Learning disabilities and autism:
A health needs assessment for children and adults in Cheshire and Merseyside

Jane Harris, Hannah Madden, Janet Ubido, Jane Oyston
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Introduction

• People with learning disabilities (LD) and autism are a diverse population with differing needs

• One of the most vulnerable groups in society frequently experiencing health inequalities, social exclusion and stigmatisation

• Health needs assessment for Cheshire and Merseyside commissioned by NHS England (Oct-Dec 2015) to determine health and wellbeing needs of people with learning disabilities in Cheshire and Merseyside
Aims and Objectives

To determine the **health and wellbeing needs** of people with learning disabilities and autism living in Cheshire and Merseyside by providing accurate data to inform the Transforming Care work programme and provide a set of evidence based recommendations for commissioners

- Describe the **size and characteristics** of the population
- Assess evidence on **health and wider wellbeing needs**
- Detail data on **service provision and use**

**Methods:** combined data from published sources (IHAL, PANSI, ONS, HSCIC, QOF etc.) with data provided by local authorities, CCGs and providers across Cheshire and Merseyside
How many adults have learning disabilities and autism across Cheshire and Merseyside?

- True prevalence estimates (PANSI): 12,012
- Known to local authority (ASCCAR): 7,775

Conflicting numbers:
- ASCCAR
- Local Authorities
- GP QOF
- SAF
How many adults have learning disabilities and autism across Cheshire and Merseyside?

- True prevalence estimates (PANSI): 35,896
- Known to local authority (ASCCAR): 12,012
- GP Learning disability register (QOF):
  - Autism: 14,578
  - Asperger’s: 7,775
  - PMLD: ?

Legend:
- True prevalence estimates (PANSI)
- GP Learning disability register (QOF)
- Known to local authority (ASCCAR)
How many children have learning disabilities and autism across Cheshire and Merseyside?

12,590 Children expected to have Learning Difficulties (IHAL, School Census)
10,800 Children with learning disabilities (SAF)
5,488 Autism
1,524

Definitions: Learning Disability vs learning difficulty
Recommendations: Data

Ensure that all health and social care data related to Learning Disability becomes more co-ordinated and systematic:

- Ensure systems allow for the sharing of data across local authority and GP systems so the needs of adults and children with learning disabilities and ASD can be truly quantified.

- Establish consistent definitions: learning disability among children, PMLD.

- Improve recording and availability across GP and LA data of age group, ethnicity, employment, accommodation and parental status and health and lifestyle data (e.g. BMI, smoking, screening).

- Consider a separate needs assessment to address some of the gaps in knowledge for those with ASD particularly Asperger’s.
Health of people with Learning Disabilities and Autism

People with learning disabilities and autism can face a number of challenges in using health services including:

• Understanding literature they have been given
• Keeping appointments
• Following treatment regimes

Therefore, important health care services identify those with learning disabilities and autism so they can make reasonable adjustments to their care
Health of people with Learning Disabilities and Autism

Available data suggests that in Cheshire and Merseyside:

• Higher proportions of adults with learning disabilities are obese compared with national average
• Rates of epilepsy are high (in line with national trends)
• Asthma, Dysphagia and Coronary Heart Disease (CHD) were also common

Health check participation and uptake is significantly higher than the national average however:

• Higher rates of women with learning disability refuse cervical screening compared with the general population
• Breast cancer screening uptake also lower (although higher than cervical screening uptake)
• Bowel cancer screening uptake has increased and in some areas is now higher than in the general population

• National studies suggest higher prevalence of dementia, hearing and sight impairment, pain and sleep impairment but local data on this was not available
• Data is not available on coverage of SRE for adults with learning disabilities
Recommendations:

• Continue to promote annual health check to achieve and maintain the 90% uptake target (IHAT, 2012)

• CCGs should work with PHE to ensure appropriate support is offered to adults with learning disabilities to improve access to screening

• Ensure quality indicators for acute trusts relate to the needs of patients with learning disabilities and that there is a senior person (e.g. acute liaison nurse) responsible for making reasonable adjustments to meet these needs

• Notify GPs and community learning disability teams when patients are admitted with an ACSC

• Develop SRE policy for learning disabilities for schools, adult and children’s services in collaboration with CCG healthcare staff

• Focus mortality prevention strategies on areas where deaths are more avoidable e.g. pneumonia, seizures, CHD and accidental deaths
Social profile of people with Learning Disabilities and Autism

People with learning disabilities do not just face problems with healthcare but face other wider inequalities:

- **Housing**: Proportion (86%) of adults living in settled accommodation (own home or with family) is higher than the national average (76%). Currently no data on housing quality
- **Community service** provision was higher than the national average (82%) in the majority of local authorities with the exception of Sefton (73%) and St Helens (76%).
- **Referrals** for abuse of vulnerable adults are higher than the national average in 7 of 9 local authorities. The largest proportion of referrals (38%) were made for physical abuse
- Data on **parental status** is not routinely available (4 out of 9 local authorities)
- **Employment** levels are below the national average in 7 out of 9 local authorities
Recommendations:

• Review the quality of housing for people with learning disabilities
• Ensure that all services are actively working to reduce social isolation
• Where a parent has learning disabilities provide collaborative support between children and adult services to enable children to live with their parents (where consistent with their welfare) through equal access to services, parenting support, information and support through any court processes
• Enable pooling of resources to support people in secure accommodation to return back to community placements (where appropriate) in their home borough
• Consider routine screening and reasonable adjustments for learning disabilities in prisons
• Improve awareness among individuals, service providers and criminal justice professionals of appropriate safeguarding referrals and hate crime
• Improve employer awareness of learning disabilities for example through making job interviews more accessible and assistance understanding the unwritten rules of the work place
Service provision for learning disabilities in Cheshire and Merseyside

- Approximately 1,500-2000 people on the case load at each service
- Roughly 3/5 clients are male and majority aged 21-60 years and of white ethnicity
- Mersey Care and CWP had approx. 3,500 referrals over 3 year period whilst 5BP had just under 2,000
- Majority of referrals were made by GPs
- Mersey Care and CWP had roughly 30,000 contacts in last year of which two third were seen face to face and just under one in ten were unsuccessful. At 5BP, there were 17,000 contacts
- Majority of discharges for all three providers were made on medical/professional advice
Conclusion

44 recommendations across four areas: empowering individuals, right care in the right place, workforce development and data.

Limitations: 2.5 months; routinely collected and readily available data

Monitoring and quality: standard information set for future JSNAs

Key gaps:
• Autism and Asperger’s
• Profound and Multiple Learning Disability
• Children: in particular the transition from children to adults services
Contact details:

Jane Harris
Intelligence and Surveillance Research Manager
Centre for Public Health
Liverpool John Moores University
0151 231 4506
j.harris1@ljmu.ac.uk