

Needs Assessment for Adults with Learning Disabilities

March 2016

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Introduction

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

In addition, the Equality Act 2010 introduced the term "protected characteristics" to refer to groups that are protected under the Act. In the Act, a person has a disability if they have a physical or mental impairment and the impairment has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities. In addition to an adult having a learning disability they may also have other conditions and disabilities which affect their daily living.

This needs assessment focuses on adults with a learning disability. In the future the aim is that the needs assessment will be an all age needs assessment.

Adults with learning disabilities are one of the most vulnerable groups in society, experiencing health inequalities, social exclusion and stigmatisation. In general, adults with learning disabilities have greater and more complex health needs than the general population, and often these needs are not identified or treated. A number of national reports have highlighted that adults with learning disabilities often experience barriers to accessing healthcare services, and receive poor levels of care. Studies have highlighted that adults with learning disabilities are more likely to die from a preventable cause than the general population. Patterns of health needs amongst adults with a learning disability are different to the general population, and therefore current programmes that target health inequalities may exclude this population group.

There are an estimated 3,980 adults with learning disabilities resident in York, of this estimate 835 have moderate/severe learning disabilities, 199 have profound multiple learning disabilities, and 59 have behaviours which challenge.²

Key issues and gaps

- There is forecast to be an increase in the prevalence of adults with learning disabilities over the next 10-15 years in line with the general population. It is to be noted that there will be a significant increase in those living longer with an estimated 31% increase in the 65+ age group and a 69% increase in the 85+ age group³.

¹ Source: WHO, 2007

² Projecting Adult Needs and Service Information website (18-65) and Projecting Older People Population Information System website (65+), February 2016

³ <http://www.poppi.org.uk/index.php?pageNo=374&PHPSESSID=a704gnmd36e8l8pd0g68v53lv2&sc=1&loc=8301&np=1>

- There will continue to be increase in the complex nature of young adults with learning disabilities entering transition that will require adult services.
- Current policy is to provide, where possible, services locally for those individuals transitioning from children to adult services. Therefore some individuals need adult Social Care input sooner than would have previously when a higher proportion went to residential college.
- There continues to be under-recording of adults with learning disabilities in primary care, especially in relation to adults with mild learning disabilities.
- Adults with learning disabilities in general suffer from poorer physical health than the general population, experiencing health inequalities.
- There continues to be limited knowledge regarding the needs of adults with learning disabilities from certain groups, such as within the Criminal Justice System.
- There is concern that services for adults with learning disabilities may come under considerable pressure due to the current economic climate and budget deficit measures.

The bigger picture – national policy

The **Valuing People White Paper**⁴ was published in 2001, with the principles of rights, independence, choice and inclusion at its heart.

Mental Capacity Act (MCA), 2005. The primary purpose of the MCA is to promote and safeguard decision making within a legal framework by empowering people to make decisions for themselves wherever possible, and by protecting people who lack capacity by providing a flexible framework that places individuals at the heart of the decision-making process.

Putting People First⁵ in 2007 set out information to support the transformation of social care, as outlined in the Health White Paper, **Our Health, Our Care, Our Say: a New Direction for Community Services**⁶ in 2006.

Healthcare for All⁷ in 2008 was an Independent Inquiry into Access to Healthcare for People with Learning Disabilities. It emphasised the need for urgent change to improve grossly inadequate NHS healthcare.

Valuing People Now⁸, 2009, reiterated Valuing People's principles and urged a more rapid implementation.

Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. It replaced previous anti-discrimination laws with a single Act, making the law easier to understand and strengthening protection in some situations.

⁴ *Valuing People White Paper*, revised Code of Practice (DfES), 2001

⁵ *Putting People First concordat*, Department of Health (DH) 2007

⁶ *Our Health, Our Care, Our Say a new direction for community services*, White Paper, Department of Health, 2006

⁷ *Healthcare for All*, Department of Health, 2008

⁸ *Valuing People Now*, Department of Health, 2009

The Care Act 2014 builds on recent reviews and reforms and replaces numerous previous laws, in order to provide a coherent approach to adult social care in England. Part one of the Act (and its Statutory Guidance) consolidates and modernises the framework of care and support law; it set out new duties for local authorities and partners, and new rights for customers and carers.

In 2011 the Winterbourne View Hospital scandal occurred when a BBC Panorama programme revealed widespread abuse by staff of people with learning disabilities. The Department of Health undertook a review and In response to this **Transforming care: A national response to Winterbourne View Hospital**⁹ was published which committed to producing a report 2 years later setting out the progress that had been made to ensure what happened at Winterbourne View is not repeated.

The subsequent report, **Winterbourne View: Transforming Care Two Years On**¹⁰, set out what had been achieved but recognised that there was still progress to be made. The national plan, **Building the Right Support**¹¹, 2015, has been developed jointly by NHS England, the LGA and ADASS, and is the next key milestone in the cross-system Transforming Care programme.

No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions¹², 2015, has four main headings; people in charge of their own support and supported by family and friends, inclusion and independence in their community, the right care in the right place, and, very clear accountability and responsibility throughout the system.

Also in 2015 was the **Government response to No voice unheard, no right ignored - a consultation for people with learning disabilities, autism and mental health conditions**¹³ responded to the consultation with the aim of people leading as fulfilling and independent lives as possible with the right support to do so. This paper feeds into the Transforming Care agenda.

The level of need in the population

Criminal Justice System

The Criminal Justice System is a term used to mean the police, courts, prison and probation. It deals with people who break the law. These people are called 'offenders'.

⁹ *Transforming care: A national response to Winterbourne View Hospital*, Department of Health Review, 2012

¹⁰ *Winterbourne View: Transforming Care Two Years On*, Department of Health Review, 2015

¹¹ *Building the Right support, A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition*, NHS England, the LGA and ADASS, 2015

¹² *No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions*, Department of Health, 2015

¹³ *Government response to No voice unheard, no right ignored - a consultation for people with learning disabilities, autism and mental health conditions*, Department of Health, 2015

Nationally, 7% of adult prisoners have an IQ of less than 70 and a further 25% have an IQ between 70-79; it is generally acknowledged that between 5 and 10% of the adult offender population has a learning disability. A learning disability in this instances is defined as an IQ score of less than 70.¹⁴

Accommodation

Across England, 73.3% of adults with learning disabilities live in their own home or with their family. In York this figure is 91.8% which means York is first in the region and fifth when scored against all Local Authorities nationally.¹⁵

The accommodation measure shows the proportion of all adults with a learning disability who are known to councils and who are recorded as living in their own home or with their family.

Employment

In England, 6.0 per cent of adults with learning disabilities were in paid employment. In York this figure is 13.7% which means York is first in the region and ninth when scored against all Local Authorities nationally.¹⁶

This measure shows the proportion of adults with a learning disability who are known to councils and are recorded as being in paid employment.

Current services in relation to need

Primary care services

The Learning Disability Health Check Enhanced Service (ES) was designed to encourage practices to identify all patients aged 14 and over with learning disabilities, to maintain a learning disabilities 'health check' register and offer them an annual health check, which will include producing a health action plan.

Summary of key points from 2014/15 data¹⁷

- There was a 66% increase on the number of health checks done in the Vale of York compared with 2013/14.¹⁸
- The coverage rate in the Vale of York increased from 33% to 51% and is now slightly above the England average.¹⁹

¹⁴ *Fair Access to Justice? support for vulnerable defendants in the criminal courts*, Prison Reform Trust, 2012

¹⁵ ASCOF, Reporting period 1 April 2014 to 31 March 2015. The Adult Social Care Outcomes Framework (ASCOF) measures performance of Local Authorities

¹⁶ ASCOF, Reporting period 1 April 2014 to 31 March 2015. The Adult Social Care Outcomes Framework (ASCOF) measures performance of Local Authorities

¹⁷ Data for 2014/15 is available at the Health and Social Care Information Centre (HSCIC) website.

¹⁸ 2014/15 covered people aged 14+ whereas previously reported from aged 18+.

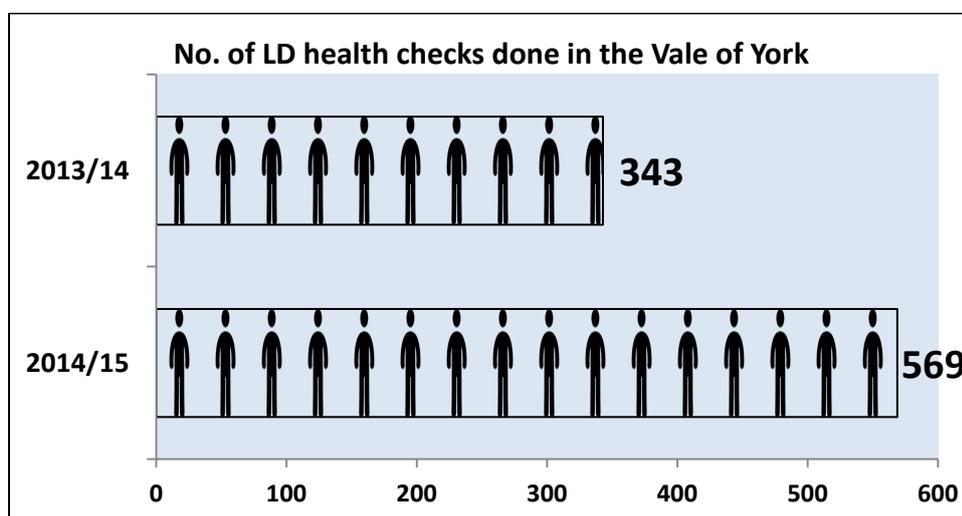
¹⁹ 2014/15 data does not cover those who were offered a health check but declined to attend, this will be included in 2015/16 return.

- The coverage rate in the York area was slightly higher at 57%
- The GP participation rate stayed about the same so the increase in coverage was achieved by greater activity amongst existing practices.
- Just over a fifth of people with a learning disability in the Vale of York were registered with a practice which did not provide health checks.
- Limited data suggests that only about 20% of health checks result in the production of a health action plan.

Number of health checks carried out

A total of 569 learning disability health checks were conducted in 2014/15 in the Vale of York CCG area. This is a 66% increase on the number done in the previous year.

Figure 1: Number of Learning Disability Health Checks conducted in the Vale of York CCG.

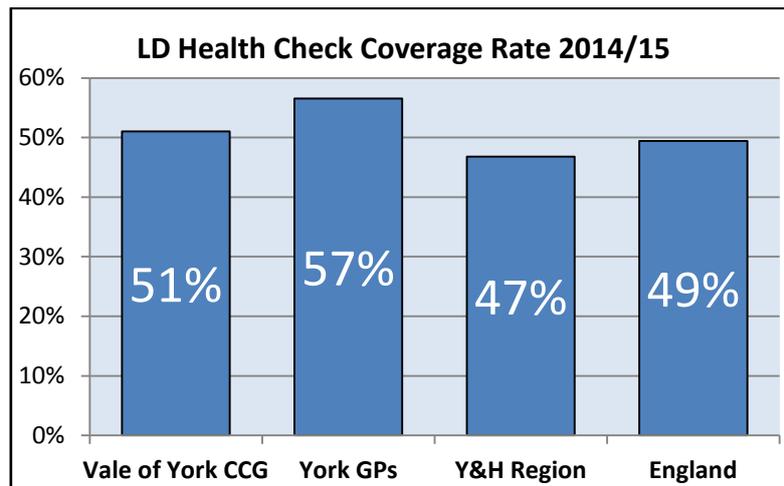


Health check coverage rate.

Coverage rate is usually calculated as the number of health checks carried out divided by the total number of patients identified as having a learning disability on the Quality and Outcomes Framework (QOF) register²⁰. Coverage in the Vale of York for 2014/15 was 51% and for the practices based in York it was 57%. The England average was 49%.

²⁰ Health checks are now done for people aged 14+ but the denominator of people with a learning disability from GP QOF records includes people of all ages, not just those aged 14+. The coverage rate is therefore likely to be an underestimate.

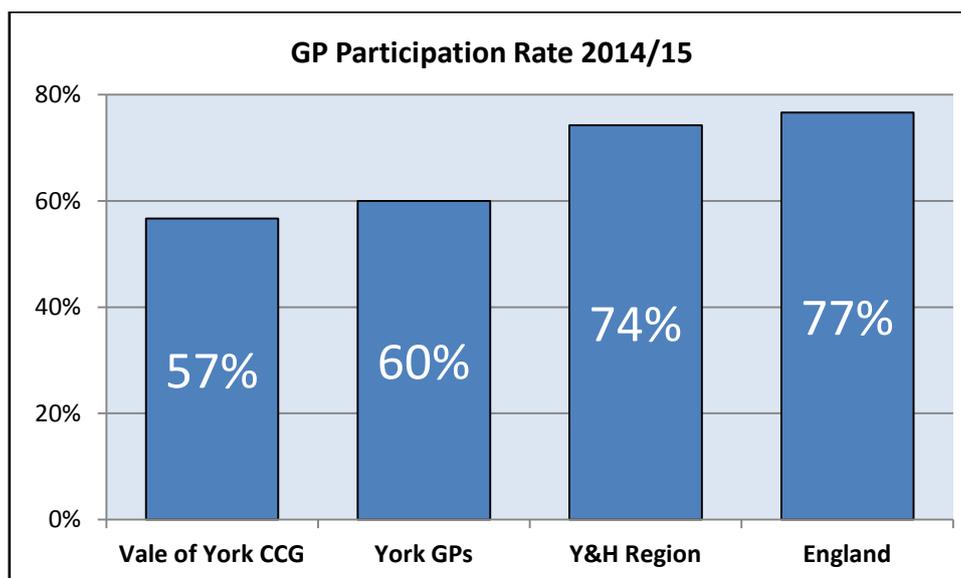
Figure: Learning disability health check coverage rate 2014/15 for York and Vale of York



GP participation rate²¹

The participation rate in the Vale of York was 57% and for the practices based in York it was 60%. The national average was 77%.

Figure: GP participation rate in Learning Disability health check programme 2014/15.



Studies²² have highlighted that obesity prevalence amongst adults with learning disabilities is an issue nationally. Weight issues should be covered individually in the Annual Health Check and actions recorded in the individual Health Action Plan but to date they are not collated within the CCG.

Specific health issues will be covered within the Annual Health Check but information has not been collated.

²¹ GP participation rate is calculated as the number of practices actively engaged in the Enhanced Service (i.e. reporting at least one health check in the reporting year) divided by the total number of practices.

²² *Health Inequalities & People with Learning Disabilities in the UK: 2011*, E Emerson, S Baines, L Allerton & V Welch

Specialist Learning Disability services

Healthcare services provided by York

The Community Learning Disability Team is a multi-disciplinary and multi-agency team that includes a range of professionals (including Consultant Psychiatrist, Community Learning Disability Nurse, Social Worker, Physiotherapist, Occupational Therapist, Speech and Language Therapist, Clinical Psychologist and Administrative support). It acts as the gate-keeper to services for adults with a learning disability living in the community.

The Assessment and Treatment Service provides a service for those adults with a learning disability and associated challenging behaviour and mental health issues, providing specialist health interventions. Oak Rise is an 8 bedded community based inpatient unit for the area of York that provides acute assessment and treatment for customers with a learning disability who present with acute mental health problems. The service has two separate patient areas, one for female service users (4 beds) and the other for male service users (4 beds). In 2014/15, 17 adults from York were admitted to the Assessment and Treatment Units.

White Horse View was an 8 bedded community based unit based in North Yorkshire, near York's boundary, and provided continuing complex rehabilitation for customers who present with longer term and enduring mental health problems. The service was male only. In 2014/15 it was accessed by 2 adults from the York area. As part of a review under Building The Right Support we have been able to scale down the services required and White Horse View closed in April 2016.

Clinical Psychologists work within the Community Learning Disability Team and also provide services to in-patient and day care facilities providing specialist knowledge and skills. From July 2014 to March 2015²³, 125 adults accessed the service.

Speech and Language Therapy services provide communication and dysphagia (eating, drinking and swallowing difficulties) support for adults with a learning disability as well as to those who support them. From July 2014 to March 2015²⁴, 121 adults accessed the service.

Continuing Health Care

Continuing Health Care is provided over an extended period of time to meet physical and mental health needs and involves support for receipt of NHS and social care services. Fully-funded NHS 'Continuing Health Care' is a package of care arranged and funded solely by the NHS, whereas 'Continuing Health and Social Care' is a joint package of care that involves services from both the NHS and Social Care. As of March 2016, 58 adults with learning disabilities in the Vale of York area received

²³ No data for Q1 of 2014/2015. The LD community team in York were not using the main patient administration system during that time. In September 2014 they moved on to the primary patient administration system recognised by the Trust.

²⁴ As footnote above.

fully-funded NHS care (including those receiving continuing care under section 117 of the Mental Health Act) and 109 adults received joint funded care (including those receiving continuing care under section 117 of the Mental Health Act). These figures cannot at the moment be broken down to be York specific.

Personal Health Budgets (PHB)

A personal health budget is an amount of money to support identified health and wellbeing needs, planned and agreed between the person and their local NHS team. The aim is to give people with long-term conditions and disabilities greater choice and control over the healthcare and support they receive.

NHS England's ambition is that by 2020 PHB's will be part of the mainstream offer for patients in the NHS, representing 1-2 people per 1,000 population. For York and North Yorkshire based on 2011 CCG population estimates this would represent an estimate of 763 people (1 person per 1,000 population) and 343 for patients living in NHS Vale of York area.

As of February 2016, in the Vale of York, there were 23 referrals for a PHB and 8 referrals had been completed and were receiving a PHB.

Social Care services

During 2014/15, 482 adults with learning disabilities aged 18+ received a service from City of York Council Adult Social Care Services. For the same period, 97% of adults with a learning disability, known to social care, received a review of their package of support.

Day activities

There are various day activity opportunities in York which include some City of York Council managed day bases as well as activities at other sites. There is also access to one to one support to access activities in the community.

During 2014/15 there were 277 adults with a learning disability receiving some day support as part of their package of care.

Hydrotherapy

City of York Council has a hydrotherapy pool which adults with a learning disability can access as part of their weekly activity programme. 2,340 sessions were accessed in 2014/15.

Supported Living

As at March 2016, there are 173 adults with a learning disability in their own tenancies with support. In addition there are 26 adults with a learning disability in an Extra Care setting with individual support. In total this is 41% of adults with a learning disability, who are known to Social Care, are in their own tenancies with support.

Residential / Nursing Care

The majority of adults with a learning disability in York who are known to Social Care live in accommodation with support or with their families, with most of the remainder living in residential care.

In 2014/15, within the York boundary there were 69 adults with a learning disability in residential care and 4 were accessing nursing care.

For the same period, 47 adults with a learning disability were in residential care outside of the York boundary and 5 who were accessing nursing care.

Adult Placement Service

The Adult Placement Service offers long term placements where an individual lives with a non-related "carer". In 2014/15 fifteen adults accessed the Adult Placement Service.

Respite Care / Short Breaks

Since April 2015 there are four Short Break beds available at the Flaxman Service which in 2015/16 was accessed by 33 adults for a total of 1,079 nights of which 852 were planned short breaks and 272 were emergency provision.

City of York Council also commission Avalon for a short breaks service. There were 276 nights commissioned in 2014/15 and 411 nights in 2015/16

Adults can and do also access short breaks through using a Direct Payment.

Direct payments

Direct Payments are cash payments made to individuals who have been assessed as needing services, in lieu of Social Care provision. The aim of a direct payment is to give more flexibility in how services are provided. By giving individuals money in lieu of Social Care services, adults have greater choice and control over their lives, and are able to make their own decisions about how their care is delivered. A snapshot in February 2016 indicated 87 adults with a learning disability were receiving direct payments.

Advocacy

Advocacy services support adults with a learning disability to use their voice and take action in their lives. Currently there is only one local provider of advocacy services for adults with a learning disability.

Transitions Team

The Transitions Team works with people from age to 14 to 25 years. The Transition Team begins by finding out about the young person's hopes and aspirations. The team provides support to, access individual budgets, find an appropriate course or work experience, access training to increase independent travel skills as well as

develop plans to live increasingly independent lives. They work with young people 14-25 across the City, they are made up of four elements:-

- Children's Health and Disability Social Workers work with young people aged 14-18 who have physical and learning difficulties or complex health needs.
- Adult Social Workers work with a young person and their family from 16 years until they are settled in adulthood.
- Connexions Advisors workers provide impartial information, advice and guidance and personal development opportunities in education and employment to ensure a smooth transition to adulthood
- York Independent Living and Travel Skills (YILTS) supports young people to gain skills and confidence in travelling independently. YILTS works with young people aged 11+

There are currently 88 adults²⁵ (age 18 to 24) who the Transitions Team are working with.

Projected service use

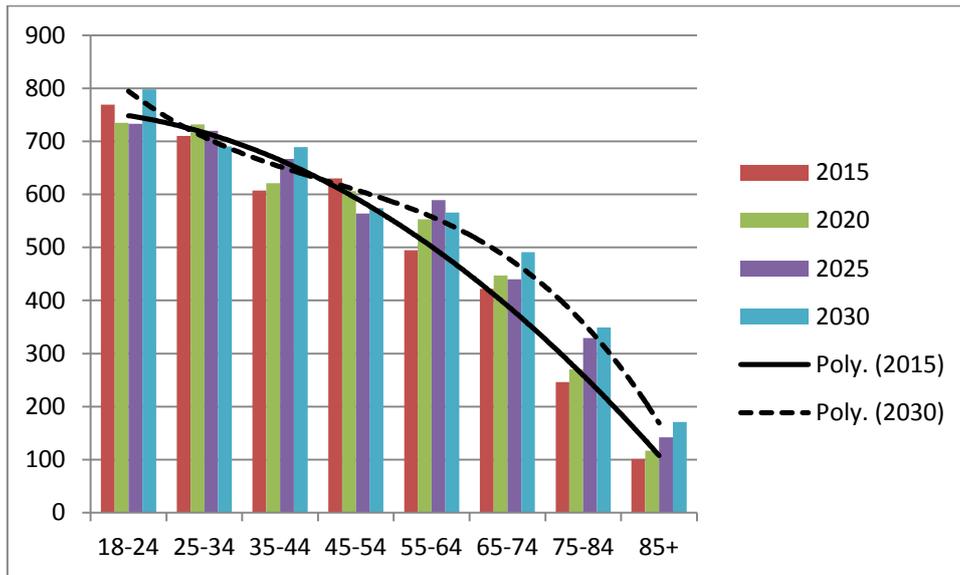
Learning Disabilities

Estimates suggest that the prevalence of adults with learning disabilities in England will increase over the next few years. There is a twofold reason; increased survival rates among young people with severe and complex disabilities and increased longevity among adults with learning disabilities, both due to improvements in medical care and reduced mortality.

In York, there is expected to be a 9% increase in adults with a learning disability from 2016-2030, in line with general population trends. The general population in York has a projected increase of older adults of 62%, however those with a learning disability projected to live to 85+ has a 69% increase which is a larger growth rate than the general population. Englands general population growth for 85+ is projected to be 74%, largely due to the increase in those expected to live over 90 within the population as a whole.

²⁵ At 31 March 2016

Learning Disability – Baseline Estimates



POPPI/PANSI, February 2016

There continues to be a steady increase of adults with a severe learning disability of 5% to age 65, there is no data for 65+.

In the next 5 years there are 45 young people with a learning disability that are currently know to services who will become 18 who are likely to need some degree of service from Adult Social Care. There are also 23 young people with a learning disability and autism that are currently known to services who are likely to need some service Adult Social Care.

These figures do not include those who are not known to Social Care / Education at present.

	Primary Need	
	Learning Disability	Learning Disability and Autism
2016	13	7
2017	10	8
2018	11	3
2019	6	4
2020	5	1

Residents Views

Customer views with regards to living in York and services provided to them are very important. Although staff and managers react to direct customer feedback on a day to day basis, and will always try to offer the best service possible, information from more formal customer feedback is recorded, collated and analysed for trends and service improvements.

In March 2015 a Public Meeting of the Mental Health and Learning Disabilities Partnership Board was held which was attended by 23 Individuals with learning disabilities / interested people. The key discussion point at this meeting was Annual Health Checks with GPs. As a result of this an easy read invitation letter (to Annual Health Checks) has been developed and is being actively promoted by the CCG.

Two consultation events were held specifically in regards to the Joint Strategic Needs Assessment during September 2015 to obtain the views of adults with learning disabilities, carers and other stakeholders. A total of 59 people attended both events; this included Partnership Board members and the Health and Wellbeing Partnerships Co-ordinator.

The engagement sessions was undertaken with 9 key themes and the customer feedback in each area is

Headline / Theme	What's good	What's not working	Other
Keeping healthy and active leisure	<ul style="list-style-type: none"> • Some good activities in place. • Hydrotherapy 	<ul style="list-style-type: none"> • Good activities with good tutors • Timing of sessions • Mental health discussions • Need healthy living advice / classes 	<ul style="list-style-type: none"> • Promote Connect to Support re groups, activities and classes
Keeping safe and hate crime	<ul style="list-style-type: none"> • York People First training • Good support from Council / Housing 	<ul style="list-style-type: none"> • No safe place scheme in York • No enough public awareness re hate crime • Don't know who to tell 	<ul style="list-style-type: none"> • Feel scared so limits evening activities • Not on buses when school children are on
People being placed in services out of their area		<ul style="list-style-type: none"> • Specialist services not in York so have to go out of York 	<ul style="list-style-type: none"> • When people move need support to keep family connections
Personal budgets and direct payments	<ul style="list-style-type: none"> • Personal budget = choice • ILS helping with recruitment / legislation 	<ul style="list-style-type: none"> • Being clear about rules for unspent personal budget • Need to understand in accessible format • Not sure people are always being supported in best way with their funds 	

Headline / Theme	What's good	What's not working	Other
Travelling in York and accessibility	<ul style="list-style-type: none"> • Fleet transport • Audio bus stops • Independent travel training 	<ul style="list-style-type: none"> • Travel card time restricted • Lack of consistency in public transport training • CYC car parks on disabled GO don't display number of disabled spaces 	<ul style="list-style-type: none"> • More training courses for bus and taxi drivers • Accessible bus map /timetables / bus stops • Independent travel training should go wider • Disabled access varies across York, have to check before go
Young people going into adult services	<ul style="list-style-type: none"> • Good support during transition • Transition support at Applefields is a real positive 	<ul style="list-style-type: none"> • Education / training – when you leave school there is none – lose literacy and numeracy skills • Move into adult services and there is nothing • Low level needs are not always met • Transitions – this varies between people, those at Applefields get a great service 	<ul style="list-style-type: none"> • Make the transitions process more consistent • Improve the support available for young people who don't meet the threshold of care around learning disabilities • Need ongoing education / training so don't lose skills
Getting a job and learning new skills	<ul style="list-style-type: none"> • Having someone to support people to do jobs 	<ul style="list-style-type: none"> • Employment opportunities limited • Proper pay • No help looking for a job 	<ul style="list-style-type: none"> • Need more help with employment – low level support
Good information and living in York if you have a disability	<ul style="list-style-type: none"> • Self advocates forum • Sports team good at keeping people informed 	<ul style="list-style-type: none"> • People feel rushed and would like more time either at home or at the doctors 	<ul style="list-style-type: none"> • Need to have some sort of information guide about what is accessible for customers would be good

Headline / Theme	What's good	What's not working	Other
Growing old and planning for the future	<ul style="list-style-type: none"> • Good quality accommodation in York • Good to stay in our own home with extra support 	<ul style="list-style-type: none"> • Some people will need more support as they get older • Need more activities for older people 	<ul style="list-style-type: none"> • Worried about losing local facilities – always need to have a car and not everyone does
Housing	<ul style="list-style-type: none"> • Have had good information about housing in the past • Feel safe and comfortable • Shared ownership housing scheme allows independence 	<ul style="list-style-type: none"> • Housing needs to be linked to support • Getting difficult to recruit PAs • Housing linked to communities • Support arrangements need to be as good as they are now 	<ul style="list-style-type: none"> • Most people like living in own home with support • Make sure there is enough housing that suits the needs of someone with a learning disability • Improve advice about housing options
Short breaks		<ul style="list-style-type: none"> • Would enjoy more time to talk to people who support me 	<ul style="list-style-type: none"> • Have ordinary holidays / short breaks – what about using hotels for people to go and stay

What is happening now

Learning disabilities

In York we have a vibrant voluntary sector with lots of day activity opportunities for adults with a learning disability as well as some learning environments and employment training opportunities. There are lots of organisations which run groups as well as parents groups which provide support.

In 2014/15 York over 40% of the adult learning disability population, that are known to social services, were supported to live in their own tenancies. In the same period, 11% were living out of the local area in residential or nursing care and 15% were in the same type of setting in York. 3% used Adult Placement Services with 30% living at home with their families. As the majority of adults known to social care are in their own long term settled tenancies we need to find more accommodation opportunities in York.

Our main drivers with regards to developing new accommodation are from those adults who are currently out of area but who wish to return to York and those customers who are coming through transition services and will become adults and

require accommodation in the future. We also know that we have some properties which will not be fit for purpose for the tenants who live in them in the future. We are planning for this and have already developed three new bespoke supported living accommodation settings over the last year.

Alongside developing accommodation options, including shared lives, York is also reviewing what individuals do during the day. We need to consider younger people coming through transitions, people coming back to York who will often have more complex needs as well as older people who are reaching retirement age and perhaps want to have a quieter day but don't want to be at home every day.

What people do during the day has not been reviewed since the closure of our larger day services in 2009. As part of the transformation programme we consulted widely in 2014 with customers, their families and carers with regards to what they would like to do. Whilst parts of peoples days are working really well, for some, alternative options need to be considered.

The need for a specialist base for those with more a learning disability and complex autism has been highlighted and we are working in partnership with a support provide to create this space at Energise. We also have an opportunity to be part of the new Burnholme site in York which will have a variety of community partners included.

Unmet needs and information gaps

National and international evidence suggests that adults with learning disabilities have higher levels of unrecognised health needs than the general population. No information is currently available to highlight unrecognised health needs being identified in York through the annual Health Checks undertaken for adults with learning disabilities. If this becomes available this information would require monitoring and action, particularly in relation to identified health needs in the local population.

There are still significant issues in how information is recorded and there are gaps in available information that is needed to inform future policy and direction.

The main gaps with regards to information / information recording are:

- There is no information with regard to individuals with a learning disability who are not known to the Local Authority and if any low level interventions could assist in their continued independence from statutory services.
- A breakdown for York specific data with regard to Health information to separate it from the whole of the CCG Vale of York area.

Recommendations for consideration

- Improve the quality of primary care learning disability registers, including improving the recording of adults with mild learning disabilities on practice registers.
- Ensure the Vale of York CCG works towards developing York specific Health information.
- Ensure Health and Social Services work with adults who use services, their families and carers, in a way which looks at peoples strengths and the capacity of the community.
- Ensure there is sufficient capability in the market to achieve the desired service models and outcomes in the community.
- Work with mainstream services and the community to ensure they are as inclusive as possible.
- Work with adults with a learning disability to understand their particular needs and experiences within the Health and Social Care system.
- Consult and engage with adults with a learning disability who use services to make sure that provider organisations are consistently delivering high-quality services and continued access to the community.
- Work with adults with a learning disability who are living longer into old age to better understand their needs.
- Scope information available with regards to individuals with a learning disability who are not known to the Local Authority. Assess robustness of information and any interventions which may assist in their continued independence from statutory services and inclusion in their community.

Further work to build on this needs assessment

- Assessment of primary care data to further understand the health needs of adults with learning disabilities in York, in particular in relation to lifestyle issues and prevalence of chronic diseases.
- Continue to assess the needs of adults with behaviours that may challenge and autism.
- Undertake an assessment of the level of demand for specialist services to ensure that provision is at required level.

National good practice examples

Learning Disabilities Good Practice Project²⁶ was published in 2013. It set out parameters for good practice indicators:

co-production - involving service users in planning their services and in some cases delivering them; a capabilities approach to disability - looking at people's

²⁶ *Learning Disabilities Good Practice Project*, Department of Health, 2013

strengths and what they can do, rather than looking at what people cannot do for themselves, community capacity building - where people can gradually rely more on community-based support, a move towards more integrated services - bringing in care, health and often housing and leisure, and, a commitment to personalisation – not as a cost cutting measure²⁷

Access to Public Health Services was one of the projects highlighted as a an area of good practice. The Health Improvement Partnership project came out of conversations between people working in Public Health Norfolk and Equal Lives (formerly Norfolk Coalition of Disabled People). The aim of the project was to provide action-based recommendations, information and advice leaflets, good practice guides on accessibility, and recommendations for training/development. The project was about people with learning disabilities working with professionals and others to make sure that disabled people get equal access to services. It was agreed that collecting the experiences and advice of people with learning disabilities was the best way to understand the difficulties people face. The project was designed to use these experiences to make recommendations about how to improve access – and so improve health outcomes. The project has tested co-production between people with learning disabilities, family carers and professionals. This has emphasised people’s capabilities and highlighted the importance of disabled people being involved in service design and delivery to “make things work”. It has also shown the value of building and supporting networks of disabled people/professionals across the county.

Supporting older people with learning disabilities: a toolkit for health and social care commissioners²⁸ provides some examples of good practice from across the country. For example, the **Older Voices**²⁹ project is funded by Comic Relief and facilitated by Mencap, the project brings together people over 50 with a learning disability to discuss the issues that matter to them and to influence decision making. It provides older people with a learning disability the opportunity to influence their community through advocacy and campaigning initiatives.

²⁷ *Learning Disabilities Good Practice Project, Department of Health, 2013, page 18-19*

²⁸ *Supporting older people with learning disabilities: a toolkit for health and social care commissioners, British Institute of Learning Disabilities (BILD), 2014*

²⁹ <https://www.mencap.org.uk/wales/projects/older-voices>