A Health Needs Assessment for Adults with a Learning Disability in Nottingham and Nottinghamshire

Executive summary

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September 2010

EXECUTIVE SUMMARY

In the last few years it has become increasingly recognised that people with learning disabilities experience many types of health inequalities. Improving the health and having a better understanding of the health needs of people with learning disabilities is now a high priority.

The aim of this Health Needs Assessment is to systematically assess the health needs of adults with learning disabilities across Nottinghamshire (including Nottingham City and Bassetlaw), review the evidence base for health need and effectiveness of services, identify gaps in current service provision and make recommendations for changes to meet their needs and reduce the health inequalities experienced by this population group.

Introduction

Learning disability is diagnosed if there is evidence of significant cognitive impairment and impairment in adaptive functioning, with both present before the age of 18. The causes of learning disability are varied and can arise at conception, during pregnancy or labour or after birth. Risk factors for developing a learning disability include being male, socioeconomic deprivation and being of South Asian ethnicity. There are a number of primary prevention interventions that can reduce the incidence of learning disabilities.

Policy context

In recent years many national policies and best practice documents have been published that highlight the health needs of adults with learning disabilities and provide examples of when adults with learning disabilities have experienced poor care in the NHS. There is joint working across NHS Nottinghamshire County, NHS Nottingham City and NHS Bassetlaw and also Nottinghamshire County Council and Nottingham City Council to improve the health of adults with a learning disability. Joint commissioning takes place locally to implement recommendations made in national documents. Leadership and governance are provided through the Learning Disability Partnership Boards and Joint Commissioning Groups. Regular performance monitoring is undertaken by both the Strategic Health Authority and the Commission for Quality Care on aspects related to the health of people with learning disability.

Health needs

The evidence base regarding the nature and scale of health needs and strategies for addressing inequalities is small due to the lack of high quality research for this population group. A review identified that adults with learning disabilities experience health inequalities and compared to the general population have:

- lower life expectancy
- different causes of death

- higher levels of unrecognised and unmet physical and mental health needs
- barriers to accessing health services
- communication disabilities
- different lifestyle and environment issues
- different patterns of health need and more complex health needs
- difficulties accessing end of life care that meets specific needs

Effectiveness of services

There are significant gaps in the evidence base looking at the effectiveness of health services for people with learning disability. The literature evaluating services and interventions for adults with learning disabilities at all levels of care is mainly limited to descriptive and uncontrolled research studies. The evidence was reviewed using a tiered approach as a framework.

- Tier 0: Community-based support and healthy lifestyle initiatives
- Tier 1: Primary healthcare services
- Tier 2: Generic secondary health services
- Tier 3: Specialist learning disability services
- Tier 4: Supra-specialist learning disability services

The review of evidence identified that:

- Improving the effectiveness of services within tiers 0-1 will reduce reliance on specialised services, and give the greatest impact on health outcomes.
- The disproportionately high use of secondary care services by those with learning disability may be reduced by more effective interventions in primary care.
- There have been significant changes in healthcare provision for people with learning disabilities in recent years, including the shift from institutional to personalised community care that has led to a greater demand for community health services.
- Insufficient local specialised services for people with complex health and behavioural needs tends to be the primary reason for out of area placements.

Epidemiology

Due to difficulties in diagnosing and recording learning disabilities, precise prevalence and incidence figures are not available. Best estimates suggest that approximately 2% of the UK population has a learning disability, with a quarter of these in contact with specialist services. There is projected to be a 20% increase in prevalence of learning disabilities between 2001 and 2021 in the UK, with a 53% increase in those aged over 50. Consequently adults with learning disabilities are developing diseases associated with age such as dementia. In Nottinghamshire (including Bassetlaw and Nottingham City) there are estimated to be 20,603 adults with learning disabilities, of these 4,293 have moderate and severe learning disabilities and 336 have profound multiple learning disabilities.

Adults known to general practice

GP practices have a learning disability register as part of the Quality and Outcomes Framework (QOF). The age-specific prevalence of adults with learning disabilities recorded on GP QOF registers is similar across NHS Nottinghamshire County (0.40%), NHS Bassetlaw (0.47%) and NHS Nottingham City (0.42%). Overall, QOF learning disability registers currently only record approximately one fifth of the expected total number of adults with learning disabilities. In addition, there is much practice- and cluster-level variation in the recorded prevalence of adults with a learning disability on GP practice QOF registers.

Adults known to local authority Adult Social Care Services

There are higher rates of adults with learning disabilities in NHS Nottinghamshire County and NHS Bassetlaw than in NHS Nottingham City. The age profile is similar in the three PCTs, with the majority of adults with learning disabilities aged between 18 and 59 years old. There is a ratio of 1.41 adult males: 1 adult female with a learning disability. Rates by ward varied from 0 to 14.5 adults with learning disabilities per 1,000 population, with the population distribution closely mirroring the distribution of registered care homes for adults with learning disabilities.

Adults known to Nottinghamshire Healthcare Trust

The majority of adults known to Nottinghamshire Healthcare Trust (NHCT) learning disability services are aged 20-59 years. There is a ratio of 1.35 adult males: 1 adult female and the ethnicity profile of the learning disability population known to NHCT is very similar to the general population.

Pattern of health need and use

Primary care: Lifestyle issues

It has not been possible to obtain information on the levels of obesity, physical activity undertaken or alcohol consumed by adults with learning disabilities in Nottinghamshire; however smoking rates appear to be much lower in adults with learning disabilities in Nottinghamshire than the general population. A Health Equity Audit is to be undertaken and additional information will be available in the near future.

Primary care: Screening Programmes

A lower proportion of eligible women with learning disabilities known to adult social care services attend breast screening appointments than the general population. In NHS Nottinghamshire County and NHS Nottingham City this is due to women not attending having been invited, however in NHS Bassetlaw

there is a higher proportion of eligible women with learning disabilities that are not invited for screening.

A much lower proportion of adults with learning disabilities known to adult social care services have participated in the bowel cancel screening programme.

Women with a learning disability known to adult social care services have a lower uptake of cervical screening. In addition, there are much higher rates of eligible women with a learning disability known to adult social care services that have been *ceased* from the screening programme and are not included in the call/recall process.

Secondary care

Admission rates to secondary healthcare are 20% - 40% higher for adults with learning disabilities known to adult social care services than the general population, with significantly higher rates for elective and emergency admissions than the general population, but significantly lower rates for maternity-related admissions. The median length of stay for adults with learning disabilities known to adult social care services is higher than the general population. They are significantly more likely to be admitted for epilepsy, schizophrenia, an oral health condition, a mental health condition, diabetes and a hearing problem than the general adult population and significantly less likely to be admitted than the general adult population for cancer, coronary heart disease, respiratory disease and gastro-intestinal disorders.

Adults with learning disabilities known to adult social care services have significantly higher attendance rates at out-patient clinics than the general population, ranging from 40% higher in NHS Nottinghamshire County and NHS Bassetlaw to 220% higher in NHS Nottingham City. Out-patient attendance rates were significantly higher for adults with learning disabilities known to adult social care services in NHS Nottingham City than NHS Nottinghamshire County and NHS Bassetlaw. Adults with learning disabilities known to adult social care services had significantly higher attendance rates than the general population for the following specialities: neurology, audiological medicine, oral surgery, rehabilitation, orthodontics, maxillo-facial surgery and mental illness and significantly lower attendance rates than the general population for the following specialities: old age psychiatry, obstetrics, clinical oncology, gynaecology, dermatology, rheumatology and general surgery.

Adults with learning disabilities known to adult social care services have significantly higher attendance rates at Accident and Emergency (A&E) than the general population and were significantly more likely to attend at A&E for a number of conditions, including cerebro-vascular conditions, psychiatric conditions, contusion/abrasions and gastro-intestinal disorders. They were

significantly more likely than the general population to have their reason for attendance coded as nothing abnormal detected, the diagnosis code left blank or as diagnosis not classifiable.

Due to the small number of clusters and smaller population sizes of cluster populations there are very few significant differences in admission and attendance rates between clusters in NHS Bassetlaw and NHS Nottingham City when compared to the overall PCT rate. In NHS Nottinghamshire County, the clusters in the north of the county had higher use of secondary care services than the clusters in the south of the county.

Life expectancy

The age profiles of adults with learning disabilities known to Adult Social Care services in Nottinghamshire suggest a shorter life expectancy than the general population. An analysis of death certificates demonstrated a median age of death of 56 years for adults with learning disabilities recorded on the death certificate, compared to 80 years for individuals with death certificates that did not record learning disabilities. Pneumonia was the most common cause of death in individuals with learning disabilities mentioned on the death certificate, followed by aspiration pneumonia and cardio-respiratory failure.

Current services for adults with learning disabilities in Nottinghamshire

Primary prevention initiatives are in place, but it is unclear how these are targeted particularly to high risk groups. There are relatively few specific health improvement projects for adults with learning disabilities and it is uncertain as to how many adults with learning disabilities access generic health improvement projects.

Tier 1: Primary care

All GP practices in Nottinghamshire have a register of adults with a learning disability. All practices in NHS Bassetlaw and just under 90% of GP practices in NHS Nottingham City and NHS Nottinghamshire County have signed up to deliver annual health checks for those who are eligible through the Learning Disability Directed Enhanced Service (DES). The total number of health checks that have been delivered and their quality is still unknown. All three PCT's have primary healthcare facilitators in post that support provision of health care for adults with learning disability in primary care.

Tier 2: Secondary care

There are currently no proactive mechanisms in place at acute hospitals to identify patients with learning disabilities. In order to improve the care of adults with learning disabilities in secondary care, both Nottingham University Hospitals Trust and Sherwood Forest Hospitals Trust have acute liaison nurses to support adults with learning disabilities during their hospital visit or

stay. There is currently no acute liaison nurse for Bassetlaw District General Hospital.

Tier 3: Specialist services
Specialist services respond to the health needs directly relating to or arising from an individual's learning disability and include community and in-patient services. Similar specialist services are provided across the three PCTs, including integrated community learning disability teams and local authority day services. There are Assessment and Treatment beds for those with mental illness, sensory impairments or challenging behaviour and Community Assessment and Treatment Teams to support people close to home for all three PCT areas. There is some variation in activity levels of specialist learning disability services between the PCTs.

Across all tiers
Health action plans enable people with learning disabilities, with the support of health professionals, to identify their health needs and record the actions needed and the services required to maintain and improve their health. Health Action Plans are available to adults with learning disabilities in Nottinghamshire, although the total number of adults with a health action plan is unknown.

Although there is an agreed list of 400 symbols to support everyday words for adults with learning disability in Nottinghamshire, these are not used consistently across all organisations or the Learning Disability Partnership Boards.

Corporate views
Consultation undertaken in 2009 as part of the NHS East Midlands Performance and Self Assessment Framework with adults with learning disabilities and their families/carers, and interviews with key individuals as part of the Health Needs Assessment has identified:

- primary care and hospital services do not provide the support that adults with learning disabilities require
- poor access to certain services, such as dentists
- training issues for staff
- transition between children and adults services are poor
- information on enquiries and complaints from adults with learning disabilities and/or their families and carers is not routinely available

Comparative assessment
When comparing the Regional Performance and Self Assessment Framework completed by the three PCT's in Nottinghamshire to others in the East Midlands and Yorkshire and Humber regions they compare favourably for campus re-provision, being safe in NHS services and meeting the Valuing People Now recommendations. They do however compare less favourably

with other NHS organisations on provision and quality of primary and acute hospital health services for adults with learning disabilities.

Gaps and recommendations

Recommendations have been made to cover the whole of the health system. It is however acknowledged that there are pockets of high quality care that some teams are already delivering which is over and above the recommendations made.

The findings of this Health Needs Assessment have been reviewed by Nottinghamshire County and Nottingham City Learning Disability Partnership Boards, Joint Commissioning Groups and the Better Health group.

The Better Health Group is tasked with developing an action plan based on the findings of this Health Needs Assessment to further improve the health of adults with learning disabilities that live in Nottinghamshire, and reduce the health inequalities they currently experience.

Further gaps and recommendations are detailed in the table on pages 8-17.

Acknowledgements

The authors would like to thank everyone who has provided advice and specialist knowledge in the development of this report, in particular Dr Stephanie Hammond, Information Analyst at NHS Nottingham City for the provision of data and support in its analysis.

Health Needs Assessment: Gaps and Recommendations

GAPS	RECOMMENDATIONS
Strategy/Policy	
• There is no process locally to systematically identify and implement national policy documents relating to learning disability.	• Ensure suitable processes are in place locally to strategically take forward national policy documents.
• Corporate strategies and plans of PCTs would benefit from considering and emphasising the health needs of adults with learning disabilities and the impact that improving the health of this population group can have in reducing the health inequality gap.	• The Learning Disability Partnership Boards with support from the Better Health group should influence PCT corporate strategies to raise the profile of health issues for adults with learning disabilities, address ways to tackle those conditions that cause premature death in this population group, and support work to tackle inequalities in health.
• The health needs of adults with learning disabilities in Nottinghamshire are not adequately reflected in both the Joint Strategic Needs Assessments (JSNAs).	• Information on the health needs of adults with learning disabilities in Nottinghamshire should be included in the Joint Strategic Needs Assessments. • Joint commissioning strategies and plans should be developed and updated to reflect the health needs for adults with learning disabilities (taking into account national strategies and local current and projected need) and their implementation regularly monitored and reviewed. • Joint commissioning groups should ensure that plans are in place to meet the needs of: - increasing numbers of adults with learning disabilities. - increasing numbers of older adults with learning disabilities. - those coming through transition.

GAPS	RECOMMENDATIONS
• Reports on the health of adults with learning disability have not been presented regularly at the Learning Disability Partnership Boards.	• Regular reports on health issues and the work of the Better Health group should be presented at Learning Disability Partnership Boards meetings.
• Performance management is currently not reviewed at Learning Disability Joint/Strategic Commissioning Groups.	• Performance of providers should be reviewed at Learning Disability Joint/Strategic Commissioning Groups.
Identification and recording of adults with learning disability	
• The prevalence of learning disability on practice Quality and Outcome Framework (QoF) learning disability registers is lower than expected and may be due to under-identification and/or under- reporting.	• Primary care should be encouraged to identify and record people with learning disability across the whole learning disability spectrum to improve the completeness and quality of the registers. • Local authority data should be used to identify those practices that under-report adults with moderate and severe learning disabilities and these practices should be prioritised for support.
• There is limited knowledge on the health needs of adults with learning disabilities from Black and minority ethnic communities, older people and those with profound and multiple learning disabilities.	• Primary care, secondary care and specialist services need to record severity of learning disability. • Primary care data on ethnicity should be reviewed. • Analysis of data is required to improve knowledge of the healthcare needs and treatment for those within Black and minority ethnic communities, older people and those with profound and multiple learning disabilities.

GAPS	RECOMMENDATIONS
• There is currently little information on the health needs of adults with mild learning disability in Nottinghamshire	• Improved recording of severity of learning disability in primary care is required to further understand the health needs of those with mild learning disabilities.
• For most health teams there is no mechanism to identify children coming through transition from children to adult health services.	• There should be improvement in and better management of continuity and co-ordination of care at transition between children and adult health services. Mechanisms need to be in place to identify children coming through transition from children to adult services to ensure they are recorded on learning disability registers.
• There are currently no processes in place locally to identify those adults that come into contact with the criminal justice system.	• Systems need to be put in place locally to improve the identification and services provided for those adults with learning disability in the criminal justice system to ensure that their needs are recognised and met.
• Learning disability is not always used as a sub-diagnosis in secondary care and on death certificates making analysis of patterns of healthcare use incomplete.	• Improving the recording of learning disability as a sub-diagnosis in secondary care coding and on death certificates will improve understanding in the health needs of adults with learning disabilities.
Reducing incidence of learning disability	
• Although there are prevention measures to reduce the incidence of learning disability it is unclear how these are targeted, particularly to high risk groups.	• Prevention measures should be encouraged and targeted at those with a higher risk of having a child with a condition that is associated with learning disability. These include: • genetic counselling, including education on the risks of consanguinity

GAPS	RECOMMENDATIONS
	• screening (in pregnancy and in the first few days of life) and diagnostic tests (that meet national standards) • immunisation for rubella and measles • programmes to reduce alcohol consumption of women of child bearing age • folic acid supplementation
Healthy lifestyle initiatives	
• There are few specific healthy lifestyle initiatives for this population group and very little information on the numbers of adults with learning disabilities accessing lifestyle interventions.	• Ensure that all services promote the opportunity for healthy lifestyles for adults with learning disability. • Ensure that all PCT commissioned lifestyle interventions (such as weight management and exercise referral schemes) are accessible to adults with learning disabilities and that this population group have comparable outcomes to the general population. • Equality Impact Assessments should be completed for all services and monitored regularly.
Primary care	
• Not all GP practices across Nottinghamshire provide annual health checks to those adults with moderate to severe learning disability.	• All GP practices should be encouraged to provide annual health checks through participation in the Learning Disability Directed Enhanced Service. • Alternative providers should be commissioned to provide annual health checks for those patients whose GP practice is

GAPS	RECOMMENDATIONS
	not participating in the Directed Enhanced Service. • The quality of health checks should be monitored.
• It is currently not known how many of those adults with learning disabilities who are eligible for an annual health check are accessing this, the quality of the health checks offered and the physical / mental health outcomes.	• Systems should be set up to ensure regular monitoring of the numbers of people accessing an annual health check. • A health equity audit should be conducted to identify any inequalities that there are in the provision of primary care services for adults with learning disability.
• A lower proportion of eligible adults with learning disabilities are participating in cancer screening programmes than the general population.	• Ensure that all eligible women with learning disabilities are offered and supported to attend breast screening and cervical screening. • Adults with learning disabilities should be encouraged and supported to take part in the bowel cancer screening programme. • The reasons why adults with learning disabilities are not being invited to participate in cancer screening programmes and why, if they are, they do not attend or participate needs to be better understood. • The higher rates of women with learning disabilities who are ceased from the cervical screening programme should be explored further to determine whether individuals are being ceased appropriately or not.
• There is currently lack of evidence of the effectiveness of primary care health facilitators in improving the health outcomes of people with learning disability in primary care.	• Commissioners should ensure that there are robust service specifications in place for primary healthcare facilitators that include agreed health outcomes.

GAPS	RECOMMENDATIONS
	• An evaluation of the effectiveness of primary care health facilitators in supporting the health needs of adults with learning disability in primary care should be undertaken.
Secondary care	
• There are currently no mechanisms in place at acute hospitals to proactively identify adults with a learning disability to ensure that pathways of care are reasonably adjusted to meet the health needs of these patients.	• Systems should be put in place to proactively identify patients with a learning disability who enter acute hospital trusts so that reasonable adjustments are put in place to meet their health needs.
• All hospitals in Nottinghamshire need to ensure that suitable level of quality of care is provided to adults with learning disabilities, including the provision of reasonable adjustments.	• Quality Panels should develop processes to inform relevant groups on the progress of acute hospitals in meeting the quality schedule measures. • The quality schedule measures should be reviewed annually to encourage continued service improvement. • All hospitals should have an acute liaison nurse in post to support adults with learning disabilities during their hospital care. • Commissioners should ensure that there are robust service specifications in place for acute liaison nurse services that include agreed health outcomes. • An evaluation of the effectiveness of acute liaison nurses in supporting the health needs of adults with learning disability in secondary care should be undertaken.

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• The appropriateness of acute admissions (including the lengths of stay) and attendances is unclear.	• Further work should be undertaken to review for adults with learning disabilities: ▪ the appropriateness of higher rates of secondary care admissions and attendances. ▪ the appropriateness of longer lengths of stay. ▪ difference between clusters in secondary healthcare use. ▪ reasons for higher rates of *nothing abnormal detected, diagnosis not classifiable and diagnosis code left blank* in Accident and Emergency attendances.
Specialist services	
• The impact that specialist services have on the health outcomes of adults with learning disabilities is unclear.	• Scope health improvement programmes currently occurring in specialist Learning Disability services. • Commissioners should ensure that there are robust service specifications for all specialist learning disability services that include agreed health outcomes measures.
• Further information is required on specialist services provided to adults with learning disabilities in each PCT.	• The monthly dataset provided by Nottinghamshire Healthcare Trust should be regularly analysed to monitor provision of specialist services within each PCT, and also to review patient pathways within the specialist services.
• There is limited information and understanding about out-of-area placements for adults with learning disabilities.	• Out-of-area placements should be mapped initially and, where possible, reviewed regularly to support future service

GAPS	RECOMMENDATIONS
	planning and commissioning of services, in particular to support these individuals nearer to home.
• Current service provision may not be sufficient to meet the increasing numbers of adults with learning disabilities in the future.	• Plans need to be in place to consider the increased numbers of adults and older adults with learning disabilities in the future.
Across all tiers	
Health action plans • The number of adults with learning disabilities that have a health action plan is currently not known.	• Systems should be put in place to monitor the number of adults who have a health action plan in Nottinghamshire.
• Health action plans are currently not being used effectively as a tool to either inform different services of a person's health needs or to help to inform future commissioning strategies.	• All adults with learning disabilities should be offered the opportunity to have a health action plan • Health action plans need to be promoted as the mechanism to enable all services/providers to be aware of an individual's health needs for all who come into contact with that person with a learning disability, particularly engagement of primary care in health action planning as part of person-centred planning. • Processes should be put in place to monitor what is being reported in health action plans to inform both the JSNA and commissioning strategies.
Dental services • Poor experiences of dental services both in the community	• Commissioners and providers should consider how to ensure

GAPS	RECOMMENDATIONS
and acute hospitals are reported.	optimal opportunities for oral health promotion and improve access to dental services and the quality of care provided. • The Special Care Dentistry Strategy should be implemented.
Complaints • For most health organisations there is very little information on the number of and types of complaints made by people with learning disabilities and their families/carers.	• Systems should be in place to enable people with learning disability to complain about health services. • Health organisations should be able to identify complaints from people with a learning disability or their families/carers. • Service specifications should specify that providers report on complaints made by adults with learning disabilities and their carers. • Complaints made by or on behalf of adults with a learning disability should be reviewed at Joint Commissioning Groups.
Patient and Public Involvement • More in-depth views and experiences of people with learning disabilities and their carers in relation to access to health care are needed to shape services in the future.	• Patient engagement and involvement with people with learning disabilities and their families should be ongoing to shape the services that are commissioned.
Training and Workforce Development • The awareness and knowledge of primary and secondary health care staff have of the issues for people with learning	• Learning disability awareness should be part of Equality and Diversity training in all organisations across Nottinghamshire.

GAPS	RECOMMENDATIONS
disabilities is currently low.	• Frontline staff should be offered training on learning disability awareness and have the skills to meet the health needs of people with learning disabilities to enable them to have a much greater understanding and awareness of the health needs of people with learning disability.
Clinical pathways • It is unknown if local clinical pathways effectively consider the needs of people with learning disabilities.	• All new clinical pathways developed should have an Equality Impact Assessment completed to ensure that any adverse impact that it may have on people with learning disabilities is considered.
End of Life • It is unclear if the needs of adults with learning disabilities at the end of life are being met	• Further work is needed to quantify and define the end of life care required for adults with learning disabilities.
Communication • There is no consistency in the use of aids to communicate with adults with learning disabilities across all organisations in Nottinghamshire.	• Whilst acknowledging that individuals with learning disabilities will have different ways of communication, to ensure consistency in communication across all organisations in Nottinghamshire an agreed set of symbols/system should be used.
Transition • Transition between primary and secondary healthcare services is reported to be poor at times.	• There should be an improvement in and better management of continuity and co-ordination of care at transition between primary and secondary care, especially for those with the greatest support needs.

GAPS	RECOMMENDATIONS
	• Implementation of Summary Care Records may assist in the sharing of information between primary and secondary care.
Safeguarding adults • The effectiveness of systems that are in place to ensure that adults with learning disabilities are safe when they access and use health services is unclear.	• The Nottinghamshire Six Lives Action Plan should be implemented to ensure that adults with learning disabilities have equity of access to health services and are safe in them.
Equitable access to health services • It is unclear if there is equitable access to all health services for adults with learning disabilities.	• All service specifications should state that health services must be accessible. An Equality Impact Assessment should be completed on all service specifications and services to ensure that any adverse impact that it may have on people with learning disabilities has been considered. • Health equity audits for both primary care and specialist services should be undertaken.
Improvement across all health services • The SHA Performance and Self-assessment Framework has identified gaps in health services.	• Each PCT should implement the action plan as required by the East Midlands Performance and Self-assessment Framework to ensure continuing improvement in health services for adults with learning disabilities.