Adults with learning disabilities

Headlines

There are an estimated 7,500 to 8,300 adults with a learning disability living in Kirklees, of which 1,530 are known to Kirklees Council adult social care services.

By 2030 this will rise faster than nationally to between 8,300 and 9,400.

The largest increase will be people with a profound and multiple learning disability and those aged over 65.

The number of learning disabled adults is higher in younger non-white groups, especially in south Asian communities.

People with learning disabilities are far more likely to die early and to die of a preventable disease, with higher rates of respiratory problems, diabetes and heart disease as well as thyroid disorders and musculoskeletal problems. They are also more likely to be obese, have mental health problems including schizophrenia and/or epilepsy, and physical and/or sensory impairments. Those with Down's syndrome aged over 50 years have a higher risk of dementia.

Demand for Kirklees Council funded adult social care services has grown by an average of 3.8% every year over the last five years and 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.

Why is this issue 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.

Nationally it is estimated that around 2.4% of the adult population have a learning disability, although this is recognised as an under-estimate in communities with a high south Asian community. There are an estimated 7,500 to 8,300 adults with a learning disability living in Kirklees, of which 1,530 are known to Kirklees Council adult social care services. By 2030 there will be between 8,600 and 10,000 and this is above the national average growth rate. The largest projected increases will be in adults under 65 with

profound and multiple learning disabilities, from 140 in 2011 to 210 in 2030 (50%), and in adults aged 65 and over with any learning disability age, from 1,360 to 2,080 (53%)¹. Nationally by 2030 there will be a 164% increase in the number of adults aged over 80 using social care services for people with a learning disability, replicating the national trend of an ageing population². This represents a relatively small number of people for whom we currently have very limited care services to meet their needs.

The predicted growth in terms of number of people with a learning disability is only 11% but the financial cost of meeting the health and social care needs will be significantly greater. Over the last five years the number of adults with learning disabilities with needs significant enough to be in receipt of a social care service has risen by 24% from 970 to 1,200. The last five years has seen a 3.8% growth each year in Kirklees Council funded adult social care services. Demand 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, children with complex needs are surviving beyond birth into adulthood and the increasing number of older parent/carers no longer able to sustain their caring role. The greatest future care cost increase will be borne by the NHS caused by the increase in the number of people with profound and multiple learning disabilities and an ageing 65+ learning disability population.

What significant factors are affecting this issue?

People with learning disabilities tend to have much poorer health than the general population with higher rates of respiratory problems, <u>diabetes</u>, heart disease, thyroid disorders and epilepsy, as well as musculoskeletal problems³. They are also more likely to have sensory and <u>physical disabilities</u> as well as <u>mental health</u> problems, which tend to increase in severity as they grow older⁴.

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 2.5 times more likely to have health problems than other people.
- Are more likely to be <u>obese</u> with 1 in 3 (33%) being obese compared with 1 in 4 of the general population
- 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
- Have increased vulnerability to early onset dementia (particularly those with Down's syndrome) over the age of 50⁵
- Are 58 times more likely to die before the age of 50 than the general population.
- The median age at death for people with learning disabilities is about 25 years (30%) younger than for those who do not have learning disabilities⁶.
- Over 80% of adults with learning disabilities engage in levels of physical activity below the Department of Health's minimum recommended level, a much lower level of physical activity than the general population (53%-64%)⁷.

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.

Which groups are most affected by this issue?

Of the 1,530 adults with learning disabilities known to Kirklees Council adult social care services 4 in 5 (83%) are white, which broadly reflects the Kirklees population. However, within the 18-24 year age group 1 in 4 (25%) are from a minority ethnic 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 group.

Where is this causing greatest concern?

The number of people with learning disabilities known to adult social care services has risen in all localities across Kirklees from 2011 to 2012. The rise has been greatest in Dewsbury (including Mirfield) where there was a rise from 18% to 20% (18.4% of the adult population live in Dewsbury), in Huddersfield South from 19% to 20% (17.9%) and in Huddersfield North from 14% to 15% (14.1%).

What could commissioners and service planners consider?

Give people with a learning disability greater choice and control over how their social
care needs are met and what outcomes they wish to achieve. Provide clear, easy to
understand information about choices and services and the support available that helps
more people with learning disabilities take control of how their needs are met.

- Work more closely with carers to understand their needs and expectations, and improve long-term succession planning particularly with older carers and parents of young people entering adulthood.
- Increase opportunities for people with a learning disability 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.
- Enable people with a learning disability to live as independently as possible, ensure care providers support people to become more independent, achieve their goals in life and maximise the use of assistive technologies.
- As the increase in the proportion of young adults from BME communities with a learning disability, 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 the changing needs of the learning disabled population are considered when make strategic long-term community planning decisions so people with a learning disability can lead a more inclusive lifestyle.
- Ensure all social and healthcare professionals develop a greater understanding and awareness of the needs of people with learning disabilities.
- Ensure there is provision of genetic counselling to address the issue of consanguinity in Kirklees.

Date this section was last reviewed

09/07/2013 (PL)

References

- Projecting Adult Needs and Service Information System (PANSI). Available from: <u>www.pansi.org.uk</u> and Planning4care Estimates; 2011.
- 2. Emerson E, Hatton C. Estimating Future Need for Social Care among Adults with Learning Disabilities in England: An Update; 2011.
- 3. Source: Disability Rights Commission. Equal Treatment: Closing the Gap; 2006. Available from: http://disability-studies.leeds.ac.uk/files/library/DRC-Health-FI-main.pdf
- 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. ⁵Hatton et al. Key Highlights Of Research Evidence on the Health of People with Learning [Intellectual] Disabilities; 2002.
- 6. Emerson et al. People with Learning Disabilities in England 2011; 2012.
- 7. Emerson E. Underweight, Obesity and Physical Activity in Adults with Intellectual Disability in Supported Accommodation in Northern England. Journal of Intellectual Disability Research 2005; 49:134-43.