

Adults with learning disabilities

Headlines

Locally there are 6,100 adults aged 16 – 64 with a learning disability. This is 24 per 1,000 population, slightly above the national average of 22 per 1,000.

The number of adults with a learning disability is predicted to increase by 9% by 2030, especially in those with severe needs and those aged over 65 years. Demand for services is predicted to grow year on year by at least 3%. This is because people with learning disabilities are living longer, also they and their families have increased expectations of an equal quality of life with non-disabled citizens, and children with complex needs are surviving beyond birth into adulthood and the increasing number of older parent/carer numbers.

Currently, about half of all adults with severe learning disabilities live with their families, often beyond the age of 40. This could change with the next generation of family carers as expectations change or as pressures on family life increase. People with learning disabilities often face very significant disadvantages in terms of both their health status and their access to effective health services, as they tend to have much poorer health than the general population.

- People with learning disabilities are far more likely to die of a preventable disease, be obese, have mental health problems including schizophrenia and/or have epilepsy.
- Many people with learning disabilities also have physical and/or sensory impairments.
- Those with Down's Syndrome aged over 50 years have a higher risk of dementia.
- Those with autism have specific unmet needs in community care assessment and social skills training. Only 15% of such adults were in fulltime employment.

Why is this group important?

Learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence).
- A reduced ability to cope independently (impaired social functioning) that started before adulthood, with a lasting effect on development.

In Kirklees there are about 6,100 adults aged 18-64 with a learning disability and of these, nearly 1,400 had a moderate or severe learning disability. These figures are predicted to grow to nearly 6,700 (9% increase) and nearly 1,600 (13% increase) respectively by 2030. The number of people aged over 65 years with a learning disability is set to rise from 1,260 to more than 1,940 (54% increase) between 2010 and 2030, with an increase in people with moderate to severe learning disability increasing from 170 to more than 250 (47%)¹.

In 2009, more than 2,050 adults in Kirklees aged 18-64 with learning disabilities had needs significant enough to be in receipt of a social care service. The level of expenditure is used as a proxy for the level of need of an individual with learning disabilities¹.

Nationally, 1 in 100 people have an autistic spectrum disorder (ASD)². So, around 2,500 adults aged 18-64 in Kirklees had an ASD¹. Nationally less than 2 in 5 (38%) of people with an ASD had a community care assessment, less than 1 in 10 (9%) were receiving social skills training and 15% of such adults were in full-time employment². A high proportion of younger adults with learning disabilities also have ASD.

What significant factors are affecting this group?

People with learning disabilities tend to have much poorer health than the general population with higher rates of respiratory problems, diabetes, heart disease, thyroid disorders and epilepsy, as well as musculoskeletal problems³. They are also more likely to have sensory and physical disabilities as well as mental health problems, which tend to increase in severity as they grow older⁴. Some individuals are still living with family carers who are in their 70s and 80s.

People with learning disabilities^{3,5}:

- Are 58 times more likely to die before the age of 50 than the general population.
- Are 2.5 times more likely to have health problems than other people.
- Are more likely to have sight and hearing problems.
- Have a greater risk of having thyroid problems, particularly those with Down's syndrome.
- Are less likely to take up breast and cervical screening.
- Are more likely to be obese with 1 in 3 (33%) being obese compared with 1 in 4 of the general population.
- Have increased vulnerability to early onset dementia (particularly those with Down's syndrome) over the age of 50.

In Kirklees in 2010, 1 in 3 (33%) people with learning disabilities had mental health issues, more than 1 in 5 (22%) had epilepsy compared with 1 in 100 of the general population and 3 in 100 (3%) had schizophrenia compared with 1 in 100 of the general population⁶.

The growth in demand for support in Kirklees

Demand for services is predicted to grow year on year by at least 3%. This is because people with learning disabilities are living longer and they and their families have increased expectations of an equal quality of life with non-disabled citizens. Children with complex needs are surviving into adulthood so increasing the number of older parents and carers⁴.

Which specific groups are affected most?

Overall in Kirklees in 2010 1,724 (more than 4 in 5, 84%) of all adults with learning disabilities known to services were white and 287 (3 in 20, 14%) were non-white, increasing in 18-24 year olds to more than 251 (1 in 4, 26%) of whom half were of Pakistani background. With a larger than national average minority ethnic community in Kirklees, there was a larger than national average increase in demand for support and services from this group⁶.

Where is this causing greatest concern?

Within Kirklees the number of people with learning disabilities known to services, in the areas with the highest rates, had continued to rise. From 2009 to 2010 the rate rose in Dewsbury (including Mirfield) from 16% to 18%, in Huddersfield South from 18% to 19% and in Huddersfield North from 13% to 14%⁶.

There is no robust local data about autism for Kirklees and further investigation into this should be undertaken.

What could commissioners and service planners consider?

Learning disability

- Give people with learning disabilities greater choice and control over how their needs are met and what outcomes they wish to achieve. Provide clear, easy to understand information about services and the support available that helps more people with learning disabilities take control of how their needs are met.
- Increase opportunities for learning disabled people to live in their own home, be supported to gain employment, develop skills, volunteer and make a positive contribution to community life without fear or prejudice.
- Maximise assistive technologies that enable people to live as independently as possible.
- As the increase in the proportion of young adults from BME communities with learning disabilities, particularly the Pakistani community, is rising, consider the need for culturally appropriate and individualised services.
- Increase awareness of the needs of people with learning disabilities in the wider community, promoting their rights as equal citizens.
- Mainstream services should develop a more inclusive approach. They should better understand the needs of people with learning disabilities and make reasonable adjustment to help meet their needs and contribute to a more inclusive community in which people with learning disabilities can become equally valued members of the community.
- Ensure all healthcare professionals develop a greater understanding and awareness of the healthcare needs of people with learning disabilities.

Autistic spectrum disorder

It is important that we make progress to improve the lives of people with autism and their families. A local joint commissioning strategy and action plan is needed that recognises that planning must take place across the life course and covers the five core areas highlighted by the national autism strategy:

1. Increasing awareness and understanding of autism among front line professionals.
2. Developing a clear, consistent pathway for diagnosis followed by a personalised needs assessment.
3. Improving access to the services and support that adults with autism need to live independently within the community.
4. Helping adults with autism into work where appropriate.
5. Enabling local partners to plan and develop appropriate services.

It will be crucial to find ways to gather qualitative and quantitative local data to improve our understanding of who is affected and how they are affected, so we must work with people with ASD alongside their families and support networks.

References

1. Projecting Adult Needs and Service Information System (PANSI)
www.pansi.org.uk
2. National Autistic Society. I exist: the message from adults with Autism. 2008.
<http://www.autism.org.uk/TDAA>
3. Disability Rights Commission. Equal Treatment: Closing the Gap. 2006.
<http://valuingpeople.gov.uk/echo/filedownload.jsp?action=dFile&key=1377>
4. Emerson E, Hatton, C. Estimating Future Need for Adults Social Care for People with Learning Disabilities in England. Centre for Disability Research, Lancaster University. 2008.
5. Hatton et al. 'Key Highlights' Of Research Evidence on the Health of People with Learning [Intellectual] Disabilities. 2002.
6. Kirklees Council (2010) Learning disability adult social care service data.