Protocol for 'Gaining entry access to primary and community health care services for adults with learning disabilities: a targeted systematic review'

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Overview

1. This work has been commissioned to provide HS&DR with an independent review of research on access to health care for people with learning disabilities to inform strategic decision-making and service design.
2. The objective is to identify, appraise and synthesise published research (including 'grey literature') on access to health care services for people with learning disabilities including barriers to access and interventions or models of service provision to improve access.
3. We will include studies about access to health care services for people with learning disabilities and/or their carers.
4. We will include UK primary and community care services where patients and carers have direct access for self-referral. This will include general practice, pharmacy, dental, optometry and audiology services and IAPT services (Improving Access to Psychological Therapies).
5. A previously produced mapping review has been used to inform the scope of the targeted systematic review.

Background

In 2015 it was estimated that 2.16% of the adult population living in England had learning disabilities (Hatton et al, 2016). People with learning disabilities (LD) face considerable, persistent and, to a degree, avoidable health inequalities (Brown et al 2010; Emerson & Baines 2010). These arise from disparities in the presence of disease (Straetmans et al., 2007), inequalities in access to, and use of, health care services (Michael & Richardson., 2008; Starling et al., 2006), and increased risk of exposure to

common social determinants of ill health (Marmot, 2010), for example, poverty and social discrimination (Emerson et al, 2016). Life expectancy of people with learning disabilities remains significantly lower than that of the general population (Tyrer and McGrother, 2009). In the past ten years several inquiries into the deaths of people with LD have concluded that inadequate health care was a contributory factor and that these deaths were avoidable (Mencap 2007 and 2012; Mazars, 2015).

Evidence suggests that people with LD use primary care services at rates less than or equal to the general population despite having greater health needs (Turk et al, 2010) and their use of primary care is lower than expected in comparison to groups with other long term conditions (Felce et al, 2008). This suggests that people with LD are not accessing primary care services proportionate to their level of health need. Primary care services are particularly important because they provide an entry point to screening, treatment and secondary care. Difficulty and delay in accessing primary care may lead to serious negative health outcomes and disengagement with future health care services with concomitant cost to the individuals and to the National Health Service (NHS). For this reason, we have chosen to focus on access to primary health care services, specifically those where individuals can refer themselves and do not require professional assessment to gain initial access, which may subsequently act as gatekeepers to further treatment and care. These include general practice, community pharmacies and high street opticians and dentists.

This work complements UK government policy which emphasises the requirement to support people with LD to lead fully inclusive lives and this means meeting their health needs within mainstream services (Valuing People Now, Department of Health 2009). 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) and health and social care services have a legal duty to reduce health inequalities under the Health and Social Care Act (2012).

This review of access to healthcare follows an earlier review by Albortz et al (2005) and provides an updated account of the evidence about people with learning disabilities' access to healthcare and the barriers they face in accessing and using health care services. The review will also consider the effectiveness of reasonable adjustments and other innovations designed to improve access for this population with the aim of identifying good practice to inform recommendations for practice, gaps in the available evidence and priority areas for further research.

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, both directly and indirectly; 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 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 review for the NHS Service Delivery & Organisation (SDO) Programme 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 focus on gaining access and use 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. However, we consider that patient engagement is crucial to the success of most health care interactions and therefore we will consider the extent to which health care services are set up or adjusted to facilitate the engagement of people with LD during health appointments. We will also review studies reporting the effectiveness of any measures or interventions designed to improve access to the relevant services.

Direct access (first contact) health care services are those to which individuals may refer themselves and require no professional assessment to determine access (Alborz et al 2005). These services are important in themselves but serve an additional role in operating as a gateway to accessing secondary and continuing health care services. This combined role of service provision and gatekeeping means that they are particularly significant when considering access.

We will review primary and community care services where patients or carers have direct access to the service. These services include:

- GP services including out of hours provision and NHS111
- NHS community dental services
- NHS community optometry services
- NHS community audiology services
- Community pharmacy services
- Improving Access to Psychological Therapies (IAPT) services

Research questions and aims

Research questions

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

Aims

Our previous mapping review of the literature followed the scope of a previous (SDO) review (Alborz, 2003 and 2005) but with a focus on primary and community care services. We propose to use findings from the mapping review to focus searches for the targeted systematic review. Searches will cover the period 2002-2018. We plan to include descriptive and comparative literature on access and qualitative research on barriers and facilitators to accessing services and relevant grey literature. Any relevant systematic reviews of learning disabilities populations published since 2002 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 targeted review.

We have chosen to build on the pre-existing SDO review for 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.

For the mapping review we drew 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 also inspected all of the, approximately 150, items that have cited the original report or its primary journal article output. The search strategy for the targeted review will be informed by the findings from the mapping review.

The mapping review produced 413 references relevant to the research questions (Cantrell, et al 2018). Descriptive data from each of these references was extracted from available abstracts (not all citations included an abstract) in order to categorise and quantify the citations across areas of interest.

We identified almost equal numbers of quantitative and qualitative study designs, suggesting a balance of quantitative findings and views contributions to the targeted review. The largest proportion of studies were carried out in the UK (n=142), which will optimize applicability to UK practice. The targeted review will limit inclusion to UK studies only. This is because services in other countries may have different models for access, making comparability problematic. We have examined the findings from the mapping review to ensure we will not lose the breadth of services covered and the results of this can be seen below.

Health professionals represented in the references included in the mapping review were predominantly GPs (n=127/287). Optometrists and pharmacists were the least well represented (n=11 and n=7 respectively). All of the health care professionals are covered in the UK papers, see table 1 demonstrating that the breadth of the review will not be reduced by focussing on the UK.

Table 1 Number of studies specifying role of health care professional

Code: Health care professional	**UK papers count**	**All papers count**
GP	53	127
Dentist	11	41
Optometrist	9	11
Pharmacist	2	7
Other community staff	49	101
Total	124	287

This could be due to a lack of research in these areas or because the mapping review extracted data only from abstracts and the full papers have not yet been examined. For the targeted review we will re-visit the search strategy to ensure comprehensive coverage for these areas.

Specialist topics (mental health, sexual health, palliative care) were evenly distributed throughout the included studies. However, “other” topics were included in 105 of 176

references. We re-examined these references to identify and quantify 39 further categories of interest, finding 17 references that focused on cancer screening and 13 on health checks and assessments. The remaining 37 categories were each included in only 1-5 references. Only twenty of the total included references were related to needs assessment. We will target the review at gaining initial access to primary and community health care services and barriers and facilitators to doing soand we will include all relevant articles regardless of the health condition. Our search terms reflect the focus on access to these services rather than any specific health care topics.We did not use specific search terms for sexual health and palliative care in the mapping review and we found relevant articles so we expect this strategy to broaden the range of specialist health topics to be included rather than to restrict it.

The mapping review identified several research studies about services for children with learning disabilities. These studies were related to specific health care professionals, specialist topics or covered the needs of children. The targeted review will be limited to adults aged 16 or over because of the range of different abilities in adults with LD and the different access requirements. Brief details of the eight studies in paediatric populations that conducted their research in the UK are provided in Table 2. This table demonstrates that the breadth of the review will not be reduced by limiting to adults.

Table 2 UK studies focused on children/paediatric

First author / year	Title
Beecham (2002)	Children with Severe Learning Disabilities: Needs, Services, and Costs
Brown (2013)	Access to mainstream health services: a case study of the difficulties faced by a child with learning disabilities
Das (2010)	Evidence that children with special needs all require visual assessment
Heer (2012)	Understanding the experiences and needs of South Asian families caring for a child with learning disabilities in the United Kingdom: an experiential-contextual framework
Mimnagh (2009)	Paediatric & adolescent diabetes nursing. Diabetes and the child with special educational needs
Schieve (2012)	Concurrent medical conditions and health care use and needs among children with learning and behavioral developmental disabilities, National Health Interview Survey, 2006-2010
Toms (2015)	Access to services by children with intellectual disability and mental health problems: Population-based evidence from the UK
Wharton (2005)	Accessibility of general NHS services for children with disabilities

We identified 87 references that mentioned barriers and 47 that referenced facilitators (not mutually exclusive) to accessing primary care for people with LD. These studies

were categorized in the mapping review to maintain consistency with the framework used by Alborz et al (2007). We will further populate the framework following detailed data extraction from full included papers in the targeted systematic review.

Searches of grey literature identified five reports that were relevant and included relevant data. We will scrutinize these sources in more detail for data to be included in the targeted review.

Following on from the mapping review, the scope of the targeted review will be limited to:

1. Services for adults aged 16 and over
2. Primary and community care services which are first contact for patients and their carers. This will include general practice (including out of hours provision), pharmacy, dental, optometry and audiology services and IAPT services (Improving Access to Psychological Therapies) where they are direct access.
3. Given our focus on services which can be accessed directly by patients and carers in the UK we will limit the review to UK studies, because models of access to these services in other countries may differ.

Overview of methods

Key elements of the targeted systematic review will be

1. focussed systematic database search following inspection of the mapping review findings
2. citation searches of key included studies
3. reference list searches of included studies and reviews
4. full data extraction of relevant studies
5. quality assessment of included full peer-reviewed papers; no formal quality assessment of conference abstracts or grey literature.

Identifying evidence

- The database search strategy (see Appendix 1) for the targeted review will be informed by the findings from the mapping review.
- The searches for the pre-existing SDO review were conducted between 1980 and 2002 so we will search from 2002 onwards.
- Multiple limits applied: humans, English language, date limits (2002-), UK filter (Ayiku et al., 2017).
- 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 and any relevant reviews.
- Further evidence may be identified from contact with topic experts, people with LD and their carers (see section on Patient and Public Involvement).

- Broad searches for grey literature for learning disabilities (irrespective of setting), as conducted during the mapping review, will provide the grey literature for the targeted review

Screening identified evidence

- Additional identified evidence will be uploaded to EPPI Reviewer
- 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 2.
- Where systematic reviews (or other review types) are identified, they will be scrutinised for references to relevant primary studies. 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.
- Full papers will be retrieved for references that conform to the inclusion criteria and these will be further scrutinised prior to inclusion. Exclusions at this point will be listed along with reasons for exclusion.

Extracting data

- Data from full included papers, reports and conference abstracts will be fully extracted (or full details added) for the targeted systematic review in EPPI. Data extraction will be based on the template developed for the mapping review (Appendix 3) but subsequently revised to meet the requirements of the targeted review.
- 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

- For the targeted systematic review, we will make an overall assessment of the evidence base, considering issues such as study types, study size, reporting etc.
- We will assess study quality of full peer reviewed papers using a range of validated checklists dependent on study design.

Synthesising data

- It is not expected that data from included references will be sufficiently homogeneous to allow meta-analysis, therefore data will be categorised and synthesised narratively.
- For relevant findings from qualitative studies we will use thematic synthesis (Thomas & Harden, 2008) to identify themes to help explain quantitative findings.

Outputs from the review

- We will produce the second and final report comprising the mapping review and the targeted review (to be delivered 31st October 2018).
- This 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. This report is intended to be used to inform and support future HS&DR research commissioning.

Patient and public involvement (PPI)

We will continue to involve patients and members of the public through the Sheffield Evidence Synthesis Centre PPI group. Members of this group will be asked to comment on the scope of the targeted systematic 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 have discussed the review with pre-existing groups of people with learning disabilities, and their paid and unpaid carers. We will discuss the findings from the targeted review with these groups and ask them to comment on the key messages for the NHS and priorities for future research.

Review Planning

Timelines

Dates	27/8	3/9	10/9	17/9	24/9	1/10	8/10	15/10	22/10	29/10
Project weeks	1	2	3	4	5	6	7	8	9	10
Core activities										
Protocol submitted										
Database search										
Additional searching if required										
Sifting										
Quality assessment										
Data extraction										
Analysis and synthesis										
Final report writing										
Final report delivered										
Other activities										
PPI workshops										
Teleconference										

ScHARR team and allocation of workload

Anna Cantrell – Project Lead and Reviewer 1 (0.2 fte)
Liz Croot – Topic Expert and Reviewer 2 (0.3 fte)
Ruth Wong - Information Specialist (0.2 fte)
Maxine Johnson - Reviewer 3 (0.2 fte)
Andrew Booth – Methodologist and Additional Reviewer (0.1 fte)

RW will undertake the searches.

AC, LC and MJ will undertake the sifting, quality assessment, data extraction, analysis and synthesis.

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

AB will provide methodological advice and as an additional reviewer where consensus is required.

Internal/external topic experts

Liz Croot – Topic expert

Appendices

Appendix 1 Search strategy for targeted review

- Adapted from the searches conducted for previous SDO review (McNally, 2004)
- Strategy informed by the findings from the mapping review
- Multiple limits applied: humans, English language, date limits (2002-), UK filter (Ayiku et al., 2017)
- 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)

Search strategy for Medline is provided below:

1	(learning adj (disab* or disorder* or difficult*)).tw.
2	((developmental* or intellectual*) adj disab*).tw.
3	(mental* adj (retard* or handicap* or subnormal* or deficien*)).tw.
4	intellectual* impair*.tw.
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*).tw.
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 opthalmolog* or eye or eyes or ear or ears or hear or hearing or audiolog* or pharmacy* or pharmacist* or chemist* or clinic or clinics or community service* or community based or community care).tw.
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	exp Great Britain/

16 (national health service* or nhs*).ti,ab,in.
17 (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
18 (gb or "g.b." or britain*).ti,ab,jw,in.
19 (british* not "british columbia").ti,ab,jw,in.
20 (uk or "u.k." or united kingdom*).ti,ab,jw,in.
21 (england* not "new england").ti,ab,jw,in.
22 ("northern ireland*" or "northern irish*" or scotland* or scottish* or welsh*).ti,ab,jw,in.
23 ((wales or south wales) not "new south wales").ti,ab,jw,in.
24 or/15-23
25 (exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp great britain/ or europe/)
26 24 not 25
27 exp Primary Health Care/
28 Community Health Services/
29 Community Mental Health Services/
30 exp Physicians, Family/
31 Pharmacies/
32 Dentists/
33 Optometry/
34 Audiology/
35 exp After-Hours Care/
36 (out of hours or ooh or after hours or walk in centre* or national health service* 111 or nhs* 111 or iapt or improving access to psychological therapies or health check* or screen* or assessment or health service* or care service*).tw.
37 or/27-36
38 5 and 37
39 38 not 13
40 (14 or 39) and 26
41 limit 40 to english language
42 limit 41 to yr="2002 -Current"

Appendix 2 Study inclusion criteria

Population	• People with learning disabilities aged 16 or older accessing health care services • Carers of people with learning disabilities accessing health care services on behalf of someone aged 16 or older with learning disabilities
Setting	• UK only • Direct access (first contact) NHS Primary care health care services • Direct access (first contact) community based services (GPs, out of hours services, NHS 111, IAPT, Pharmacists, Dentists. Optometrists and audiologists)
Outcomes	Access to a service 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.
Comparator	The general population may offer a comparator in some study types
Study design	• Qualitative research on barriers and facilitators to accessing and using services • Qualitative research on acceptability of reasonable adjustments to services • Descriptive access research • Comparative access literature • Evaluation studies • Systematic reviews on access to primary care services of learning disabilities populations published since 2002.
Other limitations	English language only Evidence published since 2002.

Appendix 3 Data extraction components from mapping review

Study ID

Study design:

- Quantitative
- Qualitative
- Mixed methods
- Review
- Unclear

Setting - Country

Health care professional:

- GP
- Dentist
- Optometrist
- Pharmacist
- Other community staff

Specialist Topic:

- Sexual health
- Live care
- Mental health
- Other

Study Population

Sample size

Needs assessment

Study outcomes

Tools used to measure outcomes

Study results

Barriers

Facilitators

References

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