

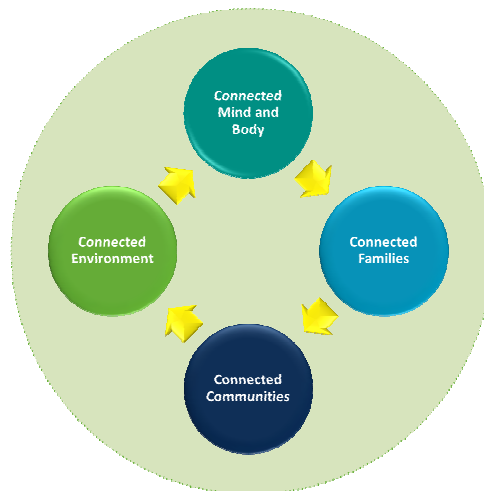
Our Services for People with Learning Disabilities

1.0 Introduction

Surrey and Borders Partnership NHS Foundation Trust is one of the largest providers of specialist health and social care services to people with learning disabilities in the country.

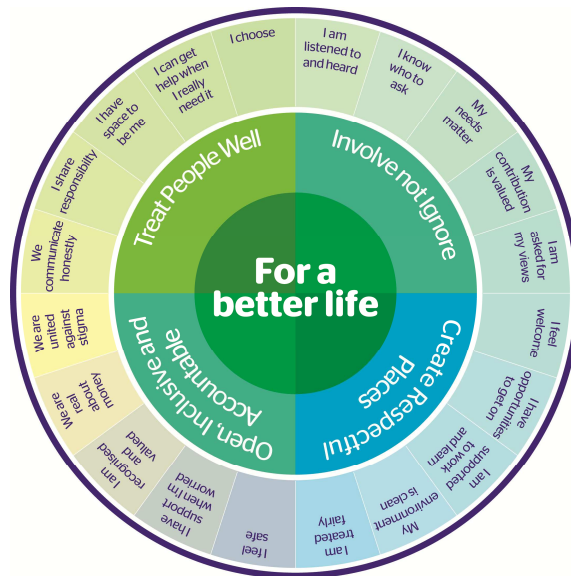
Our dedicated and expert health and social care staff work in partnership with those in other agencies, including the County Council, to provide a range of services for people with learning disabilities from supported living; consultancy, advice and training to other providers; through to specialist health assessment and treatment services.

Our services work to enable people with learning disabilities to live as independently as possible within our communities and to keep well connected with all those who are important to them.



Our values underpin our approach to ensuring that people with learning disabilities lead better lives in Surrey and to reduce the health inequalities which people with learning disabilities can experience.

For a better life



This paper seeks to provide the Surrey Health Overview and Scrutiny Committee with a brief appraisal of our important liaison services work across Surrey. Through these services our expert staff focus on working with other health and social care services to reduce the health inequalities for people who have a learning disabilities. Their specialist expertise in the care and treatment of people with learning disabilities provides important support to the rest of the system to safeguard them, as people with learning disabilities can suffer otherwise as a result of not being able to speak up for themselves. In this way they are a crucial element of ensuring equal treatment and access across all health services for people with learning disabilities.

2.0 Health Needs for People who have Learning Disabilities

Demography – Growing Demand

Within Surrey, using national prevalence rates it might be expected that approx. 22,000 people would have a learning disability with approx. 5,000 people known to health and social care services.¹ This demographic analysis also postulates that demand for learning disability services will increase by 0.5% per annum, leading to a 14% increase in growth in people who have a learning disability known to services 2001-2021 because:

- People who have profound and multiple learning disabilities are more likely to live for significantly longer due to advances in medical technology; and,
- People who have learning disabilities are generally living to an older age.

This growth is double the predicted demographic increase for the overall population levels in the UK over the same period.

¹ Emerson E, & Hatton C. Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England. Lancaster: Institute for Health Research, Lancaster University, 2008 & Emerson E, Hatton C. Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England. Lancaster: Institute for Health Research, Lancaster University, 2004.

Prevalence of specific health needs

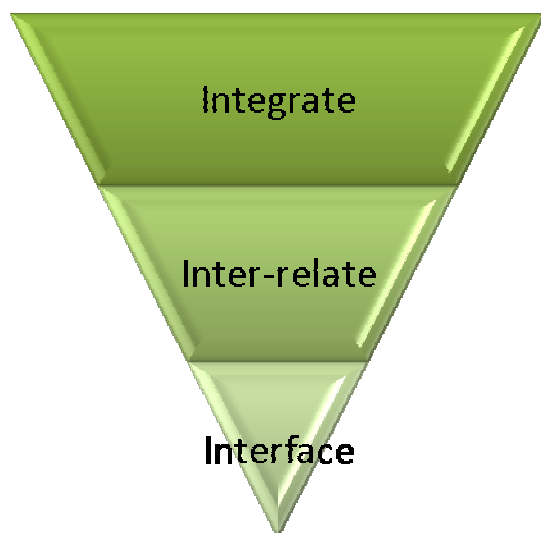
People with learning disabilities experience a range of long-term health conditions, as the wider non-learning disabled population. However, they also have a higher predisposition to some conditions. Brief details are supplied in Appendix 1.²

Many of these factors inter-relate with a consequence that people with learning disabilities have an increased risk of early death compared to the general population. Therefore there has been much recent emphasis on overcoming the health inequalities for people who have learning disabilities (as seen in reports such as “Death by Indifference,” Mencap 2007 & 2012).³

The combination of demographic growth, combined with the prevalence of specific health needs and the fact that traditionally people who have a learning disability have been subject to unequal treatment and ‘diagnostic overshadowing’ (where a health condition is not treated as it is wrongly perceived as being linked to someone’s learning disability) mean that specific attention must be paid to the healthcare needs of people who have a learning disability.

3.0 Our Learning Disability Services

Our services focus on the health and social care needs of people who have a learning disability and we work with others to ensure that equal treatment is provided in Surrey. To ensure equal treatment, we work differently in different settings and this is illustrated by the model below:



People who have learning disabilities are as individual and unique as anyone else. We know that many people live independently, with support from their family, friends and local community and can access services without any specialist intervention.

Services must provide a wide range of supports and ‘reasonable adjustments’ to enable services for people who have learning disabilities. In order to ensure people can receive equal treatment and **integrate** fully with mainstream services we provide advice on ‘easy read’ information, training on supporting people who have a learning disability and advice on reasonable adjustments.

We have contributed to www.surreyhealthaction.org.uk so that health professionals are able to create ‘easy read appointment letters’ and have access to ‘easy read’ leaflets. Over the

² References for all of the research identified can be supplied contact andy.erskine@sabp.nhs.uk

³<http://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%202014%20Deaths%20and%20counting.pdf>

past year over 3,500 people have accessed this webpage and approximately 75% have been 'new' visitors accessing this information for the first time, with visitor numbers showing an increasing trend throughout 2012 (data to August 2012) This indicates that there is a greater (and growing) awareness of this resource following the training we provide.

Some people who have a learning disability will also require some additional support from people who have expert knowledge about learning disabilities. Our teams **inter-relate** between individuals and the primary care services, providing specific support to help someone attend an appointment.

- To support this type of work NHS Surrey has enabled the Trust to employ dedicated Hospital Liaison Nurses (3wte) & GP Liaison Nurses (4wte). These nurses are learning disability experts who can help Hospital Services and GP Practices think about how they provide services to people who have a learning disability. The main aims of this service are:
 - To make sure the people who have learning disabilities (and their family carers) are well supported if they visit their GP or Acute Hospital, with consideration of their personal needs.
 - To raise awareness of the health needs of people who have a learning disability and provide awareness training as necessary.
 - To ensure that the rights of people who have a learning disability (especially with regard to the Mental Capacity Act and Human Rights Act) are supported within primary care services.
 - To ensure that GP services and hospitals have data that can show the number of people who have a learning disability who have been seen, and that they can undertake specific work (like physical health checks) to reduce health inequality.

A few people who have a learning disability will need significant support from specifically trained and experienced teams; this is where our services **interface** with primary health services so that particular support can be offered following referral from the GP.

- To support this type of work, we have community teams for people who have a learning disability (CTPLDs). These are multi-disciplinary teams containing Nurses, Consultant Psychiatrists, Occupational Therapists, Psychologists, Speech and Language Therapists, Art & Music Therapists & Physiotherapists, who have all been trained to support people who have a learning disability.

Our services all work in combination together to reduce the health inequalities for people who have a learning disability; this is illustrated by the case study below:

Ann, a 57 year old lady who has a learning disability and mental health needs, was referred to the learning disability acute liaison nurse following her admission to a Hospital after she had suffered a stroke. Following her timely discharge from hospital, the CTPLD continued to support Ann through direct interventions from Physiotherapy, Dietetics, Psychiatry and Speech and Language Therapists. This ensured that Ann was able to remain in her own home, supported by staff that she knew. Although her condition deteriorated, Ann was made comfortable due to ongoing work with the CTPLD, her GP, district nurses and the local hospice team to ensure that her needs were met. This included palliative care, and advice on postural management.

People who have learning disabilities are individual. For example, there may be 2 individuals who need a blood test, 'Ahmed' may need some joint work to plan the test, and ensure they are able to consent to the procedure through the provision of some easy read materials whilst 'Bettina' feels very anxious about the process and needs an significant preparatory clinical work to reduce her anxiety, following a best interests decision that she does need the blood test. In both instances SABP can help. For Ahmed, we would hope the GP practice makes use of the easy read information – and the GP may wish to call the liaison nurse for some brief advice. For Bettina, the situation may require a referral to our CTPLD who could offer some psychological and nursing interventions to reduce her anxiety. We work in partnership to provide effective person centred support that leads to better outcomes for every individual.

Supporting People in prisons

We are the first area of the Country to have a County-wide prison liaison nurse for people who have a learning disability. A National Report (no-one knows) has identified that 7% of the prison population may have a learning disability (compared to prevalence rates of 2% for the population as a whole). The aims of the prison liaison service are very similar to those of the hospital and GP liaison nurses. Our nurse works to raise awareness of the health needs of people who have a learning disability within prisons, and works with the prison healthcare teams and prison officers to enable them provide better services. He has developed easy read resource packs, provided training and implemented screening tools that effectively identify people who have a learning disability.

"The appointment of a learning disabilities lead nurse enhanced the prison's ability to identify prisoners with learning disabilities, and provided suitable care and treatment when required." *Government Inspection Report in a Surrey Prison.*

4.0 Summary

Liaison services provided by Surrey and Borders NHS Foundation Trust are innovative and have been followed elsewhere as a model of good practice. Our liaison nurses have been recipients of awards recognising the improvements they have made to patient care within acute hospitals. We are supporting primary health care providers to ensure equal treatment for people who have a learning disability. This programme of work continues and is demonstrating better outcomes for people who have a learning disability.

“Surrey and Borders Partnership NHS Foundation Trust and Surrey LD Partnership Board have developed an ‘Acute Hospitals Learning Disability Training Pack’ which contains information on working with people with learning disabilities, challenging behaviour, communication, consent, the legislation, and ‘best interests’ decisions. It contains protocols for the outpatients department and information to show how to make contact with the community learning disability teams who provide support.” *Extract from ‘Healthcare for All’ Independent Inquiry into the Access to Healthcare for People who have Learning Disabilities – Sir Jonathan Michael, July 2008, p.42.*

Andy Erskine
Director of Services for People with Learning Disabilities
November 2012

Appendix 1

Prevalence of Long Term Health Conditions for People who have Learning Disabilities

Some of the long-term health needs experienced by people with a learning disability include (but are not limited to):

- **Coronary Heart Disease:** Rates of CHD are increasing due to increased longevity and lifestyle changes associated with community living; it is now the 2nd most common cause of death for people who have learning disabilities.
 - Almost half of all people with Down's syndrome are affected by congenital heart problems, a much higher rate than the general population.
- **Dementia:** The prevalence of dementia is more than 3x higher amongst older adults with learning disabilities compared to the general population. People with Down's syndrome are at particularly high risk of developing dementia, with an age of onset 30-40 years younger than the general population.
- **Epilepsy:** The prevalence rate of epilepsy amongst people with learning disabilities has been reported as 22% compared to prevalence rates for the general population of 0.4%-1% (Chadwick, 1994).
- **Respiratory Disease:** Respiratory disease is the leading cause of death for people with learning disabilities occurring 3x more frequently than for people who do not have a learning disability.
- **Osteoporosis:** People with intellectual disabilities have substantially lower bone density than the general population (Aspray et al., 1998).
- **Thyroid Dysfunction:** Children and adults with Down's syndrome are at increased risk of thyroid dysfunction, particularly hypothyroidism, compared to the general population, with the incidence of thyroid dysfunction increasing with age.
- **Mental Ill Health:** estimates of prevalence of mental health problems vary from 25-40%, depending on the population sampled and the definitions used. Prevalence of anxiety and depression in people with learning disabilities is the same as the general population, yet for children and young people with a learning disability, the prevalence rate of a diagnosable psychiatric disorder is 36%, compared with 8% of those who do not have a learning disability.

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