with learning disabilities".

"Better respite care for people with complex needs so they can live with their family for a bit longer"

"Hubs, skill centre, respite, coffee shops so we can go together with our friends"

"More information available and more places to go, even if they are shared groups. eg somewhere, where people can work to help others, which is a strong desire in many people with Learning Disabilities, but often unachieved."

“Embrace behavioural methods such as ABA and PBS. It has to develop a specialist behavioural service with trained staff able to support people at all ages develop their skills and independence and manage behaviour through positive approaches not through restraint and medication”

Support for carers:

- People want more flexible ways to get a break, including choice about how and when
- Carers value having someone to turn to
- Many family carers worry about what will happen when they are no longer able to care for their adult children

“I prefer to have cover offered throughout the year for a night or two when needed to regain sleep instead of booking an annual two week block”

“The support I’ve received from our local Mencap group has been invaluable over the years

“Support (for) health needs is a biggy re carers...more likely to have mounting health needs as their young people grow older - a false economy not to start looking at carers health early. I see more consultants than my son nowadays!”

“As previously stated carers are not supported as there are no services to access. Therefore there is no choice at all. We are continuously pressurised to have a personal budget as this shifts the onus on us to find a service which would not be one of choice”

Providing regular and on-going information to parents and carers so everything is up to date

Regular meetings with family involvement and keeping family up to date with information.

To move into adulthood successfully:

- People want preparation to start early
- A simple, single point of contact for families
Better range of options for young people

“More education and support is needed for young people to make wise choices – this will assist in empowering them to progress”

“More work experience opportunities for our young people in special schools more choices of work placements and employment opportunities outside horticulture and small animals and cooking etc.”

“New Social work team working with young people in transition is welcomed”

“Need skills centre and meeting places where we can spend time with people with similar disabilities. This is not institutionalisation but where we are more comfortable instead of being the only one in the cafe in a wheelchair.”

What else do we know?

National Picture

Policy

Valuing People and Valuing People Now have delivered big changes in the way that people with a learning disability are supported to have a good life. Momentum has gathered pace and has been energised by other government policies, national directives and reports; just a few of which are highlighted below.

- Putting People First Concordat - development of personalisation (2008)
- Valuing People Now – Department of Health (2009)
- Death by Indifference and Getting it Right Charter (2007/10)
- Valuing Every Voice, Respecting Every Right (2014)
- No Voice Unheard, No Right Ignore (2015)

The Winterbourne View scandal made us all aware of the need for change and transformation of the care and support for people with learning disabilities and has resulted in three significant pieces of policy, i.e.

- The Winterbourne View Concordat – Programme of Action (2012): vulnerable people, particularly those with learning disabilities and autism should receive safe, appropriate, high quality care. The overriding presumption is that services are local and that people remain in their communities. Hospitals are not homes and thus a substantial reduction in reliance on inpatient care for these groups of people is needed.
- Transforming Care – A National Response to Winterbourne: sets out the lessons that must be learned and the actions that need to be taken to prevent the abuse that took place at Winterbourne View from happening again.
- Building the Right Support: a reinforcement of the ‘homes, not hospitals’ principle but with a specific focus on people with a learning disability and/or autism with more complex needs who display behaviour that challenges, including those with a mental health condition. On condition that they are well enough and no longer need specialist in-patient hospital care, these individuals should have their own home and be supported to live in their communities like everybody else.

Recently, we have also seen the introduction of two new Acts, The Care Act and Children and Families Act⁷. Both Acts have informed our future direction and emphasised the importance of outcomes, personalisation, transitions into adulthood and the integration of services, which are essential parts of delivering this strategy.

⁷ Live Well, Live Longer focuses on individuals with a learning disability from age 14+

Quality Checkers Programme

A national programme is being implemented by NHS England to help address the 'significant barriers' people with a learning disability and/or autism can face when accessing NHS services. These barriers can include tackling complicated forms and language, navigating their way round confusing building layouts and encounters with staff who are unsure of how to interact with them. People with a learning disability and/or autism will be recruited to become Quality Checkers helping to design and create the right tools to measure and inspect the quality of NHS services they use in the below six service areas.

1. Emergency Department (separate from Acute Hospital care)
2. Community services
3. Acute hospitals
4. Primary care (GP's)
5. Dentistry
6. Mental health services

The local response to Winterbourne and Building the Right Support

To date we have responded by reviewing the needs of all people with learning disabilities living out of area to ensure they are safe and talking to them and their family and friends about whether they are able and want to return to the local area. Within North Yorkshire we currently have 121 out of county places with plans to bring 27 of these individuals back into county⁸. Due to the size and scale of North Yorkshire, many people who are classed as out of county, actually live within a 30 mile radius of the North Yorkshire boundary and remain close to their homes, families and friends.

We are committed to reducing the use of hospital beds for people with a learning disability or autism, whose behaviours may be challenging, nine of these beds will be locally commissioned beds and one will be from the Specialist Commissioned bed which offer more secure settings.

By March 2019, local bed capacity should reflect the following national planning guidance:

- 10-15 in-patients in CCG commissioned beds (such as those in assessment and treatment units) per million population;
- For North Yorkshire and York, this equates to 9 CCG commissioned beds. The current number of occupied in-patient beds is 13;
- 20-25 inpatients in NHS England-commissioned beds (such as those in low-, medium- or high-secure units) per million population;
- For North Yorkshire and York, this equates to 15 NHS England-commissioned beds. The current number of occupied inpatient beds occupied is 17.

⁸ Figures are accurate at time of writing – update accordingly at final publication (combined figures from LA and Health TC returns)

Lessons learned from early deaths

The national Learning Disability Mortality Review Programme has been set up to drive improvement in the quality of health and social care service delivery for people with learning disabilities by looking at why people with learning disabilities typically die much earlier than average. Locally, this will involve a retrospective review to help determine the factors that contributed to a premature or early death

Cost, Quality and Budget

All public services have had to make savings and work more efficiently over the last five years.

For example the money that North Yorkshire County Council receives has reduced by over one third since 2011, but the Council is making every attempt to protect frontline services through its pioneering 2020 North Yorkshire change programme. The programme is finding new ways to offer support, and tries to help people live more independently, accessing more support in their own communities. For people with learning disabilities this has already seen new approaches to day time support, and to employment support. Where we have to look at reducing cost we will always look to ensure quality and safety is not compromised

LD Self assessment results

The aim of this framework is to provide a single, consistent way of identifying the challenges in caring for the needs of people with learning disabilities, and documenting the extent to which the shared goals of providing care are met. Locally, this helps our Learning Disability Partnership Board, Health and Wellbeing Board, Clinical Commissioning Groups (CCGs) and the Local Authority (LAs) identify the priorities and opportunities to improve care and tackle health and social care inequalities in our area. It also provides a sound evidence base against which to monitor progress.

In North Yorkshire our rating is predominantly green/amber when measured in the three domain areas of: Staying healthy, Being safe and Living well. The areas in which we score red and where we have action plans in place to make improvements are as follows:

- Improve the accuracy of GP registers in recording local people with a learning disability
- Improve the management of long term conditions (e.g. obesity, diabetes, cardiovascular disease and epilepsy)
- Increase the uptake of Annual Health Checks and the generation of Health Action Plans
- Know and understand the number of local people with a learning disability who are in the Criminal Justice System
- Ensure 90% of individuals who receive a funded care package have an annual review

Formatted: Font: (Default) Arial, 12 pt

- Publish a local employment strategy to help increase the number of people with a learning disability into paid work

Budget

Budget 2015/16 – Social Care

In 2015-16 NYCC incurred gross spend of £56.4m (net £42.7m) on social care provision for people with a learning disability. This figure excludes expenditure relating to supported employment. This was made up of £1.4m on assessment teams, £3.4m of directly provided services and £51.6m on services purchased from the private and voluntary sectors.

Budget 2015/16 – Health

There are approximately 400 people with a learning disability funded by North Yorkshire and York based NHS Clinical Commissioning Groups (CCGs) receiving a Continuous Health Care (CHC) package (i.e. a life-long care package), representing a total cost of £24.9 million (average cost per person £62,000). £11.4 million is joint funded with Local Authority.

There are approximately 40 vulnerable adults with a learning disability aged 18-64 who are in receipt of healthcare services funded by the CCGs, representing a total cost in the region of £3.3 million (average cost per person £86,000). Of this amount, approximately £1 million is joint funded with Local Authority.

Adult Learning Disability Services (including Community Learning Disability Teams and inpatient Assessment and Treatment services) are provided by Tees Esk Weir Valley NHS Foundation Trust and commissioned by the North Yorkshire and York CCGs. The annual budget for 15/16 was approximately £7.7 million.

*Please note that these figures do also include the Vale of York CCG because this organisation serves the population of Selby in addition to the City of York.

Local Strategies

The 2015 Health and Wellbeing Strategy is shaped around five themes: *Connected Communities, Start well, Live well, Age well. Dying well*

The strategy sets out ambitions for:

- Vibrant and self-reliant communities in all parts of North Yorkshire, with local people and organisations working together to develop community libraries, community transport services and activities for all age groups;
- Dementia friendly communities;
- Fewer people saying that they feel socially isolated in their local communities;

- More people receiving personal budgets for their care, to give them choice and control over their lives;
- Improved employment opportunities, including in rural areas and particularly for young people and those people who often face most barriers in the labour market (for example, people with mental health issues, people with autism and people with disabilities).

We have also developed several other joint local strategies in the areas of autism (*The Changing Landscape of Autism in North Yorkshire*), mental health (*Hope, Choice and Control*) and children's services (*Young and Yorkshire*). Many of the priorities and strategic themes identified within these plans compliment the joint thinking revealed in this local strategy for people with learning disabilities. All the strategies commit to appreciating the whole person, working with people as equal partners in designing and improving their care, spending money wisely and joining support services to offer a seamless experience.

The Mental Health Strategy has committed partners to three key priority areas:

- Resilience – supporting individuals families and communities to help themselves
- Responsiveness – better services designed in partnership with the people who use them
- Reaching out – recognising the full extent of people's needs

The Autism Strategy has committed to

- Improving support for people with autism and their families, including information and signposting
- Improving assessment and diagnosis
- Raising awareness and training and developing education and employment support
- Supporting people with autism during key life changes.

Our Priorities

Our priorities are shaped by what people with a learning disability and their carers have told us, together with the overarching Health and Wellbeing Strategy and national policy expectation. We have set out six priorities specific to learning disabilities:

1. Improve choice and control
2. Improve health and reduce health inequalities
3. Increase access to care 'closer to home' within community settings and improve opportunities for people to live in their own home
4. Increase opportunities for people with learning disabilities to feel safe and included in their communities social
5. Provide support for families and carers
6. Support young people into adulthood

Our Principles

Underpinning everything we do, and to enable us to meet our priorities, we are committed to:

- Working with people with a learning disability and their carers whenever we are making plans or changes
- Understanding what matters to people and finding ways to support people achieve the outcomes they want
- Working together to be more effective
- Making the best use we can of the resources available to us
- Ensuring that decisions are built on an understanding, and careful consideration, of the information and evidence available.

Where do we want to be?

The next five years will be a period of major transition and transformation for health and social care within North Yorkshire. There is an expectation that health and care services will become more integrated. Services for people with a disability will become more flexible so they can be personalised and offer people greater choice and control over every aspect of their lives, from the place where they live, to the way they choose to access support and care. Personalisation will also take account of access to education, employment, leisure and social opportunities, so that individuals are enabled to live full and rewarding lives. As we make these changes we will also be needing to deliver further efficiencies and ensure we use our resources as effectively as possible.

Priorities

As previously set out we have to **provide the best quality services that meet local needs and offer the best value for money**. To realise the vision of 'Live Well, Live Longer', the priorities specific for people with a learning disability have been distilled as follows:

1. Improve choice and control
2. Improve health and reduce health inequalities
3. Increase access to care 'closer to home' within community settings and improve opportunities for 'independent/supported living'
4. Improve social inclusion
5. Provide support for families and carers
6. Support young people into adulthood

Outcomes

In the next 5 years we aspire for people to live longer, healthier and more independent lives and we will know that we have achieved this when we put appropriate measurements in place to see the following outcomes:

1. Increased self-determination and independence

(Live an independent life – with support when I need it)

More people with a learning disability will have a greater say and be able to decide for themselves the way they live their lives and choose how they are supported.

2. Reduction in premature deaths

(Live a longer life and Live a healthier life)

More people with a learning disability will have health concerns or problems identified and treated at an earlier stage via increasing the uptake of annual health checks

3. Increased opportunities for independent living locally

(Care and support where I live)

More people will be supported to live independently and safely within their own homes and community for as long as possible, having their own tenancies – or even have the opportunity to *own* a home. We will also see a **reduction in the number of people cared for ‘out of area’** and a **reduction in the use of in-patient services and length of stay in hospital settings;** ensuring that those with more complex needs are able to live, and be supported, locally.

4. Improved quality of life: health and wellbeing

(Live a healthier life)

People with a learning disability will become more active citizens in their communities. By supporting people with their personal goals e.g. seeking employment and/or learning opportunities, we hope that their personal resilience and self-esteem will increase. By supporting families and carers, we will be able to maintain and uphold their vital role in caring for their family members who have a learning disability.

5. Raised awareness and understanding of future adult world for young people and their families/carers.

Young people and their families will be supported and prepared effectively to move into adulthood.

Success in delivering all of these outcomes will also contribute to more people having a **positive experience of healthcare and social care services** (a key outcome in the NHS Five Year Forward strategy).

We already have some plans in place

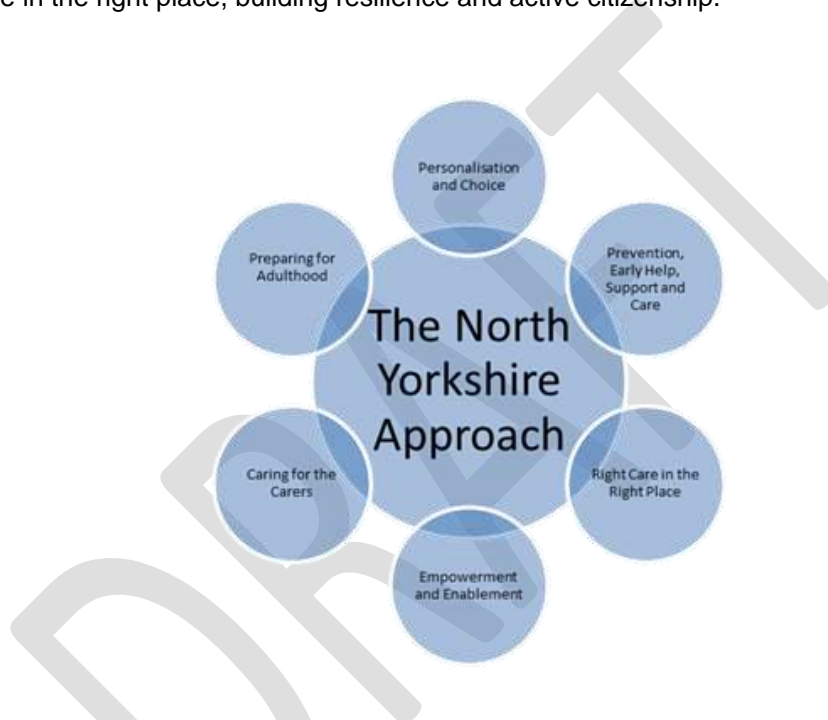
- We have developed a local relationship between the NHS, Public Health, the Learning Disability Partnership Board and North Yorkshire County Council and continue to plan together to make improvements in the number of people able to access health checks and screening programmes
- We have a plan to ‘**Build the Right Support**’ which will prevent unnecessary admission to a learning Disability hospital bed by developing new responses to crisis, and ensuring all our providers are equipped and supported to care for people on a bespoke and individualised basis. When a hospital admission is necessary we will work closely with people and their families/carers to ensure care and treatment plans and discharge plans are co-produced and personalised so that time spent in hospital is for as short a period as possible

- We plan to introduce an 'at risk of admission' register, in consultation with those who might benefit from the register, which can be shared across all relevant professionals from different agencies involved in the treatment and care of those who are vulnerable. This will help ensure their care is planned more proactively and joined-up. Together, with the individual and their family/carer, an integrated multidisciplinary team with specialists from both health and social care can work together through a 'Collaborative Care' model and formulate a person-centred plan.
- We are developing an employment strategy. The employment strategy will highlight best practice and ensure that the aspiration to be in paid employment for people with a learning disability is encouraged and supported.
- The County Council plans to grow a range of housing options. This will be extended to include those with complex needs.

DRAFT

How do we get there? – The North Yorkshire Approach

In order to tackle our priorities and achieve our outcomes, we will need to embed a number of approaches to commissioning and new ways of working which will help us overcome some of the issues we have identified in North Yorkshire. Our approach is a framework and not a comprehensive list of the work we will undertake as this will be detailed in the implementation plan. Overall our strategic approach will be to place a much greater emphasis on personalisation, prevention, delivering the right care in the right place, building resilience and active citizenship.



Personalisation and Choice

Individuals will have real choice and control over how their personal outcomes are achieved. This can include personal budgets (and a personal health budget for those whom are eligible and receive a Continuous Health Care support package), direct payments and co-producing a range of individually tailored ways of support. This fundamentally involves a shift in power from the Local Authority and the NHS to individuals themselves as we move towards working in partnership with each individual to understand their specific needs and develop tailored and 'personalised' care plans accordingly.

To achieve this we will

- Focus on developing person-centred care, treatment and support plans in partnership with individuals and their family carers
- Increase the availability and choice of services via clear signposting; 'what's on?' guides and directories
- Explain clearly the advantages and benefits of direct payments and personal budgets; providing access to independent advocacy and financial advice services so that sensible, practical and 'informed' choices can be made
- Develop a local offer to provide personal health budgets for those whom are eligible and promote the advantages and benefits of this option
- Conduct a review of all local housing and accommodation options; identifying gaps and work with local housing providers to fill gaps
- Stimulate the market to develop personalised and flexible services

Prevention, Early Help, Treatment, Support and Care

A greater focus on early intervention and prevention in terms of health treatment will help to tackle health inequalities and reduce premature deaths. It also means supporting people with a learning disability to stay as independent as possible, including the right low level support being in place to help people to remain at home. This might include ensuring that someone has the right opportunity for exercise and equipment so they do not have to go into hospital or supporting someone with a learning disability into employment rather than into a day centre.

Naturally, the same principle of prevention and early help applies to those individuals who have more complex health needs in order to avoid and/or delay hospital admissions and prevent episodes of crisis or breakdown. With regard to those who exhibit offending behaviour emphasis will be on putting in place early measures to avoid contact with the Criminal Justice System.

To achieve this we will

- Identify, offer support and treat as early as possible (from childhood onwards)
- Assist people with a learning disability to access universal and mainstream health and wellbeing services; making reasonable adjustments where necessary and having 'liaison' staff in place
- Roll-out the gold standard version of an Annual Health Check within primary care across North Yorkshire; including a basic mental health assessment⁹
- Raises awareness of individuals being entitled to an annual health check; which must be viewed as compulsory activity within primary care together with a dedicated and routine approach to cancer screening and enhanced eye tests
- Tailor health promotion programmes to meet individual needs; empowering young people with learning disabilities to make healthy decisions and lead

⁹ 25-45% of people with learning disabilities also have a mental health condition

healthy lifestyles with regard to diet, exercise, sexual health and alcohol awareness

- Embed an 'at risk of admission' register and 'Collaborative Care' models for individuals with complex needs requiring intensive support
- Invest in enhancing community learning disability health services; psychology, crisis, Positive Behavioural Support, primary care liaison, transitions to adult services, and forensic outreach
- Support and train the wider 'mainstream' workforce to increase their awareness and understanding of learning disabilities
- Embrace the 'Quality Checkers' approach

Right Care in the Right Place; Maximise and Enhance Community Support

We will place a growing emphasis on stronger support in the community and more person-centred delivery. This strategic area has a strong focus on human rights, supporting independent living and will also help tackle health inequalities. A greater use of individual social capital – being a part of the community in which you live is a key part of being an active citizen. Ensuring that those natural community and family supports are in place and supplemented by paid support services will be an important part of an individual's support plan.

This will involve improving access to mainstream/universal resources, making reasonable adjustments to achieve this. Universal services have a critical role in making sure that the services and support they offer are available to the whole community, including people with a learning disability and in supporting people to remain healthy and socially active. This includes health services, adult education, employment services, information and advice, advocacy, housing and leisure.

At the most specialised and complex end of the learning disability and/or autism spectrum and with the right enhanced community measures in place (crisis prevention, early intervention, the availability of expert 24 hour supported living in local settings and integrated pathways), individuals who are well enough can expect to live their lives in their own 'home' and not a hospital setting. In-patient services would then only need to be used by those who present with severe and immediate risk to their own health (and/or the safety of others) for as short a time as possible.

To achieve this we will

- Provide care and support within own home or community, or as close as possible
- Develop and invest in community-based care and support projects (NYCC Public Health Agenda: Stronger Communities Programme)
- Explore different models of suitable accommodation and reduce the need for out of county placements; including providing small-scale specialist supported living for individuals with more complex needs and short term accommodation ('crash pads' available for a few weeks) used in times of potential crisis to prevent an avoidable admission into an in-patient setting

- Assist individuals to access mainstream services – for example, using the Green Light Toolkit to make improvements for people with a learning disability when accessing mainstream mental health services
- Put in place clear discharge planning to return individuals to the community or their own home
- Review traditional service models of delivery; replacing any outmoded in-patient provision with enhanced community services for those who are well enough to be cared for and supported in a community setting
- Support and train the wider 'mainstream' workforce; incorporate Positive Behavioural Support (PBS) training where relevant

Empowerment and Enablement

We will facilitate and support people to do things for themselves rather than 'doing it for them.' This will involve building skills and strengths and providing and promoting opportunities for people who have the capability to be involved, to learn, to work and to socialise within their communities.

To achieve this we will

- Strengthen the voices of people with learning disabilities locally (co-produce the design of services)
- Strengthen personal and practical 'life' skills to increase independence and confidence
- Provide access to learning opportunities; take part in education
- Encourage the pursuit of every day leisure activities and hobbies - sports, music, the arts, gardening, cooking, DIY – the list is endless!
- Encourage and support more people with a learning disability into paid employment; matching capabilities with appropriate jobs
- Encourage the uptake of voluntary work to develop skills and improve integration within the community
- Share success stories and case studies to inspire others

Caring for the Carers

We recognise that family carers of people with a learning disability often experience difficulty negotiating their way through the various health, social care and education systems and that this can be extremely challenging. We also know that having a break and finding support is crucial to meeting the needs of our carers. We want to ensure that our levels of support are appropriate and that our carers are well equipped and informed, feel part of a wider network and are able to flourish as individuals within their own right.

To achieve this we will

- Provide support, information and advice
- Offer opportunities to network and feel part of a larger 'care' community; signposting to local voluntary organisations and groups who can be an invaluable source of information and support
- Review respite provision with a view to providing more flexible respite services; tailoring options to individual carers' needs
- Ensure all carers receive their statutory right to an annual assessment
- Provide specialist support and Positive Behavioural Support (PBS) training for family carers of those with more complex needs and whose behaviour can be challenging
- Adopt a proactive approach to planning for the future

Preparing for Adulthood

The first four priorities highlighted in the strategy naturally apply to all people of all ages with a learning disability and/or autism. However, we recognise that the strategic area of 'Prevention and Early Help' and getting this right is critical for children and young people and that the move from the world of Children's to Adult services needs careful planning and management.

We will improve our planning for young people at the point of transition into adulthood through a holistic approach that enables young people to take advantage of wider opportunities that support their aspirations, such as achieving greater independence, accessing employment and/or learning opportunities and accessing social and leisure services in the community. We will also continue to develop a greater range of pathways into adulthood, including local personalised learning for young people post-19 with the most complex needs and ensure that they are equipped with the right skills to achieve their individual outcomes

To achieve this we will

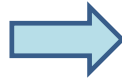
- Ensure clear and consistent planning through into adulthood and that services are better integrated; commencing and preparing for transition from age 14+
- Equip young people with practical 'life', independent and decision-making skills
- Inform and educate about 'keeping safe' in the community: hate crime, mate crime, good sexual health, drug and alcohol awareness, etc.
- Implement the Preparing for Adulthood Model

'Live Well, Live Longer' - Strategy Overview

Where Do We Want To Be?

PRIORITIES

Improve choice and control



How Will We Get There?

STRATEGIES

Personalisation

Flexible services; tailored personal plans according to individual need



What Will Success Look Like?

OUTCOMES

Increased self determination

Reduce health inequalities



Prevention, Early Help & Support

Offer AHCs, early treatment, support
Tailored health promotion and
Screening programmes



Reduction in premature deaths

Increase access to care 'closer to home'
& improve opportunities for independent/
supported living



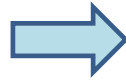
Right Care in the Right Place

Care and support within own home
or a community setting
Review accommodation needs



Increased opportunities for
living independently and locally

Improve social inclusion



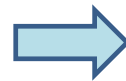
Empowerment and Enablement

- 'Active' service-user consultation and co-production
- Strengthen life skills
- Access to learning and/or employment opportunities
- Pursuit of leisure activities and hobbies



Improved quality of life and wellbeing

Provide support for families and carers



Caring for the Carers

- Information and advice networks
- Short-breaks and respite care



Improved quality of life and wellbeing

Support young people into adulthood



Preparing for Adulthood

- Multi-disciplinary team approach
- Clear and consistent planning
- Equip with life skills



Raised awareness and understanding of future adult world

Next steps / Timeline

Over the next 12 months, our joint plan for people with learning disabilities in North Yorkshire will outline in detail the actions we need to undertake to deliver this strategy and the resources available. This will be co-produced with people with a learning disability to make sure that we devise the right solutions for them.

Together, we will scope and define measurements for each outcome that we have established and report on progress against these on an annual basis to the Health and Wellbeing Board and the North Yorkshire Learning Disability Partnership Board.

DRAFT