

Access to primary and community health-care services for people 16 years and over with intellectual disabilities: a mapping and targeted systematic review

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Scientific summary

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Background

Intellectual 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 when the disability starts before adulthood and has a lasting effect on development. The terms 'intellectual disability' and 'learning disability' are used interchangeably, but in this report we will generally use the former, in line with current academic practice.

In 2015, it was estimated that 2.16% of the adult population living in England had intellectual disabilities. People with intellectual disabilities face considerable health inequalities and their life expectancy remains significantly shorter than that of the general population. In the past 10 years, several inquiries into the deaths of people with intellectual disabilities have concluded that inadequate health care was a contributory factor and that these deaths were avoidable.

People with intellectual disabilities use primary care services at rates less than or equal to the general population, despite having greater health needs. 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.

This report focuses on access to primary health-care services, specifically those to which individuals can refer themselves. These include general practice, community pharmacies and high-street opticians and dentists. We carried out an initial mapping review of the literature to inform and finalise the scope of a targeted systematic review focused on evidence relevant to the UK NHS.

Objectives

This report aims to address the following questions with reference to the NHS in the UK:

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

Methods

The research was carried out in two stages. We performed a systematic mapping review of the literature on access to primary health-care for people with intellectual disabilities in the UK and in the health systems of similarly developed countries. The findings of the mapping review were used to clarify the scope of a targeted systematic review. Similar methods of searching and study selection were used for the two reviews, but the mapping review did not involve quality assessment or detailed data extraction. The methods described below refer to the targeted systematic review unless otherwise stated.

We searched MEDLINE, The Cochrane Library, Web of Science, CINAHL (Cumulative Index of Nursing and Allied Health Literature), ASSIA (Applied Social Science Index), PsycINFO and ERIC (Educational Resources Index) for studies published from 1 January 2002 (the end date of the previous systematic review) to September 2018. A validated filter was used to identify UK studies. Broad searches for grey literature on intellectual/learning disabilities (irrespective of setting) that were conducted during the mapping review provided the grey literature for the targeted review.

Search results were uploaded to EPPI-Reviewer 4 (Evidence for Policy and Practice Information and Co-ordinating Centre, University of London, London, UK) for title and abstract screening. Screening was performed by a team of three reviewers, and a random sample of 10% of records from each reviewer were double screened.

Inclusion criteria for the targeted review were as follows:

- Population – people with intellectual disabilities aged ≥ 16 years accessing health-care services or carers accessing services on their behalf.
- Setting – direct-access (first contact) UK NHS primary care or community-based services (general practitioners, out-of-hours services, NHS 111, Improving Access to Psychological Therapies services, pharmacists, dentists, optometrists and audiologists).
- Outcomes – access to a service listed above. We also included studies reporting the effectiveness of any measures or interventions designed to improve access to the relevant services.
- Comparator – no comparator was required for inclusion, but the general population formed a relevant comparator for some study types.
- Study design – we included qualitative research on barriers to and facilitators of accessing and using services, qualitative research on acceptability of ‘reasonable adjustments’ to services, descriptive access research, comparative access literature and evaluation studies.
- Other limitations – English-language evidence published since 2002.

The mapping review also included studies on children and had a wider geographical scope, covering Canada, Australia, New Zealand and European countries as well as the UK. Based on the mapping review findings, the targeted review was restricted to studies of adults (aged ≥ 16 years) in UK settings.

Full papers were obtained for records that appeared potentially to meet the inclusion criteria. Screening of full texts followed a similar process to that for title and abstract screening. Any queries were resolved by discussion. Systematic and non-systematic reviews were not included in the review but were considered as sources of additional references. Conference abstracts were included only if they were published in 2014 or later.

Data extraction (coding) was completed in EPPI-Reviewer 4 using a mixture of tick-box and open questions. We focused on the barriers to and facilitators of service access, service acceptability and the effectiveness of implementing reasonable adjustments to primary care services for people with learning disabilities.

Quality (risk of bias) was assessed using validated checklists published by the US National Heart, Lung and Blood Institute for quantitative study designs. Qualitative studies were assessed using the Critical Appraisal Skills Programme checklist for qualitative studies.

Narrative synthesis was based around a pathway with three steps leading to access to services: identifying need, accessing services and interaction during a consultation. Studies of innovations/interventions to improve access were synthesised separately. The pathway model emerged from the examination of included study characteristics and was agreed by consensus within the review team.

The factors (i.e. barriers and facilitators) influencing access at each stage were identified as part of data extraction. A common group of factors that appeared to act at all stages was used to structure the narrative synthesis for each cluster of studies.

We consulted people with intellectual disabilities, family carers and formal paid carers to ensure that the review was informed by their perspectives. We met a group of people with intellectual disabilities ($n = 8$, plus one personal assistant) and a group of family carers ($n = 5$). Snowball sampling was used to identify formal carers and we spoke to staff who manage support services ($n = 2$). Discussions were loosely guided by a topic guide covering how people identify a health need, what actions they take, issues influencing their decision to take a particular course of action, and the barriers to and facilitators of their access to and use of the chosen service. Notes from the discussions were written up in detail to identify relevant search terms and for future comparison with barriers and facilitators identified in the qualitative literature. We discussed the findings and recommendations from the review with a family carer representing the group of family carers involved in the earlier consultation ($n = 1$) and with a group of people with learning disabilities ($n = 10$) plus a member of staff supporting the group ($n = 1$). These discussions covered the main findings and recommendations from the review. Prompts were used when needed to ensure that the discussions covered whether or not these findings were an accurate reflection of their experiences and whether there was anything missing or anything they wanted to add to the findings or recommendations. Minor changes were made as needed following these discussions.

Results

A total of 413 studies were included in the mapping review, 142 of which were from the UK. Based on the mapping review findings, we decided to focus the targeted review on first-contact services and to include studies of people with all grades of severity of intellectual disabilities. The targeted literature search (including rescreening of potentially included studies from the mapping review) identified 6370 potentially relevant records, 518 of which were examined as full texts, and 82 papers reporting 80 studies were finally included in the review. A calculation of inter-rater agreement demonstrated excellent agreement between reviewers ($\kappa = 0.933$, 95% confidence interval 0.904 to 0.962).

The studies were organised into the following groups for analysis: identifying needs (14 studies), accessing services (24 studies), interaction during a consultation (19 studies) and innovations to improve access (23 studies).

Overall, the studies included in the review were rating as having a relatively high risk of bias. There were only two controlled intervention studies and only one of these was randomised (by clusters). For quantitative (cohort and cross-sectional) observational studies, the main limitations identified were lack of a power calculation or justification of sample size, the absence of blinded outcome assessment and no consideration of possible confounding factors in the analysis. Studies often had small samples of people with intellectual disabilities who had been recruited from specialist settings and hence these samples were not necessarily representative. Other studies provided the perspectives of health professionals only. The main limitations of the included qualitative studies were that some did not consider the relationship between researchers and participants, while others reported few details about the data analysis, meaning that whether or not the analysis was sufficiently rigorous was unclear.

Health checks were evaluated in 15 studies and found to help identify health needs, improve monitoring of people with long-term conditions, reduce long-term need for referral and interventions and increase health promotion activities aimed at people with intellectual disabilities. Three studies found that incentivisation schemes increased tests and checks, and one study found health checks to be cost-effective. Challenges to the introduction and uptake of health checks included defining eligibility. The included studies did not investigate the quality of the health checks.

Five studies investigated training of staff, but the diversity of the staff/services involved and the methodological limitations of the studies made it difficult to draw firm conclusions about effective training. One-to-one counselling and a teaching programme for people with intellectual disabilities were evaluated in small methodologically limited studies. An analysis of a general practice patient survey indicated that weekend opening would be unlikely to improve access to general practitioners for people with intellectual disabilities, most of whom would be able to attend during normal opening hours. However, this study also had weaknesses, including a low response rate and that it evaluated perceptions about weekend services rather than the actual use of these.

In terms of influencing access to services, the review found the following factors that cut across the literature:

- consistency of care – relationship, trust, monitoring change over time, important for good communication
- involvement of carers (formal/paid, relatives or other supporters)
- training for care staff – awareness of screening available and how to support people to access and take up screening offered, recognising hidden health needs such as hearing loss
- communication skills of all who come into contact with people with intellectual disabilities – value, respect, ability to tailor information to the abilities of the individual with intellectual disabilities
- use of accessible resources including use of pain recognition and communication tools
- extra time needed to communicate effectively with people with intellectual disabilities
- communication within services, close teamworking, sharing knowledge of client and consistency of staff team
- communication between services – mainstream health services, specialist intellectual disabilities services, day services and residential services, family carers and other paid carers and supporters (e.g. personal assistants, advocates)
- need for systems that allow joined-up working between services
- accurate record-keeping.

Conclusions

The review identified 82 papers reporting 80 studies that met the inclusion criteria. The included studies were heterogeneous, covering a wide range of people with intellectual disabilities. Methodological quality was generally low.

The review identified the following implications for health care or service delivery:

- Staff retention is a key issue. The high turnover of paid carers means that it can be difficult for carers to develop a relationship with adults with intellectual disabilities that enables them to effectively realise when the adult is ill or in pain and when they need to access services.
- Developing and providing training for health-care professionals and carers (paid) could potentially help adults with intellectual disabilities to access health care. This can happen only if employers promote the training as important and provide all staff with the time to attend.
- Joint working across services is important to ensure that information about patients is shared and that skills can be utilised. Health-care professionals with specific knowledge about and skills relating to intellectual disabilities can share these and help others to develop.
- Ensuring that patients have appointments with the same health professional may enable them to develop a relationship that can help each understand the other better. Double appointments give health professionals and patients longer to discuss health problems and decide on treatment while ensuring understanding on both sides. Improved communication also includes ensuring that all signage is clear and that any leaflets or letters produced are easy to understand.

- Clear record-keeping can enable key information about a patient to be passed on to other health professionals quickly and easily. The included studies found that it was often difficult for general practitioners to generate a full list of all adults with intellectual disabilities and that Read codes were not always used consistently.
- Health services need to be aware that patients with intellectual disabilities have varying abilities that can affect their capacity to consent to treatment. Consent requires that patients be provided with clear information and, when proxy consent is sought, it should be clear that the person providing consent is appropriate.
- Health services need to balance patients' right to autonomy with safeguarding needs, while recognising that there may be a tension between these. It can be difficult to support people who are making poor health choices and it may be necessary to consider whether or not the person is able to understand the consequences of their actions.

The review findings support the following recommendations for research:

1. The review found that many of the studies were judged to be of poor quality, perhaps because of the many ethical, logistical and financial challenges of carrying out research, for example in using randomisation or a control group, given the complexity of the population. Developing creative study designs that are feasible and ethical to implement and that meaningfully include people with intellectual disabilities is an important step to address the complex issues highlighted in this review.
2. The majority of the included studies addressed general practitioners' services. Research studies are needed that investigate other primary care services (e.g. opticians, Improving Access to Psychological Therapies services).
3. The included research sometimes focused on particular groups of people; for example, Jones and Kemp (Jones J, Kemp K. Down syndrome: exploring the knowledge, attitudes and practice of GPs. *Learning Dis Pract* 2007;10:18–21) explored general practitioners' attitudes and experience of working with people with Down syndrome, making findings applicable only to that group. In other cases, the severity of intellectual disabilities and, perhaps more significant to the review, the functional ability of those included was not clear, making it difficult to determine whether or not the findings are relevant to all people with intellectual disabilities. Research is needed to identify needs across the whole spectrum of intellectual disabilities, with clear information given about the functional ability of participants.
4. There was little research about how carers can support people with intellectual disabilities who are able to have some autonomy; thus, research to produce guidance on how carers can support people with some autonomy, and how to balance autonomy and risk of harm, is recommended.
5. The literature found that carers had a pivotal role but high turnover limited their impact; thus, research into interventions to improve retention of care staff is recommended.
6. Research is recommended to develop, implement and evaluate interventions to improve communication between organisations/sectors.

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This report

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