

## Adults with Learning Disabilities

### Introduction

There are several definitions of learning disability used in the UK. Mencap define a learning disability as 'a reduced intellectual ability and difficulty with everyday activities – for example household task, socialising or managing money - which affects someone for their whole life'<sup>1</sup>. Whilst an older document, *Valuing People: White Paper for England about health and social care support for people with a learning disability (2001)* explains how a learning disability can affect individuals including:

- a significantly reduced ability to understand new or complex information or to learn new skills;
- a reduced ability to cope independently;
- an impairment that started before adulthood, with a lasting effect on development.

### Summary

In 2015 it was estimated that in England there were 1,087,100 people with learning disabilities, of these 930,400 are adults. This is the equivalent to 2.16% of the adult population in England. In 2015 the number of working aged adults known to councils, who were receiving long-term support was 124,000<sup>2</sup>. It is predicted that there are over 16,500 adults in Norfolk that have a learning disability, of which 12,000 are of working age. Of these it is predicted that there are around 3,500 adults that have a moderate to severe learning disability. Approximately 4,500 adults and children with learning disabilities who could require some form of support are known to Norfolk County Council's Social Services department.

### Headlines

Compared to the rest of the population, adults with learning disabilities have:

- **Lower life expectancy** – evidence shows that adults with learning disabilities have a significantly shorter life expectancy than those of the general population. On average, a female with learning disabilities has around an 18 years and males 14 years shorter life expectancy than those in the general population<sup>3</sup>.
- **Different causes of death** – the main causes of death in adults with learning disabilities in England are circulatory diseases (22.9%), respiratory diseases (17.1%) and cancer (13.1%)<sup>4</sup>. This differs to the general population, of which 28.5% of all deaths registered in 2016 were the cause of cancer, 25.5% circulatory diseases and 13.8% respiratory diseases<sup>5</sup>. A possible reason for this difference is that adults with a learning disability have a lower life expectancy than the general population and probability of getting cancer increases with age. Although compared to the general population the life expectancy is lower, within the population group it is actually increasing each year. Estimated population figures show that, over the next 10 years there will be an increase in the number of adults aged 65 and over with a learning disability<sup>6</sup>.
- **Different lifestyle issues** – adults with learning disabilities have higher rates of obesity and are more likely to be overweight in comparison to people who do not have a learning disability. Many adults with learning disabilities are less likely to eat a well-balanced healthy diet and have low levels of physical activity<sup>7</sup>.

<sup>1</sup> Mencap, Annual Report 2017, <https://www.mencap.org.uk/about-us/annual-reports>

<sup>2</sup> Public Health England (2016) Learning Disabilities Observatory: People with learning disabilities in England 2015: Main report.

<sup>3</sup> NHS Digital, Health and Care of people with Learning Disabilities: Experimental Statistics: 2015-16 <http://digital.nhs.uk/catalogue/PUB23781>

<sup>4</sup> Public Health England (2016) Learning Disabilities Observatory: People with learning disabilities in England 2015: Main report.

<sup>5</sup> Office for National Statistics, Deaths registered in England and Wales: 2016 <https://www.ons.gov.uk>

<sup>6</sup> POPPI, <http://www.poppi.org.uk/index.php?&PHPSESSID=n3t75vvafpc9qpe9sp28o9g8i0&sc=1&pageNo=374&loc=8268>

<sup>7</sup> NHS Health Scotland, People with Learning Abilities in Scotland (2004)

- **Different levels of severity and impact** – a learning disability is lifelong, however there are different types which can alter the impact a learning disability has on an individual's life. Those with a mild learning disability are often able to mix well with others and cope with most everyday task. They may only require support in small areas of their life, such as filling out forms. Adults with a severe learning disability will need more support in areas such as mobility, personal care and communication. Some people with a moderate learning disability may also need support in these areas, but not definitely.
- **Different levels of complexity** – some people with a learning disability have complex and multiple need including those with both LD and Autism which brings complex needs and behaviours that can challenge as well as multiple and profound needs.

## People supported by Norfolk County Council

- Currently in Norfolk there are just over 2,700 adults with learning disabilities that are known to Norfolk County Council's Adult Social Services Department. Of those adults 90% are receiving some form of long-term support. Long-term support is described as '*support provided with the intention of maintaining quality of life for an individual on an ongoing basis*<sup>8</sup> and covers services such as residential and nursing care, day services and supported living.
- The vast majority of adults with learning disabilities supported by Norfolk County Council Adult Social Services Department are of working age (18-64), with 88.2% falling within that age category. This is to be expected due to the lower life expectancy of those with learning disabilities, however based on previous estimates we anticipate the number of those in Norfolk aged 65+ with a learning disability to increase over time.
- It is also important to take into consideration those children that are about to enter the transition phrase. The transition phrase is when an individual starts the transition from the responsibility of Childrens Services to Adult Social Services. The transition age bracket is 14-24 years old. Figures taken from Childrens Services department show that by 2020 there will be 258 children with learning disabilities entering the transition phrase. Transition for children to adult care and support is covered in the Care Act 2014. The Care Act states a child, young carer or an adult person into work / adult life to promote their independence and reduce their long term needs for care and support.<sup>9</sup>

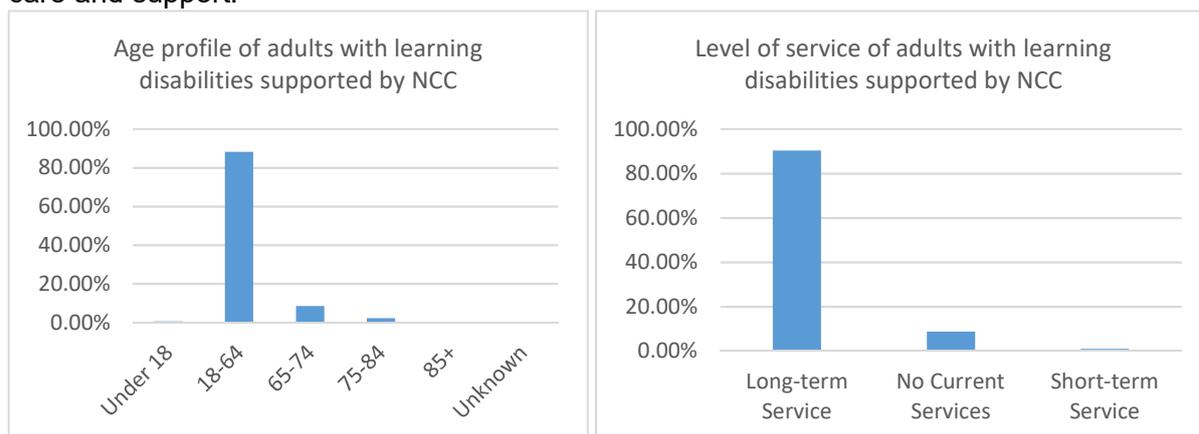


Figure 1: Age profile & level of service of adults with learning disabilities supported by NCC - Source: Norfolk County Council Active to Adult Social Services Monitor 31/10/17

<sup>8</sup> NHS Digital, Short and Long Term Data Return 2017-18 Guidance

<sup>9</sup> <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets#factsheet-11-transition-for-children-to-adult-care-and-support>

Of the service users in Norfolk, 3.3% are in some form of paid employment. This figure is lower than the middle ranked local authority in England, of which 5.5% of working age adults with learning disabilities were in any form of paid employment<sup>10</sup>. This is significantly lower than that of the general population. In Norfolk 46% of adults in the general population are in some form of paid employment. Norfolk's employment rate is slightly lower than that of England, which is 47%<sup>11</sup>.

Adults with learning disabilities who are in paid employment have higher rates of part time working, with 71% of those working 16 hours or less a week in England, compared to 9.6% of working age adults without a learning disability<sup>12</sup>. The number of adults with learning disabilities in paid employment known to Norfolk County Council working 16 hours or less is considerably lower than the national rate for adults with learning disabilities. Of the service users only 19.18% of working adults with learning disabilities work less than 16 hours per week<sup>13</sup>.

There is substantial evidence showing an association between work and health outcomes<sup>14</sup>. Being unemployed is detrimental for physical and mental health and wellbeing<sup>15</sup>. Long term unemployment is associated with higher risk of early mortality and it has been found that being in work reduces the risk of depression. A study on unemployment and mental health found those who were unemployed over 70% said that it affected their mental health, noticing an increase in depression and anxiety<sup>16</sup>.

Residential care is the biggest category of long-term support expenditure for people who have a learning disability in Adult Social Services in England. In 2014/15 £1.7 billion was spent on residential care for adults with learning disabilities (figure 2).

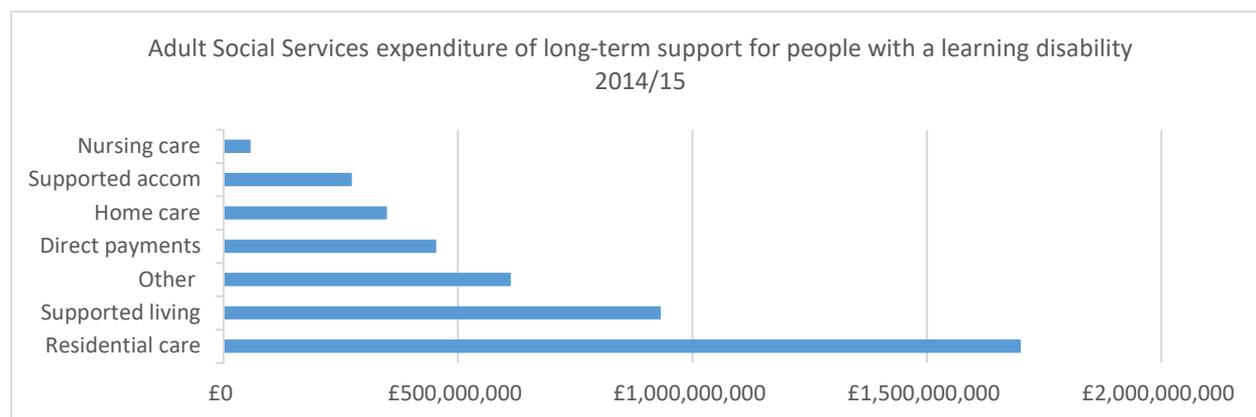


Figure 2: Adult social services expenditure of long-term support 2014/15 Source: Public Health England (2016) Learning Disabilities Observatory: People with learning disabilities in England 2015: Main report.

<sup>10</sup> Public Health England (2016) Learning Disabilities Observatory: People with learning disabilities in England 2015: Main report.

<sup>11</sup> Norfolk Insight, Census 2011, <http://www.norfolkinsight.org.uk/data-explorer/>

<sup>12</sup> Norfolk Insight, Census 2011 Hours worked <http://www.norfolkinsight.org.uk/data-explorer/>

<sup>13</sup> Norfolk County Council, Adult Social Services Performance Monitor October 2017

<sup>14</sup> <http://publichealthmatters.blog.gov.uk/2016/09/14/understanding-the-relationship-between-health-work-and-worklessness/>

<sup>15</sup> Department for Health & Social Care, Work health and disability green paper: Improving lives <https://www.gov.uk/government/consultations/work-health-and-disability-improving-lives/work-health-and-disability-green-paper-improving-lives>

<sup>16</sup> Health watch Blackburn with Darwen, The impact of unemployment on mental health and wellbeing [https://www.healthwatchblackburnwithdarwen.co.uk/sites/default/files/the\\_impact\\_of\\_unemployment\\_on\\_mental\\_health\\_wellbeing\\_report.pdf](https://www.healthwatchblackburnwithdarwen.co.uk/sites/default/files/the_impact_of_unemployment_on_mental_health_wellbeing_report.pdf)

# Norfolk JSNA Briefing Document

There has been a slight increase in the number of adults with learning disabilities living in stable and appropriate accommodation in Norfolk, 71.9% in 2011 to 74% in 2016. This is still lower than the rate for England, which is 75.4% but is equal to that of the East of England<sup>17</sup>. The categories that are considered to be a form of settled accommodation can be found on the Public Health Quality Outcome Framework<sup>18</sup>.

Over 26% of adults with learning disabilities receiving support from Norfolk County Council are in residential care. This is higher than the percentage of adults with learning disabilities known to local authorities in residential care for England, which is 18%<sup>19</sup>. As at 30 September 2017 there were 47 permanent admissions to residential care for the year to date (1 Apr 2017 – 30 Sep 2017) in Norfolk, of those 17 (36%) where adults with a learning disability. A permanent admission is an admission to residential care without an end date.

Figure 2 is information taken from the Public Health Outcome Framework Learning Disability Profile that shows Norfolk has a higher rate of adults with learning disabilities known to local authorities than England and the East of England region. The rate for Norfolk is also one of the highest among Norfolk's CIPFA (Chartered Institute of Public Finance and Accountancy) nearest neighbours. Figure 3 shows that this rate has been increasing over time and is increasing at a quicker rate than that of England.

Indicator	Period	England	Norfolk	1 - Suffolk	2 - Lincolnshire	3 - Somerset	4 - Derbyshire	5 - Worcestershire	6 - Cumbria	7 - Gloucestershire	8 - Nottinghamshire	9 - Warwickshire	10 - Staffordshire	11 - North Yorkshire	12 - Devon	13 - Leicestershire	14 - Lancashire	15 - East Sussex
(Superseded) - Adults (18 to 64) with learning disability known to Local Authorities per 1,000 population	2013/14	4.3	4.9	3.9	4.1	5.0	4.1	3.9	4.6	4.8	5.3	3.9	4.1	5.2	5.0	2.7	4.2	4.4

Figure 2: Adults (18 to 64) with learning disability known to Local Authorities per 1,000 population Source: Public Health Outcome Framework <https://fingertips.phe.org.uk/profile/learning-disabilities/>

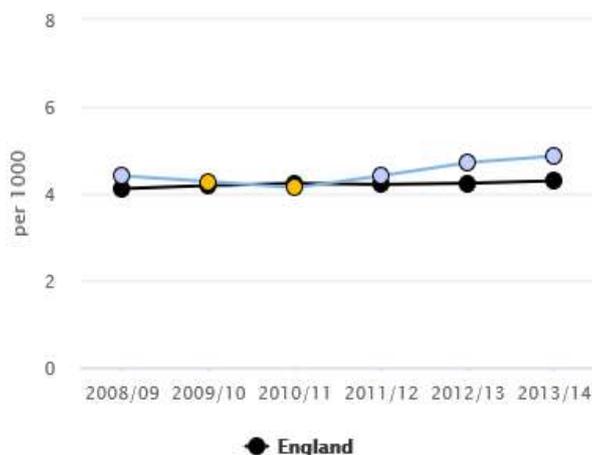


Figure 3: Adults (18 to 64) with learning disability known to Local Authorities per 1,000 population over time Source: Public Health Outcome Framework <https://fingertips.phe.org.uk/profile/learning-disabilities/>

<sup>17</sup> Public Health Outcomes Framework, 1.06i Adults with a learning disability who live in stable and appropriate accommodation <https://fingertips.phe.org.uk/profile/public-health-outcomes-framework/>

<sup>18</sup> Public Health Quality Outcome Framework, <https://fingertips.phe.org.uk/profile/learning-disabilities/data#page/6/gid/1938132704/pat/6/par/E12000006/ati/102/are/E10000020/iid/93126/age/183/sex/4>

<sup>19</sup> Public Health England (2016) Learning Disabilities Observatory: People with learning disabilities in England 2015: Data tables.

## Influences on Health and Wellbeing

The cost of residential care is not only financial, it can also have a negative effect on the health and wellbeing of the residents if admitted without other options being explored. The loss of independence that can be experienced from a stay in residential care can have a lasting effect and create a reliability on care. This can increase the length of time an individual spends in a residential care home. People can lose contact with neighbours and friends and can end up suffering from loneliness which affects their health and wellbeing.

People who have learning disabilities have more difficulty in identifying health problems and getting treatment for them compared to those that do not have a learning disability. This can have an effect on the life expectancy of adults with learning disabilities and can result in pressure on the hospital services as conditions that are left will deteriorate and can result in hospitalisation. As a response to this the NHS introduced annual learning disability health checks in 2008.

In Norfolk, of those eligible adults with a learning disability almost 50% have had a GP health check. This is in line with East of England (49.3%) and is higher than England (44.2%). Within the East of England region Norfolk sits within the middle of the other areas, with the best being 70.1% and the worse 29.6%.

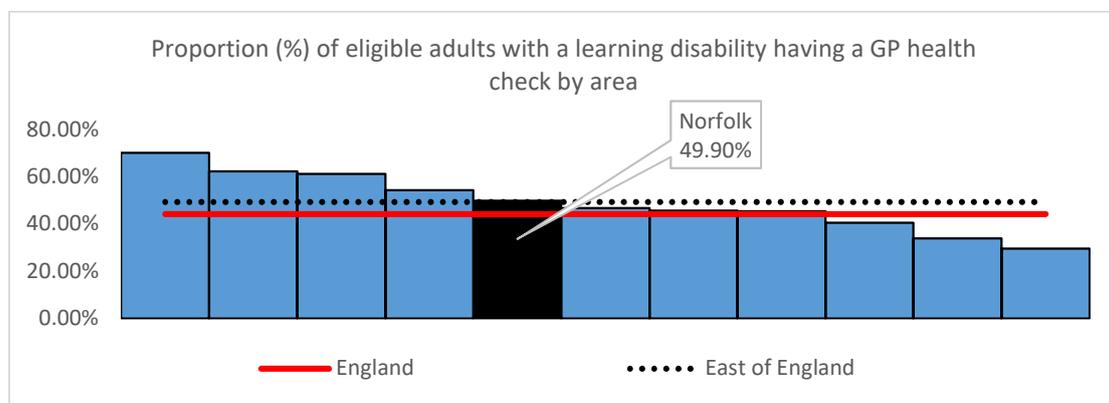


Figure 4: Proportion (%) of eligible adults with a learning disability having a GP health check Source: Public Health Outcome Framework <https://fingertips.phe.org.uk/profile/learning-disabilities/>

Following an inquiry into premature deaths of people with learning disabilities the Healthcare Quality Improvement Partnership on behalf of NHS England commissioned the Learning Disabilities Mortality Review (LeDeR) Programme. The LeDeR programme aims to make improvements in the quality of health and social care for people with learning disabilities and to reduce premature deaths among this population<sup>20</sup>. As part of this programme Norfolk County Council undertakes a review of each person with learning disabilities that has died.

## Current services, local plans and strategies

Norfolk County Council is working in partnership with key stakeholders including through co-production with people that have a learning disability and their families to develop through the development of a Learning Disabilities Strategy 2018 – 2022. The priorities of the strategy have been identified by people with a learning disability and in addition articulates a better joined up consistent approach across with those who are involved in the lives of people with a learning disability. Through the delivery of a more person centred and preventative approach NCC and partners will seek to reduce the number of people receiving residential and hospital provision through recognising needs earlier and preventing them from escalating.

<sup>20</sup> Adass, <https://www.adass.org.uk/the-learning-disability-mortality-review-leder-programme/>

In addition to providing more opportunities for people with a learning disability to access their local communities and mainstream resources, with a particular focus on raising the aspirations and preparing young people into adult life

This is supported through the NCC Promoting Independence project and an increased focus on workforce development and operational delivery in the delivery of a strengths based approach called the 3 conversations.

Norfolk County Council aims to further increase the recording of carers particularly elderly carers and the offer of a carers assessment.

The learning disabilities website<sup>21</sup> has links to local services and opportunities that encourage people with learning disabilities to get out and get involved in the community. There is also information on the housing options available and guides on what to consider to ensure the most suitable option is selected.

The Norfolk Community Learning Service offers a course called Independent Living Skills, which has been designed for adults with learning disabilities to develop the skills they need to live independently, such as cookery skills, money and time management and personal safety<sup>22</sup>.

One of the priorities of Mencap for 2018, is increase the number of adults with a learning disability in paid employment. They offer a range of advice and support services and projects aimed at getting people who have a learning disability into paid employment. Some of these projects are –

- The Right Place – work placements for SEND learners. This project offers work placements for students aged between 16 and 25 and allows SEND students to develop real life work place skills and experience that will increase the likelihood of them gaining paid employment.
- Employ Me – training programme aimed at learning new skills, developing self-confidence and gaining work experience.

The Norfolk Learning Disabilities Partnership Board plays an important role in shaping the priorities for the future and delivering a partnership and co-produced approach. It provides challenge and governance to support the continued improvement of life outcomes, opportunities, quality service development and increasing community inclusion. It supports offers such as the Safer Places Scheme and host contact details on its websites for various services for people with learning disabilities, such as the Housing and Support Alliance<sup>23</sup>.

Staying Safe is recognised by Norfolk LD Strategy 2018- 2022, published summer 2017, to support people's equal engagement within their local community. In addition to safeguarding it offers support for young people and adults with a learning disability to develop greater awareness of their needs and their own wellbeing, including preventing exploitation and mate crime.

Norfolk County Council's Adult Social Services department is the lead organisation identifying and preventing abuse of vulnerable adults and as part of this work hosts the Norfolk Safeguarding Adults Board (NSAB). The NSBA six key priorities are Empowerment, Prevention, Proportionality, Protection, Partnership and Accountability. They offer training and guidance to professionals on how to identify signs of abuse and neglect in adults at risk.

Safeguarding is the prevention of physical, emotional, sexual and financial abuse of vulnerable adults who have care and support needs. The NSAB provides information also runs programmes to aid

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<sup>21</sup> Norfolk County Council Learning Disabilities <https://www.norfolk.gov.uk/care-support-and-health/disabilities/learning-difficulties>

<sup>22</sup> Norfolk Community Learning Service <https://www.norfolk.gov.uk/education-and-learning/adult-learning/courses/adults-with-learning-disabilities>

<sup>23</sup> The Norfolk Learning Disabilities Partnership Board <http://www.norfolklearningdisability.info/>

safeguarding of vulnerable adults. Train the Trainer is a programme run by the NSAB that supports providers with training materials for basic awareness training. By the end of March 2017 24 providers had completed the training programme<sup>24</sup>. This course is still running with new dates recently added and is currently only available to staff and volunteers of service providers.

The Green Light Toolkit, developed by the National Development Team for Inclusion (NDTi), has been designed to improve the quality of mental health services for adults with learning disabilities and/or autism. The toolkit includes an audit framework to support reviews, an 'easy-read' version of the framework and a database of examples of adjustments made by services to aid people seeking innovative ideas and shared learning<sup>25</sup>.

## **Voice – the perspective from the public, service users, referrers and front line staff**

In the 2016 Adult Social Care Summary Report published by CIPFA Norfolk (47.5%) scored higher than the national average (42.54%) for service users who reported that they had as much social contact as they would like. Norfolk also had a higher percentage (67.6%) of service users who are satisfied with their care and support services than the national average (63.38%).

The development of Norfolk Learning Disability strategy 2018 – 2022 focused on co-production and participation with over 850 people completing questionnaires from people with a learning disability, carers, workers and the wider community. In addition to the co-production steering group, Norfolk County Council also held an event called the Thinking Day. This was attended by people with learning disabilities, their families and members of the public and service.

Quotes taken from this event show that there is still room for improvement and a desire to enable opportunities to be more independent by people with a learning disability, with quotes from the day including.

*'Opportunity to get out and about and meet people', 'Support independence not doing it for me', 'I stay in my home 24 hours a day and am losing my friends. I have a need for wider relationships and not just my home care'*

## **Considerations for Health and Wellbeing Board and commissioners**

Norfolk County Council has in partnership with Health Commissioners a responsibility to support people with a learning disability and their families to enable increasing opportunities to equally access universal and mainstream services, ensuring that services are of good quality and maximise their health and wellbeing.

The statutory requirements of the undertaking of the Care Act should equally apply to people with a learning disability with preventative and responsive services working in partnership at a universal, targeted and specialist thresholds of need which is based upon the individual needs and outcomes delivered via a person centred approach.

Transforming Care and building the right support articulates the importance of reducing the use of institutions with a specific focus on reducing the numbers of children and adults in hospital environments for those people with a learning disabilities and or Autism, increasingly locally there is a greater focus on prevention and developing a sustainable model.

<sup>24</sup> Norfolk Safeguard Adults Board, <https://www.norfolksafeguardingadultsboard.info>

<sup>25</sup> National Development Team for Inclusion, The Green Light Toolkit, [http://www.ndti.org.uk/uploads/files/Green\\_Light\\_Toolkit\\_22\\_Nov\\_2013\\_final.pdf](http://www.ndti.org.uk/uploads/files/Green_Light_Toolkit_22_Nov_2013_final.pdf)

For those people with a learning disabilities and Autism consideration is also given to the Autism Act and Statutory guidance in delivering reasonably adjusted services and a workforce with the knowledge in being able to assess and take into consideration the impact of autism in their lives and needs.

In Norfolk work is underway to map the housing and support requirements across the county, informed by the operational teams. In addition to targeted programmes of work to improve and maximise the opportunities for people to live in appropriate accommodation, access meaningful daytime activity, including accessing employment, raising aspirations into adulthood and enabling people's health and wellbeing, including the importance of relationships. These are included within Norfolk LD Strategy and Promoting independence project NCC

Work to promote the opportunities, equality and independence for adults with learning disabilities must remain a priority. Adults with learning disabilities want to live as independently as possible and remain in stable accommodation. Moving away from a risk adverse and reactive culture to one of greater independence will not only improve the lives of those adults with learning disabilities, but will also reduce the expenditure impact of the Adult Social Services Department.

The training of professionals in the signs of abuse and adults at risk is important to ensure that the safeguarding responsibilities of Norfolk County Council are fulfilled. There is a responsibility to ensure that those using social services feel safe and protected from any potential abuse and harm.

Evidence<sup>26</sup> shows that those in work have better health and wellbeing than those who are unemployed, so work to get adults with learning disabilities into paid employment has to be continued. Working closely with charities and potentially local business to offer work experience or development courses to build up essential work place skills should be a consideration of the Health and Wellbeing Board. This would allow those with learning disabilities the best possible chance of gaining paid employment.

## References and information

Public Health England (2016) Learning Disabilities Observatory: People with learning disabilities in England 2015: Main report <https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england-2015>

Public Health Outcomes Framework

<https://fingertips.phe.org.uk/profile/public-health-outcomes-framework/data#page/10/qid/1000041/pat/6/par/E12000006/ati/102/are/E10000020>

Mencap

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Email: [JSNA@norfolk.gov.uk](mailto:JSNA@norfolk.gov.uk)

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<sup>26</sup> <sup>26</sup> Department for Health & Social Care, Work health and disability green paper: Improving lives <https://www.gov.uk/government/consultations/work-health-and-disability-improving-lives/work-health-and-disability-green-paper-improving-lives>