

Healthy Ambitions for People with Learning Disabilities

September 2010

1. Introduction

This chapter (based on the work of the Learning Disabilities Clinical Pathway Group (CPG) – full report available at www.healthyambitions.co.uk) sets out what we need to do to make sure everyone with a learning disability can get the best care. An Easy Read version of the chapter is also available on the website.

2. Case for Change

People with learning disabilities:

- **are four times more likely to die of preventable causes than other people** - there is evidence of a significant level of avoidable suffering due to untreated ill health, and a high likelihood that avoidable deaths are occurring¹
- **are 58 times more likely to die before the age of 50 than other people** - it appears that life expectancy is shortest for those with the greatest support needs and the most complex and/or multiple conditions²; ... ethnicity is a salient factor with morbidity and mortality being higher amongst those with learning disability from a minority ethnic group³
- **do not have the same access to health services as other people** - ... the term 'institutional discrimination' does not seem too strong to describe what is happening in some quarters⁴
- **have higher levels of unmet need and receive less effective treatment than the rest of the population** - they are less likely to get standard evidence-based treatments and checks; less likely to be given pain relief, and less likely to receive palliative care - especially if from a minority ethnic group⁵
- **still encounter discrimination, abuse and neglect in health services** - the absence of understanding of individual needs, empathy for the situation in which individuals were placed, and a basic concern for them as people, led to prolonged suffering and inappropriate care⁶

In England approximately 2% of the population is estimated to have a learning disability, this would equate to approximately 103,000 people of all ages in our region.

Approximately 900 people with learning disabilities have their first assessment completed each year in Y&H. In the same period 14,000 people with learning disabilities received services provided, purchased or supported by Local Authorities, following a community care assessment. 79% (11,000) of people receiving services were provided with community based services. An estimated 1,800 (12.9%) of those receiving services were aged 65 and over.

¹ Healthcare for All - 2008

² Healthcare for All - 2008

³ Mir G, et al. Learning difficulties and ethnicity - 2004

⁴ Dr David Wolfe – Equal Treatment One year On - 2007

⁵ Healthcare for All - 2008

⁶ Ombudsman's Report 'Six Lives' - 2009

It is estimated there will be an 11% increase between 2001 and 2011 and a 14% increase between 2001 and 2021 in the numbers of people with learning disabilities known to learning disability services.

The Learning Disability CPG therefore established the following aims:

- To ensure that people with a learning disability have the same access to healthcare as everyone else, including getting the support they need to become and stay healthy
- To have a positive experience of receiving healthcare in both community and inpatient settings
- To have support from skilled learning disability specialist health professionals when they need or choose to access it
- To be safe in services commissioned or delivered by the NHS
- Not to die early from preventable causes

3. Key Recommendations

The key recommendations outlined in this section cover a number of important areas, starting with 4 key targets chosen to have maximum impact. The second recommendation covers the influencing of the other Healthy Ambitions pathways. The other recommendations follow the structure of the annual Performance and Self Assessment Framework for learning disability. This was piloted in Yorkshire and Humber, first completed in 2008 and the region is therefore in a unique position of being able to use this cumulative data to transform the healthcare of learning disabled people.

a) Key targets

- To ensure all relevant Primary Care stakeholders are building on the preliminary work undertaken as part of the DES and are working towards provision of robust data, which in turn will inform individualised care planning and service planning for people with learning disabilities
- To ensure acute care providers are able to evidence the steps they have taken to make 'reasonable adjustments' in order to suitably support and care for any person with a learning disability accessing their services
- To ensure the two previous targets are embedded within mainstream performance management, this will be achieved locally by:
 - i) Commissioners adopting the LD Self Assessment Framework as the tool to benchmark how these targets are progressing and where action is required
 - ii) Partnership Boards declaring to CQC statements on acute provider adjustments

- To ensure full engagement of all health agencies in Safeguarding Adult processes and lessons learnt

b) The Learning Disability Pathway should contribute to the development of all Healthy Ambition Pathways by:

- Identifying those parts of the pathways where planning and intervention is needed to ensure people with learning disabilities can receive equal or enhanced treatment. (Appendix 2 of the full CPG report available at www.healthyambitions.co.uk sets these out in detail for each pathway)
- Agreeing one or two outcome measures for each pathway which would demonstrate improved health of learning disabled people
- Assisting each Pathway Leadership Board with their Equality Impact Screening and assessment process
- Advising what LD specific information would be useful to collect and facilitating each Board's work by ensuring that key outputs are made accessible
- Gaining detailed knowledge of the Pathways and briefing Partnership Board colleagues and those on regional groups

The following areas or conditions have been highlighted as requiring further dedicated work in order to improve the health of people with learning disabilities:

- **People with profound or multiple learning disabilities** should be addressed by the Long Term Conditions Pathway but with significant/joint involvement of Learning Disability specialists. This care pathway should incorporate mobility and postural impairments as well as swallowing, respiratory and nutritional difficulties and sensory impairments
- **People with mental health problems** should be addressed by the Mental Health Pathway, with significant involvement of Learning Disability specialists
- **People who challenge** should be addressed by the Learning Disability Pathway, but with strong links to Mental Health, Autism, Offender Health Pathways
- **People with an offending profile** should be addressed by the Learning Disability Pathway
- **People with autism spectrum conditions** should be addressed by the Mental Health Pathway and Learning Disability specialists with a multiagency whole systems approach
- **Epilepsy** should be addressed by the Long Term Conditions Pathway. Best practice shows greatest benefit from Neurology leadership with input and support from Learning Disability specialists
- **Dementia** should be addressed by either the Mental Health Pathway or Learning Disability Pathway
- **People ageing with a learning disability** should be addressed by the whole system involving a number of Healthy Ambitions Pathways, including End of Life Care and Learning Disability specialist input

- **Health promotion activity including screening** should be addressed by the Staying Healthy Pathway with input from Learning Disability specialists

c) Meeting the DH target linked to hospital campus reprovion

- Existing plans for the resettlement of the remaining small numbers of people in campus accommodation need to be realised. All campus reprovion should be completed by the national target date of 2010

d) Addressing health inequalities: access to and experience of mainstream healthcare

- Further analysis is required in areas that demonstrate a wide variation such as completion of Healthy Action Plans and to bring clarity to interpretation of objectives e.g. safeguarding partnership working
- PCTs should ensure the information about people with LD and their health needs contained in GP registers is validated and cross referenced with social services
- GP practices should offer annual health checks and receive training to help them better understand people with learning disabilities. PCTs should consider introducing the Learning Disabilities DES and encouraging local GPs to adopt it
- Health Action Plans should be introduced in all areas, linked with Annual Health Checks and the information in both embedded in GP practice records with systems in place to ensure follow through
- Access to wider primary care services (e.g. dentists, pharmacists etc) should be improved building on existing regional best practice
- Priority should be given to improving key aspects of people's experience of acute care in the general hospital setting
- Localities should assess and meet the needs of minority ethnic groups with learning disabilities
- Particular attention needs to be paid to people with profound disabilities and their carers to identify them and their specific needs. Regional good practice in addressing these needs should be widely shared and adopted

e) Safety in both services commissioned and those delivered by NHS

- Learning from Healthcare Commission Investigation recommendations, Healthcare for All and the Ombudsman's report: Six Lives should be systematically applied in all areas
- NHS organisations and staff should understand the legal framework in which they are commissioning and delivering services
- A consistent approach needs to be developed across Trusts to adverse incident reporting, analysis thereof, and corresponding impact on practice
- Effective partnerships should be put in place across care sectors and local agencies to ensure a coherent approach to protecting people from abuse

f) Progress being made on Valuing People health objectives

- Good information and linked plans for people whose care is being commissioned from organisations out of area
- Better inclusive, person centred planning for young people in transition
- A comprehensive range of specialist learning disability services should be developed to support people at home, including those who challenge services
- Cross system approaches need to be developed to plan services for people with autistic spectrum conditions building on existing regional best practice
- Reasonable adjustments need to be made to improve admission, treatment, discharge and aftercare of learning disabled people with mental health problems
- Other groups that require specific attention (more details can be found in the full CPG report) are:
 - People who challenge services
 - People aging with a learning disability
 - People with profound and multiple disabilities

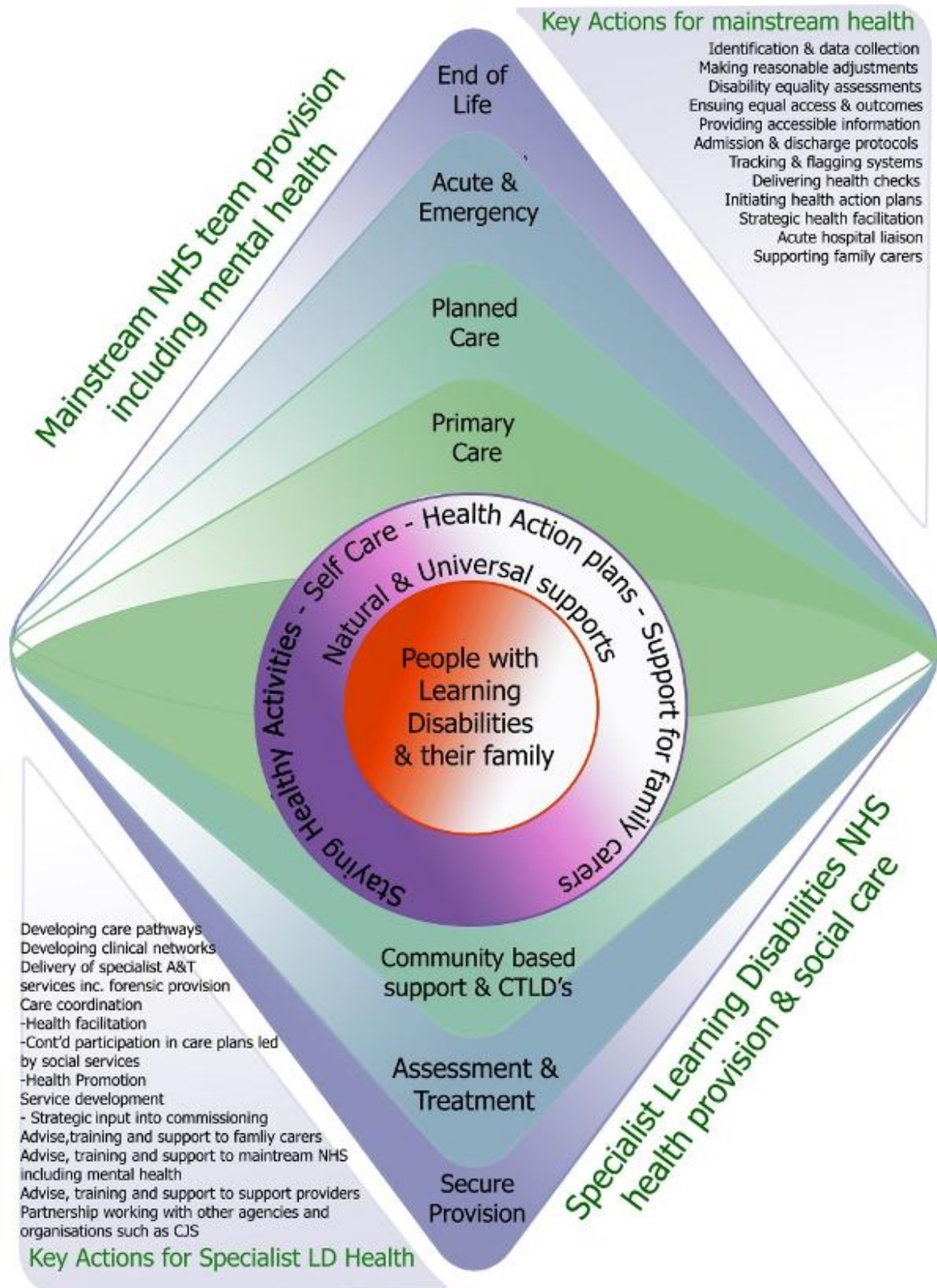
4. Learning Disability Service Model

Diagram 1 illustrates how placing people and their families firmly at the centre of healthcare delivery enables us to construct pathways to meet their needs. This includes regard for the wider determinants of good health such as housing, as well as more specialist interventions.

Helping people to develop healthy lifestyles, supporting self care and enabling them to make use of universal services such as leisure, are important building blocks for improving health outcomes. Furthermore such health promotion activities would represent a more productive use of resources in preventing significant morbidity and subsequent use of secondary services. One example is the inclusion of information on activities and exercise for learning disabled people and their carers in the “Active Leeds” initiative website.

Supporting the role of family carers and optimising their health and wellbeing is also a key objective.

Diagram 1 – Learning Disability Service Model



5. Specialist health support and interventions

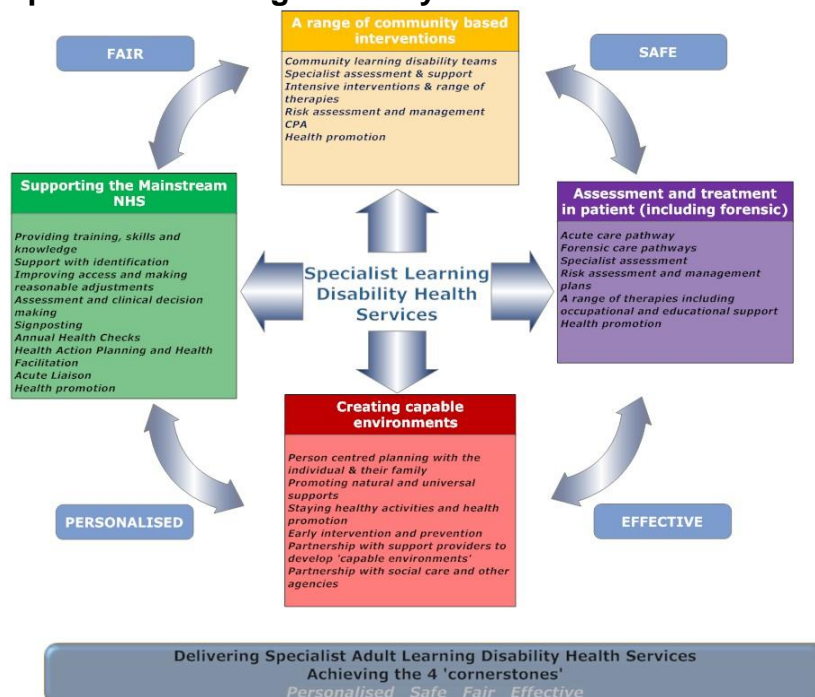
Specialist learning disability professionals provide expertise and knowledge throughout the whole healthcare system. As well as providing direct interventions they have a key role in enabling mainstream NHS and other agencies to provide inclusive services and create capable environments. It is a challenge to balance these direct and facilitative elements to make most effective use of the specialist resource. The more that mainstream services embrace inclusion, the more specialist resources will be available for direct work particularly in areas of unmet need e.g. the prison population.

The work of specialist learning disability health services can be seen to fall into four main areas (illustrated in Diagram 2 below). These are:

- Supporting the mainstream NHS
- Providing a range of community based interventions
- Assessment and treatment inpatient services including forensic
- Creating Capable Environments

Community interventions and inpatient services will vary across the region depending on local need and demand. They will however need to be set in the context of appropriate access to mainstream mental health services and a flexible range of social care provision. They also need defined pathways to ensure that inpatient services are only utilised after responsive intensive community interventions have been delivered. Local specialist services need to be equipped both to manage the care of people with complex needs returning from out-of-area placements and to prevent further out-of-area placements taking place.

Diagram 2 – Specialist learning disability health services



6. The Pathway in Practice

a) Information

Accurate and timely information will be the cornerstone of healthcare delivery in Yorkshire and Humber. This applies at all levels of the healthcare system.

- Developing accurate whole-system local registers
- Developing comprehensive local JSNAs
- Ongoing and evolving SHA annual self-assessment exercise
- Primary care to have up-to-date information on the health needs of the learning disabled people they serve
- Service user accessible information on healthcare systems and specific health issues to be widely available

b) Access

Healthcare for All outlines processes to ensure appropriate access to primary and secondary health services, especially acute care, with a focus on reasonable adjustments. The Healthy Ambitions pathway supports those processes and will support the various health care agencies in meeting the standards. The active involvement of Acute Trusts across the region is particularly crucial in meeting this recommendation. Specialist health services also need to be accessible and equitable according to need, with a single point of referral and no waiting lists.

c) Impact

The enhanced access to, and reasonable adjustments made by primary and secondary care health providers should make a difference in terms of avoidable deaths that can be monitored by the Public Health Observatory. Similarly the inclusion of specific learning disability targets in public health and health promotion initiatives should show reductions in some of the morbidities that are over-represented in the learning disabled population e.g. obesity and gastrointestinal cancers.

d) Involvement

Service user and carer involvement should continue to be embedded and strengthened in both individual and strategic decision-making.

All organisations should include the views of service users and carers in proactive and meaningful ways if they are to change or develop services which can effectively respond to, and meet the needs of the individuals with often complex and enduring needs.

e) Personalisation

The personalisation agenda should build on the advances made in person-centred planning to enable the delivery of individualised packages of health interventions for people with a learning disability.

Services should be developing the principles of person centred care and from this, be able to evidence how this is making a difference to people's lives, how they involve individuals in their own planning, and what actions they take to overcome exclusion and ensure positive outcomes for people.

f) Workforce

Commissioners will need to provide the appropriate support to realise the Healthy Ambitions objectives. This will require the continued commitment of healthcare staff with the right training to be able assess people's needs, facilitate reasonable adjustments and apply effectively the principles of personalised care.

Commissioners, provider organisations and academic establishments will need to work in partnership in order to assure we have effectively trained staff working across primary, secondary and acute healthcare settings and a workforce which is equipped to meet the future needs of people with learning disabilities.

This will include work with the faculties of medicine and GP training schools across the region to ensure our future medical staff are equipped to engage and respond the needs of people with learning disabilities.

Organisations should support workforce innovation and seek to invest in new ways of working in order to enable both new and extended roles to develop.

g) Pathway work

There needs to be agreement on the range of condition/needs based pathways to be developed. These should be commissioned and developed on an across-system and inter-agency basis. The balance of local and regional development of these pathways should be agreed. Some of this pathway work should be jointly facilitated with other Healthy Ambitions Pathways, for example the Mental Health, Long Term Conditions and Staying Healthy Pathways.

h) Specialist services

The role of specialist learning disability health services in facilitating access to primary and secondary services should reduce as those mainstream services make reasonable adjustments and access improves.

A tiered specialist learning disability healthcare assessment and treatment pathway should be in place within each locality, covering community and inpatient components. The pathway needs to promote delivery of care close to home and to include a range of alternatives to hospital admission.

Assessment and treatment inpatient services should be delivered to specified standards with clear admission and discharge criteria and measurable outcomes.

A specialist service pathway with community and inpatient components also needs to be in place for forensic services. This may need to be planned with mainstream forensic services and to cover more than one locality.

i) Inclusiveness

The Healthy Ambitions Learning Disability Pathway will be inclusive, paying particular regard to populations that have traditionally received patchy input e.g. learning disabled prisoners, those in out-of-area placements, those with developmental disorders (ASC/ADHD).

Creative and flexible partnership working will be essential to make progress with these groups, and finding new ways of engaging mainstream and specialist services to work much more closely, will be a central challenge of the work.

7. What patients want and need

The development of this document has been informed throughout by service users, self-advocates and carers as well as commissioners and clinicians. There have been a number of stakeholder workshops during the process to date. In addition the national documents Six Lives (2009) and Healthcare for All (2008) are drawn directly from the experiences of service users and carers who have contributed to and endorsed the recommendations made.

8. Good Practice

Appendix 1 of the full CPG report draws together good and innovative practice examples from around the region. These examples were put forward by localities in the 2009 self assessment exercise, collated into one document and distributed to all the localities thus sharing good practice. Specific areas of work being taken forward in a regional plan include access to acute care and standards for specialist services. The collection and dissemination of good practice will continue to be a major objective of the annual self assessment process.

9. What is required to achieve our objectives?

- Leadership will be required as will the need for a shared service ‘vision’
- Raised awareness of learning disability issues in mainstream practice, improved training and cultural change
- Clear commissioning responsibility and accountability
- External scrutiny and performance management of services
- A robust complaints process with service contestability
- Person-centred care planning embedded in service planning, delivery and monitoring
- Service user and carer involvement and communication
- Strong safeguarding of vulnerable people
- A clear role for the specific, rather than the universal, role of specialist learning disability services

10. Conclusion

This chapter sets out recommendations for improving the care of people with learning disability – it is important that it is considered by each organisation providing NHS care in Yorkshire and the Humber and that the recommendations for improvement are taken forward locally.