

Protocol for Access to health care for people with learning disabilities: a systematic mapping review and targeted systematic review

Anna Cantrell, Liz Croot, Andrew Booth, Maxine Johnson and Ruth Wong – April 2018

Overview

- This work has been commissioned to provide HS&DR with an independent review of research in this area to inform strategic decision-making and service design.
- The objective is to identify, appraise and synthesise published research (including 'grey literature') on access to health care for people with learning disabilities including barriers to their access and interventions or models of service provision that improve access to health services for people with learning disabilities.
- We will include studies about access to health services for people with learning disabilities and/or their carers.
- We will provide a mapping review which will then inform the scope of the systematic review.

Background

In 2015 it was estimated that 2.16% of the adult population living in England have learning disabilities (Hatton et al., 2016). People with learning disabilities face significant health inequalities (Brown et al 2010; Emerson & Baines 2010). These include disparities in the presence of disease (Straetmans et al., 2007), access to healthcare (Michael & Richardson., 2008), use of healthcare services (Starling et al., 2006) and health outcomes (Department of Health, 2001). Life expectancy of people with learning disabilities remains significantly lower than that of the general population (Tyrrer and McGrother., 2009). The volume of enquiry into the access and utilisation of services by people with learning disabilities is growing (e.g. Emerson et al., 2012).

However, there are still gaps in our understanding of the specific obstacles that people with learning disabilities and their carers face in accessing healthcare services.

People with learning disabilities are less likely to be able to access uniformly delivered health interventions (Allerton and Emerson., 2012). Public bodies have a legal duty to make `reasonable adjustments' to policies and practices to provide fair access and treatment for people with learning disabilities (Equality Act 2010) however primary care services are often inaccessible to people with learning disabilities because they have not put into place effective adjustments to address this. This review will examine the evidence about quality of access to primary health care services for people with learning disabilities.

Definitions

Learning disability has been defined as a significantly reduced ability to understand new or complex information and to learn new skills, along with a reduced ability to cope independently where this disability starts before adulthood, with a lasting effect on development (Department of Health, 2001). However in practice studies may recruit participants on the basis that they are known to statutory service providers. People with severe learning disabilities are likely to be known to service providers however some people with mild learning disabilities may prefer to avoid the stigma of this label and live without service intervention. We anticipate that reported studies will include people known to statutory services and this may be used as a proxy definition for learning disability.

This review will include research about people with learning disabilities accessing services and in recognition of the fact that many people with LD are reliant on others to facilitate access to services (Ptomey et al., 2017) we will also include research about the experiences of people who access NHS health care services on behalf of people with learning disabilities. These people could be family, friends and paid or unpaid carers.

In the pre-existing SDO review Alborz et al. (2003) used Gulliford's model of access which distinguishes between: having access, where services are notionally available;

gaining access, where the user gains entry and use of an appropriate service; and maintaining access, that is continued use of a service (Gulliford et al., 2001). We plan to use this framework to facilitate mapping and data extraction. Additionally, Alborz et al. (2003) distinguished between access and effectiveness and focussed on the ability to use a service rather than whether or not the service is provided to a high standard. We will focus on access to a service as the primary outcome rather than the quality of the service received. We will also review studies reporting the effectiveness of any measures or interventions designed to improve access to the relevant services.

The review will include:

- NHS Primary Care
- First point community based services (GPs, Pharmacists, Dentists and Optometrists)
- Sexual health
- Health screening, delivered in the context of primary and community care.
- Palliative and end of life care, delivered in the context of primary care.

Research questions and aims

Research questions

- What are the gaps in evidence with regard to access to primary and community healthcare for people with learning disabilities?
- What are the barriers to accessing primary and community healthcare services for people with learning disabilities and their carers?
- What actions, interventions or models of service provision improve access to health services for people with learning disabilities and their carers?

Aims

We propose to begin with a mapping review of the literature following the scope of a previous (SDO) review (Alborz, 2003 and 2005). Searches will cover the period 2002-2018 but will focus only on primary and community care services. We plan to include comparative access literature and qualitative research on barriers and facilitators to accessing services together with any systematic reviews of learning disabilities populations published since 2002.

We have chosen to build on the pre-existing SDO review for the four compelling reasons:

1. We can follow (and hopefully enhance) the methods of the original review
2. The time period that has elapsed since the original work (approximately 15 years) provides a manageable quantity of literature for logistic purposes.
3. The conceptual framework produced by the original team can be used as a template for data extraction
4. Following seamlessly from the original Programme work demonstrates coherence and consistency.

We will draw on the separately published account of the search strategy and methodology for the previous review (Alborz, 2003 and MacNally and Alborz, 2004). In recognition of the diffuse terminology that surrounds the topic we will also inspect all of the, approximately 150, items that have cited the original report or its primary journal article output.

We will use the mapping review (James et al. 2016) as a deliverable in its own right to identify areas of research activity and research gaps, comparing this with findings from the earlier review. However, the mapping review will fulfil a further function in helping to finalise the scope of a targeted review which will examine access to primary and community health and social care services for people with learning disabilities and their carers.

Issues around the scope of the targeted review that we will seek to determine from the mapping review are:

1. The feasibility of including both child and adult services.
2. The feasibility of including non-NHS health services delivered in community settings e.g. optometry, dentistry, pharmacy etcetera.
3. The feasibility of including palliative care and end of life care where the delineation between primary and secondary care is less distinct.
4. The feasibility of including screening services within the targeted review or whether to address these in a separate commissioned review.

Overview of methods

Key elements of the mapping review will be 1) systematic database search following the methods from the pre-existing SDO review 2) brief data extraction of relevant studies 3) No formal quality assessment of included studies.

Identifying evidence

- The decision that we will search seven of the 14 bibliographic databases in the pre-existing SDO review, is informed by the article on identifying the literature by McNally and Alborz (2004) (see Appendix 2).
- The database search strategy will be informed by the pre-existing SDO review identifying the literature article (McNally and Alborz, 2004) to include keywords for learning disabilities and access. Additional terminology will be incorporated into the search to include the primary care setting (GP, dentists, optometrists) and current legislation or guidance terms such as Disability and Discrimination Act and reasonable adjustments (see Appendix 2).
- The searches for the pre-existing SDO review were conducted between 1980 and 2002 so we will search from 2002 onwards.
- Searches will be restricted to English Language and Human studies (where available within database functionality).
- Grey literature searching of Google and websites such as key UK charities and associations will be undertaken to identify reports about initiatives to improve access to services for people with learning disabilities (see Appendix 2).
- To acknowledge the limitations of database searching, snowballing by citation searching of included studies will be performed in Google Scholar.
- We will scrutinise reference lists of included papers.
- Further evidence may be identified from contact with topic experts, people with LD and their carers (see section on Patient and Public Involvement).

Screening identified evidence

- Identified evidence will be uploaded to EPPI Reviewer
- An initial set of 100 references will be screened by the three reviewers in order to test the screening tool.
- Evidence will be screened at title and abstract by three reviewers with a random sample of 10% from each reviewer being double screened.
- Evidence will be screened according to the study inclusion criteria in Appendix 1.
- Evidence included in the mapping review will be further screened to identify which studies will be included in the targeted review.
- Where systematic reviews (or other review types) are identified, they will be scrutinised for the primary studies that they include. Any post 2002 studies included in these reviews that meet our inclusion criteria will be included in the mapping and where appropriate the targeted review.

Extracting data

- Brief data will be extracted for the **mapping** review using a template that will be developed in EPPI. This extraction template will include bibliographic information, details of the population accessing the service, the service being accessed, geographical setting, details of the participant group and headline messages about barriers and facilitators to service access or the outcome of the study (where outcomes have been measured). Brief details of interventions will be extracted for research on interventions or models of service provision designed to improve access to health services for people with learning disabilities.
- For the targeted review data extraction will focus on the barriers and facilitators to service access, service acceptability and effectiveness of the implementation of reasonable adjustments to primary care services for people with learning disabilities.

Assessing study quality and relevance

- The mapping review will make an overall assessment of the evidence base, considering issues such as study types, study size, reporting etc.
- As the purpose of the initial mapping review is to assess the size of the evidence base it will not include any assessment of study quality using formal checklists.
- For the targeted review an assessment of study quality will be undertaken using a range of appropriate formal checklists dependent on study design.

Synthesising data

- For the mapping review we will provide a numerical and narrative overview of the evidence identified.
- For the targeted review data will be synthesised narratively.
- The final report will include both the mapping and targeted reviews.

Outputs from the review

- We will produce two reports for this review
 - The first interim report will present a mapping review of the research identified (to be delivered 31st July 2018).
 - The second and final report will comprise the mapping review and the targeted review (to be delivered 30th September 2018).

- The first report will be for interim use (HS&DR and ScHARR) only. The second composite report will constitute the definitive report, for peer review and publication in the HS&DR Journals Library
- Once the final report has been published, we will produce an evidence brief and an open access peer reviewed publication. It is also hoped that this report will be used to support future HS&DR research commissioning.

Patient and public involvement (PPI)

We will involve patients and members of the public through the Sheffield Evidence Synthesis Centre PPI group. Involvement will be determined in conjunction with the group members. Their input will include asking the members to comment on the scope of the review, the plain language summaries and other relevant outputs and to give their perspective on relevant contextual factors and key messages for the NHS. We will also discuss the review with pre-existing groups of people with learning disabilities, and their paid and unpaid carers. We will use these discussions to share the findings of our mapping review, refine terms for our targeted review and to highlight gaps where further research is needed.

Review Planning

Timelines

| Dates | M | A | M | J | J | A | S | O |
|--|---|---|---|---|---|---|---|---|
| Project months | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| Core activities | | | | | | | | |
| Database search | | | | | | | | |
| Additional searching if required | | | | | | | | |
| Screening and mapping for mapping review | | | | | | | | |
| Mapping review delivered | | | | | | | | |
| Targeted review | | | | | | | | |
| Final report writing | | | | | | | | |
| Final report delivered | | | | | | | | |
| Other activities | | | | | | | | |
| Protocol submitted | | | | | | | | |
| PPI workshops | | | | | | | | |
| Teleconferences - Louise Wallace/SchHARR | | | | | | | | |

SCHARR team and allocation of workload

Anna Cantrell – Project Lead and Reviewer 1 (0.2 fte)

Liz Croot – Topic Expert and Reviewer 2 (0.2 fte from 1st April 2018, 0.3 fte from 1st July 2018)

Ruth Wong - Information Specialist (0.2 fte)

Maxine Johnson - Reviewer 3 (0.2 fte from 1st July 2018)

Andrew Booth – Methodologist and Additional Reviewer (0.1 fte)

RW will undertake the searches.

AC, LC and MJ will sift the results from the searches.

AC, LC and MJ will conduct the mapping review.

AC, LC and MJ will conduct the targeted review.

AC LC and MJ will collate and author the final report.

Internal/external topic experts

Liz Croot – Topic expert

Appendices

Appendix 1 Study inclusion criteria

| | |
|------------|--|
| Population | <ul style="list-style-type: none"> • People with learning disabilities of any age accessing health services • Carers of people with learning disabilities accessing health services on behalf of someone with learning disabilities |
| Setting | <ul style="list-style-type: none"> • NHS Primary Care health services • First point community based services (GPs, Pharmacists, Dentists and Optometrists) • Sexual health • Health screening, delivered in the context of primary and community care. • Palliative and end of life care, delivered in the context of primary care. <p>Evidence from any of the following settings: UK, Canada, Australia, New Zealand or Europe.</p> <p>The above settings have been selected due to their similar health care systems. Papers from USA will be excluded because USA private service provision is not comparable to the UK primary care setting. However, the mapping review will investigate the impact of including qualitative research papers from USA depending on their relevance.</p> |
| Outcomes | <p>Access to a service</p> <p>Alborz et al distinguished between access and effectiveness and focussed on the ability to use a service rather than whether or not the service is provided to a high standard. We will also review studies reporting the effectiveness of any measures or interventions designed to improve access to the relevant services.</p> |

| | |
|-------------------|---|
| Comparator | The general population may offer a comparator in some study types |
| Study design | <ul style="list-style-type: none"> • Qualitative research on barriers and facilitators to accessing and using services • Qualitative research on acceptability of reasonable adjustments to services • Comparative access literature • Evaluation studies • Systematic reviews on access to primary care services of learning disabilities populations published since 2002. |
| Other limitations | <p>English language only</p> <p>Evidence published since 2002.</p> |

Appendix 2 Search Strategy

- Adapted from the searches conducted for previous SDO review (McNally, 2004)
- Multiple limits applied: humans, English language and date limits (2002-)
- Seven databases to search
 - MEDLINE
 - Cochrane Library (Cochrane Database of Systematic Reviews; Database of Abstracts of Reviews of Effect; Cochrane Central Register of Controlled Trials; Health Technology Assessment Database; NHS Economic Evaluations Database)
 - Web of Science (Science Citation Index Expanded; Social Sciences Citation Index)
 - CINAHL (Cumulative Index to Nursing & Allied Health)
 - ASSIA (Applied Social Science Index)
 - PsycINFO
 - ERIC (Educational Resources Index)
- Grey literature UK websites will include but not limited to:
 - Association of Chartered Physiotherapists for People with Learning Disabilities
 - British Institute of Learning Disabilities (BILD)
 - Department of Health and Social Care
 - Dimensions UK
 - Disability Rights UK
 - Foundation for People with Learning Disabilities
 - IHaL - The Learning Disabilities Public Health Observatory
 - Learning Disability Wales
 - Mencap
 - Mind
 - Scope
 - The Hearing and Learning Disabilities Group
 - British Academy of Childhood Disability (BACD)
 - British Society for Disability and Oral Health (BSDH)
 - Focus on Disability
 - Sexual Health and Disability Alliance (SHADA)
 - Voluntary Organisations Disability Group (VODG)

Search strategy for Medline is provided below:

| # | Searches |
|---|---|
| 1 | (learning adj (disab* or disorder* or difficult*).tw. |
| 2 | ((developmental* or intellectual*) adj disab*).ti. |
| 3 | (mental* adj (retard* or handicap* or subnormal* or deficient*).ti. |
| 4 | intellectual* impair*.ti. |
| 5 | or/1-4 |
| 6 | (access* or advoca* or barrier* or communication* or information or uptake or utili*ation or need* or provision or consent* or help seeking or help-seeking or utili*e or inaccessib* or availab* or prohibit* or affordab* or applicab* or refer*).ti. |
| 7 | (primary care or nhs or general practi* or gp or family practi* or family doctor* or doctor* surgery* or dentist* or dental or optician* or optical or optometrist* or eye or |

pharmacy* or pharmacist* or clinic or clinics or community service* or community based).ti.

8 (reasonable adjustment* or equality act or disability discrimination act or mental capacity act or care act).tw.

9 or/6-8

10 5 and 9

11 exp Animals/

12 Humans/

13 11 not (11 and 12)

14 10 not 13

15 limit 14 to english language

16 limit 15 to yr="2002 -Current"

References

Alborz, A., McNally, R., Swallow, A., and Glendinning, C. 2003. *From the Cradle to the Grave: a literature review of access to health care for people with learning disabilities across the lifespan*. London: National Co-ordinating Centre for NHS Service Delivery and Organisation.

Alborz, A., McNally, R., and Glendinning, C. 2005. Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. *Journal of Health Services Research & Policy*; 10(3):173–82. Available at: <http://dx.doi.org/10.1258/1355819054338997> [Accessed 02 May 2018]

Allerton, L. and Emerson E. 2012. British adults with chronic health conditions or impairments face significant barriers to accessing health services. *Public Health*; 126(11):920-927.

Brown, M., MacArthur, J., McKechnie, A., Hayes, M. and Fletcher, J. 2010. Equality and access to general health care for people with learning disabilities: reality or rhetoric? *Journal of Research in Nursing*; 15(4):351-361.

Department of Health. 2001. *Valuing People: A new strategy for learning disability for the 21st Century*. London: HMSO.

Emerson, E., Baines, S., Allerton, L. and Welch, V. 2010. *Health inequalities and people with learning disabilities in the UK: 2010*. Durham: Improving Health & Lives: Learning Disabilities Observatory.

Emerson, E., Baines, S., Allerton, L. and Welch, V. 2012. *Health Inequalities & People with Learning Disabilities in the UK: 2012*. Durham: Improving Health & Lives: Learning Disabilities Observatory.

Gulliford, M., Morgan, M., Hughes, D., Beech, R., Figeroa-Muñoz, J., Gibson, B. et al. 2001. *Access to Health Care. Report of a scoping exercise for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)*. London: NCCSDO.

Hatton, C., Glover, G., Emerson, E. and Brown, I. 2016. *Learning Disabilities Observatory People with learning disabilities in England 2015: Main report*. London: Public Health England.

James, K.L., Randall, N.P. and Haddaway, N.R. 2016. A methodology for systematic mapping in environmental sciences. *Environmental Evidence*; 5(1):7. Available at: <https://doi.org/10.1186/s13750-016-0059-6> [Accessed 02 May 2018].

Legislation.gov.uk. 2010. *Equality Act 2010*. [online] Available at: <http://www.legislation.gov.uk/ukpga/2010/15/contents> [Accessed 02 May 2018].

McNally, R. and Alborz, A. 2004. Developing methods for systematic reviewing in health services delivery and organization: an example from a review of access to health care for people with learning disabilities. Part 1. Identifying the literature. *Health Information and Libraries Journal*; 21(3):182-92.

Michael, J. and Richardson, A. 2008. Healthcare for All: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities. *Tizard Learning Disability Review*; 13: 28-34.

Ptomey, L.T., Gibson, C.A., Lee, J., Sullivan, D.K., Washburn, R.A., Gorczyca, A.M. and Donnelly, J.E. 2017. Caregivers' effect on weight management in adults with intellectual and developmental disabilities. *Disability and health journal*; 10(4):542-547.

Starling, S., Willis, A., Dracup, M., Burton, M. and Pratt, C. 2006. 'Right to sight': Accessing eye care for adults who are learning disabled. *Journal of Intellectual Disabilities*; 10(4):337-355.

Straetmans, J.M., van Schrojenstein Lantman-de, H.M., Schellevis, F.G., Dinant, G.J. 2007. Health problems of people with intellectual disabilities: the impact for general practice. *British Journal of General Practice*; 57(534):64-66.

Tyrer, F. and McGrother, C. 2009. Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. *Journal of Intellectual Disability Research*; 53(11):898-904.