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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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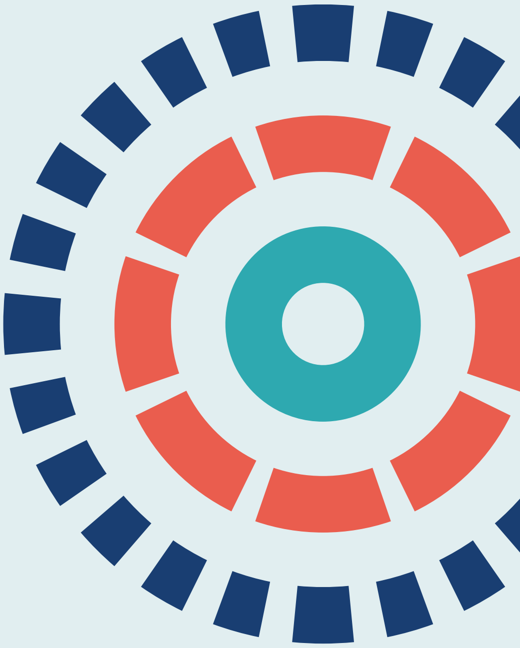

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Access to primary and community health-care services for people 16 years and over with intellectual disabilities: a mapping and targeted systematic review

Anna Cantrell,* Elizabeth Croot, Maxine Johnson, Ruth Wong, Duncan Chambers, Susan K Baxter and Andrew Booth

School for Health and Related Research (ScHARR), University of Sheffield, Sheffield, UK

*Corresponding author

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Abstract

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

Anna Cantrell,* Elizabeth Croot, Maxine Johnson, Ruth Wong, Duncan Chambers, Susan K Baxter and Andrew Booth

School for Health and Related Research (ScHARR), University of Sheffield, Sheffield, UK

*Corresponding author a.j.cantrell@sheffield.ac.uk

Background: In 2015, approximately 2.16% of adults were recorded as having intellectual disabilities. UK government policy is that adults with intellectual disabilities should access mainstream health services. However, people with intellectual disabilities experience challenges when accessing primary and community health services that can lead to inequalities and shorter life expectancy.

Objectives: To map and review the evidence on access to primary and community health-care services for adults with intellectual disabilities and their carers. To identify influencing factors for gaining access to primary and community health-care services. To determine which actions, interventions or models of service provision improve entry access to these services for people with intellectual disabilities and their carers. Finally, to identify the gaps in evidence and provide implications for health care and recommendations for research.

Data sources: MEDLINE, The Cochrane Library, Web of Science, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Applied Social Sciences Index and Abstracts (ASSIA) and Education Resources Information Center (ERIC) were searched from 2002 to 2018.

Review methods: The mapping review methodology included an extensive literature search, article selection and data extraction of relevant abstracts. Findings from the mapping review informed the scope of the targeted systematic review. Methodology for the targeted systematic review included an extensive literature search informed by the mapping review, article selection, data extraction, quality appraisal and narrative synthesis.

Results: The mapping review included 413 studies with data extraction completed on abstracts. The targeted systematic review synthesised the evidence from 80 studies reported in 82 publications. During the review process, the team identified three key points at which people with intellectual disabilities potentially interacted with primary and community health-care services: identifying needs, accessing services and interaction during a consultation. In addition, there were a number of papers about interventions or innovations to improve access. Evidence from the studies was synthesised within the four clusters. Influencing factors were identified: staff knowledge/skills, joint working with learning disability services, service delivery model, uptake, appointment making, carer/support role, relationship with staff, time, accessible information and communication. The influencing factors were cross-cutting through the literature, with certain factors having more importance in certain clusters.

Limitations: The main limitation was the weak evidence base. The studies generally had small samples, had study designs that were open to potential biases and measured only short-term outcomes.

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Conclusions: Health checks were found to help identify health needs and improve the care of long-term conditions. Important factors for accessing health services for adults with intellectual disabilities were consistency of care and support, staff training, communication skills and time to communicate, and provision of accessible information. Health professionals need to ensure that there is joint working between different services, clear communication and accurate record-keeping. Future research questions centre on the need to develop and value creative study designs capable of addressing the complex issues identified in the findings of the review for this complex population.

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Contents

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List of tables

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List of figures

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List of supplementary material

Report Supplementary Material 1 Intellectual disabilities mapping review protocol

Report Supplementary Material 2 Intellectual disabilities targeted systematic review protocol

Supplementary material can be found on the NIHR Journals Library report project page under the ‘Download report documents’ section on the Toolkit (https://doi.org/10.3310/hsdr08050).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

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List of abbreviations

CASP	Critical Appraisal Skills Programme
GP	general practitioner
HCP	health-care professional
IAPT	Improving Access to Psychological Therapies
ID	intellectual disabilities
LD	learning disability
LD-DES	learning disability direct enhanced service
LeDeR	Learning Disabilities Mortality Review
MCA	Mental Capacity Act 2005
PPI	patient and public involvement
QOF	Quality and Outcomes Framework
SDO	Service Delivery and Organisation

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Plain English summary

In 2015, around 2.16% of adults in England were recorded as having a learning disability. People with a learning disability can find it difficult to understand new and complicated information, learn new skills and live independently. People with a learning disability face inequalities when accessing and using health-care services, including primary care. This may shorten their life expectancy and reduce their quality of life.

We looked at studies from the UK about adults with a learning disability using primary care services, or about carers supporting them to use primary care services. Carers could include family members, friends, paid carers, staff working in day centres, personal assistants and anyone else who might provide support to access health services. Services we were interested in included general practitioners, out-of-hours care, NHS 111, mental health services, pharmacists, dentists, and eye and hearing specialists.

We looked at research studies about ways to improve access and research that described factors that might help access or make access difficult. We analysed the research using a pathway of care model with three stages: first, research findings about how to identify health needs; second, research findings about accessing services; and, third, research findings about engaging with services.

We found that most studies were carried out with only small groups of people, and the results were often not very detailed. This makes it difficult to make clear recommendations. However, the research suggested that regular health checks could help to identify the health needs of people with a learning disability, and that these were useful for improving care for people who had additional long-term conditions. Factors that helped access for people with a learning disability were consistency of care and support, staff training, good staff communication, sufficient time during appointments, joined-up working and accurate record-keeping.

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Scientific summary

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.

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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 $\geq$ 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 $\geq$ 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.

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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.

Funding

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Chapter 1 Introduction

Background to the topic

In 2015 it was estimated that 2.16% of the adult population living in England had intellectual disabilities (ID).[1] People with ID face considerable, persistent and, to a degree, avoidable health inequalities.[2,3] These arise from disparities in the presence of disease,[4] inequalities in access to and use of health-care services,[5,6] and increased risk of exposure to common social determinants of ill health,[7] for example poverty and social discrimination.[8] The life expectancy of people with ID remains significantly lower than that of the general population.[9] In the past 10 years, several inquiries into the deaths of people with ID have concluded that inadequate health care was a contributory factor and that these deaths were avoidable.[10–12]

A number of inquiries into the early deaths of people with ID have reported shortcomings across a range of health services.[12–14] These point to factors, such as poor communication, that may be common across the full range of health services. Although our review covers initial access to primary care services rather than quality of ongoing health care provided, there are important lessons from these inquiries that are relevant to initial access to primary care.

UK government policy is for people with ID to have their health needs met in mainstream services, although there is considerable evidence that some people with ID may not be able to respond to and benefit from uniformly delivered services.[15] The statutory position is that mainstream services have a legal duty to make reasonable adjustments to enable those with protected characteristics to access these services; however, there is little guidance about what constitutes a reasonable adjustment.

People with ID are less likely to be able to access uniformly delivered health interventions. 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 (LDs).[16] However, more needs to be done in primary care, where services are often inaccessible to people with LDs because effective adjustments have not been put in place.[17]

Similarly, some of the problems of access to primary health care sit outside health service responsibilities, for example the ability of paid support staff to recognise when an adult with intellectual disabilities might need primary care. Although the focus of this report focuses on access to primary care, the barriers to access and interventions shown by social care providers and disability organisations to be successful in improving access among this population have an important role to play in enabling access to these services.

Evidence suggests that people with ID use primary care services at rates less than or equal to the general population despite having greater health needs[18] and their use of primary care is lower than expected in comparison with groups with other long-term conditions.[19] This suggests that people with ID do not access primary care services proportionately 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 UK NHS.

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This work complements UK government policy, which emphasises the requirement to support people with ID to lead fully inclusive lives and this means meeting their health needs within mainstream services.[17] Public bodies have a legal duty to make 'reasonable adjustments' to policies and practices to provide fair access and treatment for people with LDs[16] and health and social care services have a legal duty to reduce health inequalities under the Health and Social Care Act 2012.[20]

Definitions

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 where this disability starts before adulthood, with a lasting effect on development. However, in practice, studies may recruit participants on the basis that they are known to statutory service providers. People with severe ID are likely to be known to service providers, however, some people with mild ID may live independently without service intervention, either from choice or because they do not meet eligibility criteria for ID services and, therefore, are not able to access support. This review will use the term ID throughout in recognition of the increasing use of this term in research.

In a review for the NHS Service Delivery and Organisation (SDO) programme, Alborz *et al.*[21] used Gulliford's model of access; this distinguishes between having access, where services are notionally available; gaining access, where the user gains entry to and use of an appropriate service; and maintaining access, that is having continued use of a service.[22] We plan to focus on gaining access and use because the review focuses on first contact with services such as primary/community care. In addition, Alborz *et al.*[21] distinguished between access and effectiveness and focused on the ability to use a service rather than whether or not the service was provided to a high standard. In this review, we 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; therefore, we will consider the extent to which health-care services are set up or adjusted to facilitate the engagement of people with ID during health appointments. We will also examine evidence for the effectiveness of any measures or interventions designed to improve access to relevant services.

Chapter 2 The mapping review methods

A systematic mapping review was undertaken to map the literature in the topic area and to help decide on the final scope for the targeted systematic review.

The mapping review aimed to examine the volume and characteristics of the available evidence about quality of access to primary health-care services for people with ID. The protocol for the mapping review is provided in *Report Supplementary Material 1*.

The mapping review includes the following types of health service:

- NHS primary care
- first-point community-based services [general practitioners (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

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

Methods

The systematic mapping review was conducted in accordance with published methods.[23] The mapping review followed the scope of a previous review,[21,24] with the exception that it focused on only primary and community care services.

We chose to build on the existing review for four compelling reasons:

1. We could follow (and hopefully enhance) the methods of the original review.
2. The time that had elapsed since the original work (approximately 15 years) provided a manageable quantity of literature for logistic purposes.
3. The conceptual framework produced by the original team could be used as a template for data extraction if appropriate.
4. Our updated review would follow seamlessly from the original work.

Areas of research activity and research gaps identified in the mapping review helped inform and finalise the scope for the targeted systematic review.

Literature search for the mapping review

The literature search was informed by methods of identifying the literature described by McNally and Alborz.[25]

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We searched the following databases (seven of the 14 bibliographic databases in the Alborz *et al.* review[21]):

- MEDLINE (via Ovid, 1946 to 2018)
- Science Citation Index Expanded; Social Sciences Citation Index (via Web of Science, 1900 to 2018)
- The Cochrane Library
    - Cochrane Database of Systematic Reviews (1996 to 2018)
    - Database of Abstracts of Reviews of Effect (1995 to 2015)
    - Cochrane Central Register of Controlled Trials (1898 to 2018)
    - Health Technology Assessment Database (1995 to 2016)
    - NHS Economic Evaluations Database (1995 to 2015)
- Cumulative Index to Nursing and Allied Health (via EBSCO*host* 1974 to 2018)
- Applied Social Science Index (via ProQuest, 1987 to 2018)
- PsycINFO (via Ovid, 1806 to 2018)
- Educational Resources Index (via ProQuest, 1966 to 2018).

The database search strategy was adapted from methods described in the existing review for identifying the literature.[25] The search strategy comprised key terms for ID and access. Additional terminology was added to include the primary care setting (e.g. GPs, dentists, optometrists) and recent or current legislation or guidance terms, such as the Disability Discrimination Act and 'reasonable adjustments'. The existing review was conducted between 1980 and 2002 so this search was limited from 1 January 2002 onwards, thereby ensuring continuity of the evidence base. The search was also restricted to English-language and human studies. The search strategy is provided in *Appendix 1*.

Supplementary searching included grey literature searching of the websites of key UK charities and associations to identify reports about initiatives to improve access to services for people with ID. Snowballing by citation searching key studies was also performed in Google Scholar™ (Google Inc., Mountain View, CA, USA) and reference lists of included papers were scrutinised.

Screening

Study screening and selection was undertaken in EPPI-Reviewer 4 (Evidence for Policy and Practice Information and Co-ordinating Centre, University of London, London, UK). A team of three reviewers screened the identified references. An initial 100 references were screened by all three reviewers to check for consistency. Any queries were resolved through discussion with the other two reviewers.

Study selection was undertaken according to the inclusion criteria outlined in *Table 1*.

Following screening at the title and abstract stage, the references that potentially met the inclusion criteria were considered further, and data were extracted for inclusion in the review. Citations not meeting the inclusion criteria were excluded.

Data extraction

Data extraction based on abstracts was undertaken in EPPI-Reviewer 4 using a template designed for the mapping review (see *Appendix 2*). Mapping at the abstract level is a typical component of systematic mapping review methodology, given that the primary purpose is to plan a subsequent review. The extraction form comprised the following items: paper identifying code, author, date, study design, setting – country, health-care professional (HCP), specialist topic, study population, sample size, needs assessment, study

TABLE 1 Study selection criteria

Criterion	Eligibility
Population	• People with ID of any age accessing health services • Carers of people with ID (carers could include family members, friends, paid carers, staff working in day centres, personal assistants and anyone else who might provide support to access health services) accessing health services on behalf of someone with ID
Setting	• 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 Evidence from any of the following settings: the UK, Canada, Australia, New Zealand or Europe The above settings have been selected because of their similar health-care systems. Papers from the USA will be excluded because US private service provision is not comparable with the UK primary care setting. However, the mapping review will investigate the impact of including qualitative research papers from the USA depending on their relevance
Outcomes	Access to a service Alborz *et al.*[21] distinguished between access and effectiveness and focused on the ability to use a service rather than whether or not the service was 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 to and facilitators of 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 ID populations published since 2002
Other limitations	English language only Evidence published since 2002; the Alborz *et al.*[21] review searched up to 2002

outcomes, tools used to measure outcomes, study result, and barriers and facilitators. For mapping purposes, references were categorised into sets according to HCP or specialist topic, and 'needs assessment' papers were also considered as a separate categorisation. Data extraction was completed using data included in each abstract. If the abstract was unavailable, brief details were extracted from the title for the mapping review on the understanding that the full text would be obtained if included in the targeted systematic review. An example of a completed data extraction table is in *Appendix 3*.

Patient and public involvement

During the mapping review, we consulted people with ID, family carers and formal paid carers so that the review of access to health care for people with ID could be informed by the views and experiences of stakeholders. The aim of this consultation was to:

- illuminate the model of access to health care for people with ID
- inform and refine our search strategies by identifying barriers to accessing health care and any solutions developed
- identify gaps in the literature.

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We contacted the clinical director and senior commissioning manager for services for people with ID in a Clinical Commissioning Group and asked them to identify relevant community groups for people with ID and their carers. We sent information about the review to these groups and asked to visit to discuss their experiences of accessing health care.

We met a group of people with ID ($n = 8$, 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 ($n = 2$). These were convenience samples depending on who attended the group or meeting on the day we visited.

Discussions were loosely guided by a topic guide covering how people identify a health need, what actions they take, the issues influencing their decision to take a particular course of action and the barriers to and facilitators of their access and use of the chosen service.[21] Notes were taken during each meeting and these were written up afterwards using bullet points to document the barriers and facilitators. These were organised under the headings 'identifying and communicating symptoms of ill health', 'arranging and attending health appointments' and 'continuing access to services'. A brief summary is provided in *Table 2*.

The barriers and facilitators were used to identify relevant search terms and for future comparison with the barriers and facilitators identified in the qualitative literature.

Detailed notes from the patient and public involvement (PPI) meetings are provided in *Appendix 4*.

TABLE 2 Patient and public involvement discussions

Barriers	**Facilitators**
Identifying and communicating symptoms of ill health	
• Difficult for individuals to understand that some conditions are asymptomatic but potentially serious, for example high blood pressure • People do not always say when there is a minor problem and so it becomes a major problem • Determining when a symptom needs further investigation, for example abdominal pain	• Having a consistent support worker who knows the person so they can recognise when something is wrong
Arranging and attending health appointments	
• Booking transport for same-day doctors' appointments • Availability of support staff to attend same-day appointments • Unhelpful attitudes of reception staff • Fear of unfamiliar place/people/procedures	• Offering home visits • Quiet area to wait in • Being 'understood': that means being shown respect, listened to, given information you can understand • Good communication between service providers and carers
Continuing access to services	
• Treatment not accepted by patient, for example refusal to attend cervical screening • May need to access several different services that are difficult to co-ordinate • Text appointment reminders may be ignored by person with ID • Voicemail appointment messages can be confusing and alarming	• Consistent person coordinating appointments • Record of when appointments are due, for example dental check-ups

We plan to present our findings following completion of the targeted review with the pre-existing groups of people with ID, and their paid and unpaid carers. Comments on the *Plain English summary* were received from the facilitator of the pre-existing group of people with ID.

We have continued to involve patients and members of the public through the Sheffield Evidence Synthesis Centre PPI group. Members of this group were asked to comment on the scope of the targeted systematic review.

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Chapter 3 Mapping review findings

Literature search

The database search retrieved 7558 records. Following deduplication, a total of 3972 records remained for screening. A total of 594 references were identified as 'potentially include'. After further scrutiny, 181 of these were excluded. Common reasons for exclusion were that the study setting was secondary rather than primary care, the study was about a different population, the study was not about access to health care and the study was not a research study. A total of 413 papers met the criteria for inclusion in the mapping review (*Figure 1*).

Results

The mapping review comprised 413 studies.

Study design

All included abstracts were coded with one of the following study designs: quantitative, qualitative, mixed methods, review or unclear. *Figure 2* shows the number of papers coded with each study design.

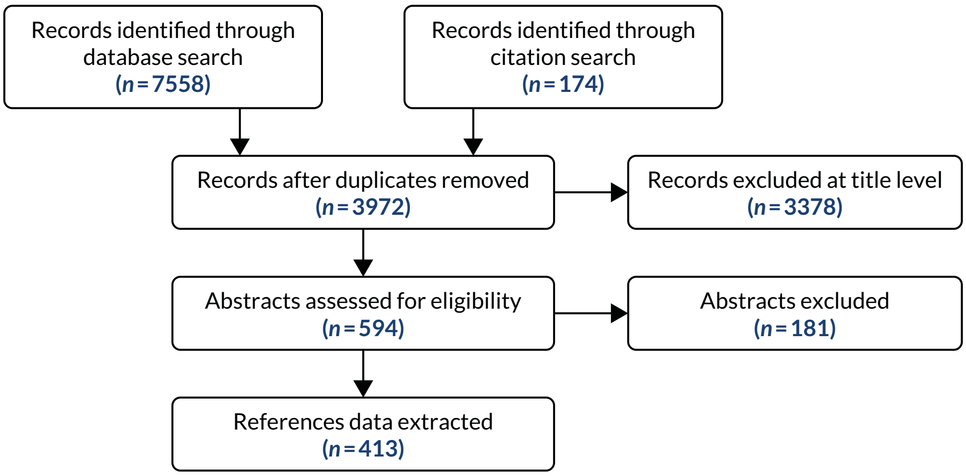

FIGURE 1 Modified PRISMA flow diagram for mapping review.

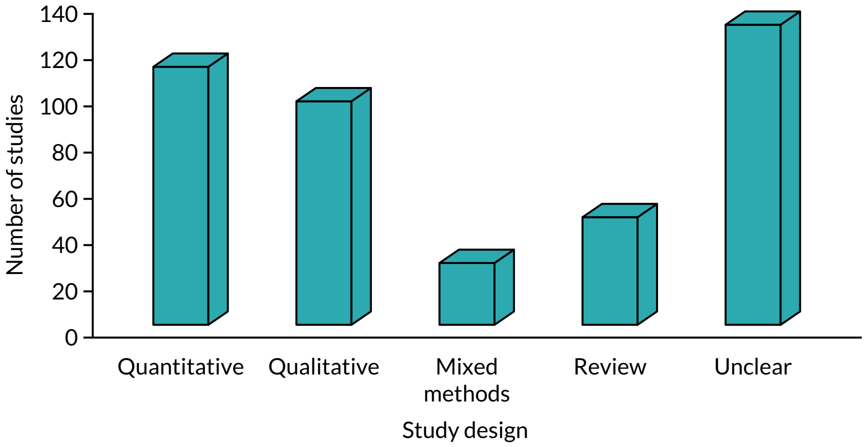

FIGURE 2 Chart detailing study designs.

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The chart shows an almost equal distribution of quantitative and qualitative studies. The large number of papers coded as having an unclear study design was a result of the limited information available in abstracts.

Geographical distribution of studies

Table 3 details the country of origin of included studies. The mapping review extracted data from abstracts only, meaning that country information was not available for a large proportion ($n = 136$) of the studies. The largest proportion of research studies investigated populations in the UK, followed by the USA, Australia and Canada.

Health-care professional

Table 4 shows the number of studies in the mapping review in which the role of a specific HCP was researched. A number of the studies were undertaken with multiple HCP participants.

General practitioner

One hundred and twenty-seven of the studies specifically investigated the GP role. The papers investigated a broad range of topics, including quality of primary health care, health checks, education or training for GPs, communication skills of GPs, out-of-hours primary care services and how to identify patients with an intellectual disability.

TABLE 3 Geographical distribution of studies

Country	Count
UK	142
USA	33
Australia	27
Canada	20
Ireland	12
The Netherlands	11
France	3
Norway	2
Spain	2
China	1
Germany	1
Greece	1
Hong Kong	1
India	1
Malaysia	1
Poland, Romania, Slovenia	1
Saudi Arabia	1
Taiwan	1
International (i.e. multiple countries)	16
Not stated	136

TABLE 4 Number of studies specifying the role of health professional

Code: HCP	Count
GP	127
Dentist	41
Optometrist	11
Pharmacist	7
Other community staff	101
Total	287

Dentist

Forty-one papers researched the role of dentists in treating people with ID. These studies investigated a variety of topics, including factors affecting access to dental service, oral care needs of people with ID, experiences of dental services from the viewpoint of people with ID and their carers, training of dentists and ethical issues to consider when treating patients with ID.

Optometrist

The role of the optometrist was researched in 11 of the included studies. These studies investigated the visual health needs of adults and children with ID, diabetic eye screening, inequalities in access to eye care and screening and how optometrists can provide eye care services to this population.

Pharmacist

Seven of the included studies related to the role of pharmacists. Topics researched included knowledge that people with ID have about their medicine, information that they want about their medications, medication-related interventions from pharmacists and whether or not pharmacists could play a role in blood pressure screening for hypertension in this population.

Other community staff

The 'other community staff' category covered a diverse range of staff, including practice nurses, health visitors, occupational therapists, community nurses and intellectual disability care staff. Within this large category, issues investigated included the needs of the population, the experiences of professionals and people with ID, health information exchange, the attitudes of professionals towards this population, training of staff, rural health care and the needs of specific groups within this population, including women and children.

Specialist topic

Table 5 shows the number of studies in the mapping review that related to services for specific conditions.

TABLE 5 Number of studies describing a specific area of service provision

Code: specialist topic	Count
Mental health	30
Palliative care	25
Sexual health	21
Other	105
Total	176

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Sexual health

The delivery of sexual health services was researched in 21 of the included studies. The populations investigated in these studies can be subdivided into people receiving services (14 studies), professionals delivering services (five studies) and carers of people receiving services (one study). In addition, there was one study researching family carers, support workers and professional staff, as shown in *Figure 3*.

The studies investigated sexual health services for people with ID. Topics of research included services available, self-advocacy, experiences, barriers, contraception, cervical smear testing, capacity to consent to sexual relations, service provision for gay men, and breast screening.

Palliative care

The delivery of palliative care services to people with ID was researched in 25 of the studies. The populations investigated in these studies can be subdivided into people receiving services (11 studies) and professionals delivering services (12 studies); one study researched a person with ID and the professionals involved in his care, and another study considered people with ID and their carers (*Figure 4*).

The included studies researched challenges in providing palliative care to this population, identification of needs by HCPs, communication about illness, death and dying, and the role of carers in end-of-life care.

Mental health

Thirty of the studies in the mapping review researched the delivery of mental health services to people with ID. The populations investigated in these studies can be subdivided into people receiving services (18 studies) and professionals delivering services (seven studies); three studies researched people receiving the service, their carers and the professionals delivering the service, and two studies considered people with ID and their carers. The breakdown is shown in *Figure 5*. These studies investigated services

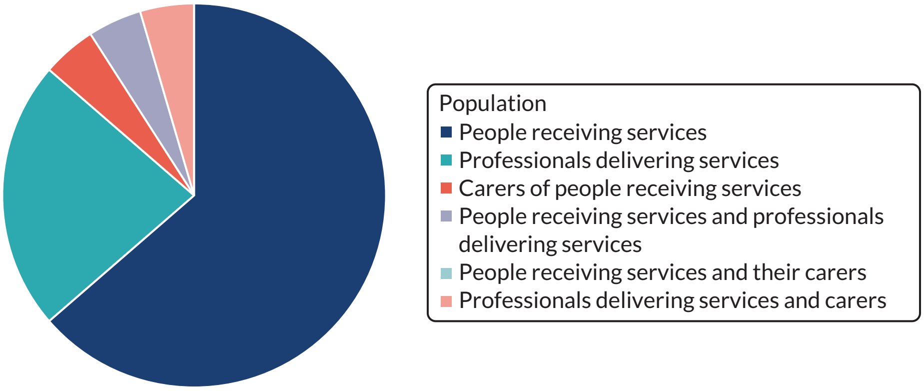

FIGURE 3 Pie chart of broad populations researched in sexual health studies.

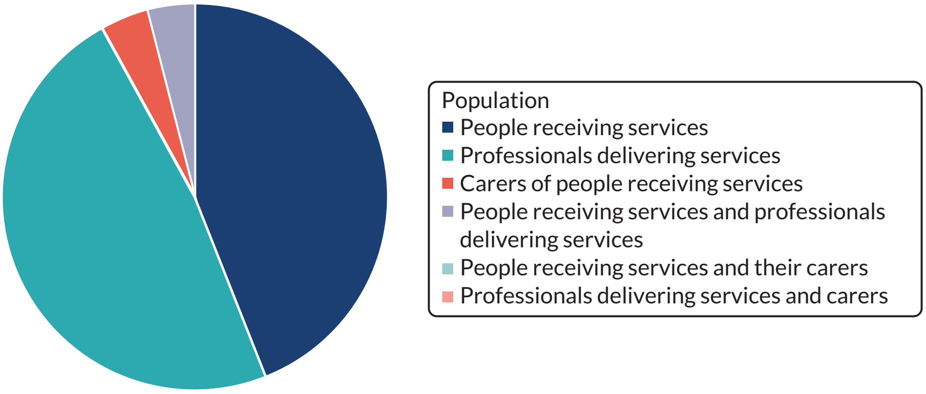

FIGURE 4 Pie chart of broad populations researched in palliative care studies.

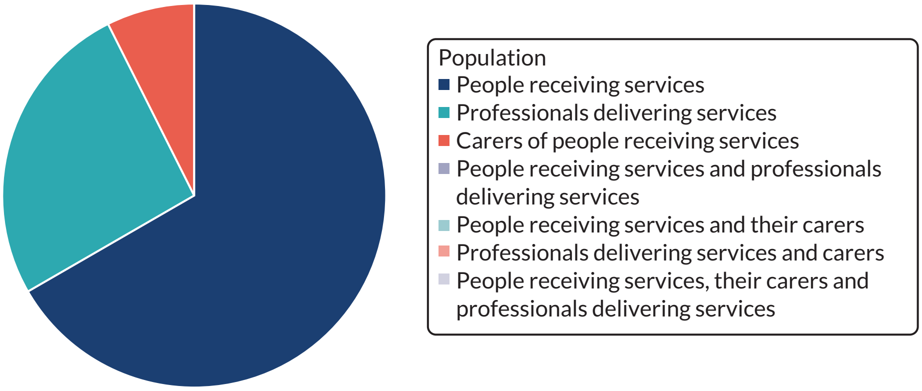

FIGURE 5 Pie chart of broad populations researched in mental health studies.

available for people with ID and mental health problems, access to these services, experiences of these services and the needs of people with ID who develop dementia.

Other

The ‘other’ category covered a broad range of specialist topics; more detail of the different areas of service provision is provided in *Table 6*.

The ‘other’ category covers a variety of topics. Papers about cancer screening were the most common, followed by papers about health checks/assessments.

Needs assessment

Twenty of the 413 included references were coded as relating to needs assessment. *Table 7* provides details of the different populations investigated.

TABLE 6 Details of different areas of service provision covered by ‘other’ category

Specialist topic	Count
Access to health care	3
Accessible information	1
Autism	1
Blood test	3
Cancer care, not necessarily palliative	2
Cancer information	1
Cancer screening (includes breast and cervical)	17
Children and young people	4
Communication skills	3
Dementia	4
Diabetes services	4
Epilepsy	1
General practice	1
Gynaecological/reproductive health	1
Health checks/assessments	13
Health inequalities	1
Health information exchange	1

continued

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TABLE 6 Details of different areas of service provision covered by 'other' category (*continued*)

Specialist topic	Count
Health promotion	5
Health status, care utilisation and medical outcomes (review)	1
Health visiting	1
Hearing	2
Mainstream health services	1
Maternity services	3
Older people	4
Oral health care	3
Out-of-hours care	2
Pain	2
Polypharmacy and medication review	1
Primary care	3
Range of needs	1
Research	1
Satisfaction with care	1
Social prescribing	1
Substance use	1
Preventative health care	3
Rural health	1
Training	1
Transition paediatric to adult health care	1
Unmet need	1

TABLE 7 Populations investigated in needs assessment studies

Population	Number of references
Older people	5
Children and young people	4
Staff working with people with ID	2
Palliative care needs of people with ID	2
Adults with ID	1
Mental health needs of people with ID	1
Adults with cerebral palsy and ID	1
Men with HIV with or without ID	1
People with ID and dementia	1
Evaluation of a needs assessment tool	1
Not given	1

HIV, human immunodeficiency virus.

Reasonable adjustments

Several articles specifically considered changes or reasonable adjustments introduced to make services more accessible; examples are a specialist multiprofessional visual assessment clinic at a day centre to provide appropriate eye care to people with ID, techniques to engage people with ID in physical health assessment measures and the implementation of health checks.

Grey literature

A total of 16 UK-based sources (mainly comprising charitable associations) were searched for relevant grey literature (see *Appendix 1*). Of these, seven provided no further information relevant to the review. The remaining nine sources linked to between one and six documents that appeared relevant from the title, with a total of 28 documents potentially meeting our inclusion criteria.

Twenty-three of the documents were excluded on the grounds that they included no data (these were mainly guidance documents). Of the remaining five reports, one was a short review of the literature, thus providing a source for further identification of includable studies, three contained practice examples and case studies (without reporting outcome data) and one was a qualitative research study (*Table 8*).

Two reports considered the implementation and uptake of health checks; one focused on reasonable adjustments to encourage uptake of screening for cervical, breast and bowel cancer; one identified barriers to accessing oral health care; and a final, Mencap-led, research study explored access to pharmacy services.

Data in the mapping review related to barriers and facilitators

Data relating to potential barriers to and facilitators of access for people with ID were extracted from results sections, where available. Of the included citations, 87 abstracts mentioned barriers to and 47 mentioned facilitators of access to primary health care. From the information available in the abstracts, we categorised the barriers and facilitators (some abstracts included more than one) in *Tables 9* (barriers) and *10* (facilitators).

TABLE 8 Grey literature documents

Author(s) and date	Title	Relevant data	Section(s) and page(s)
Faculty of Dental Surgery 2012[26]	*Clinical Guidelines and Integrated Care Pathways for the Oral Health Care of People with Learning Disabilities*	Guidelines with a short review of barriers to oral health care	Barriers to oral health care, pp. 7–10
Public Health England 2015[27]	*Health Checks for People with Learning Disabilities: Including Young People Aged 14 and Over, and Producing Health Action Plans*	Suggestions for improving uptake of health checks (no outcome data)	Practice examples and case studies, pp. 11–14
Public Health England 2016[28]	*Making Reasonable Adjustments to Cancer Screening*	Background: screening programmes, short review of research, short case studies of reasonable adjustments (no outcome data)	Resources and case studies, pp. 14–44
Public Health England 2016[29]	*People with Learning Disabilities in England: Main Report 2015*	Initiation and uptake of health check for people with ID	Health services, pp. 22–23
The Disability Partnership 2016[30]	*Evaluation Report of the 2015–16 Mencap-led Pharmacy Project*	Results from surveys, interviews and focus groups about access to pharmacy services	All (methods and results are included)

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TABLE 9 Numbers of citations including barriers to access

Barrier	Number of citations
Wider determinants	
Independent living	1
Undefined roles for carers	1
Lack of knowledge of services	1
People with ID having difficulties attending (e.g. distance, finances, physical difficulties)	3
People with ID not understanding information/health literacy	2
ID factors (general)	1
People with ID communication skills	1
Identification of need	
Lack of perceived need/lack of willingness/fear of intervention	4
Organisation of health care	
Organisational/primary care characteristics	5
Facilities	1
Partnership working	1
Lack of services (including out of hours) and funding	2
Waiting times	1
Time/length of appointment times	2
Late referrals	1
HCPs	
Lack of guidelines/support for staff	2
Staff training/education	3
Staff knowledge/skill/confidence level	6
Staff awareness	2
Staff experience with people with ID	2
Identification of people with ID	1
Access to first-contact health care	
Interpersonal skills/welcoming	2
Staff communication skills	11
Staff attitudes and behaviour/lack of understanding/not supporting autonomy/lack of cultural sensitivity	7
Opportunities to engage in discussion about care	1
Consent	2
Comorbidities	1
Continuing health care	
Continuity of care	1
Monitoring health problems	1

TABLE 10 Numbers of citations including facilitators to access

Facilitator	Number of citations
Wider determinants	
Social cohesion/community connectedness	2
Residence (in relation to services)	2
Family characteristics/support/advocacy for people with ID	3
Liaison between family and carers	1
Education (HCP/peers)	1
Caregiver support/interventions	3
Identification of need	
Health check programmes/regular health checks	2
Organisation of health care	
Financial incentive for health checks (practice)	1
Walk-in clinics	1
Co-ordinated care	1
Adapted resources/methods	4
Lead practitioner or GP with a special interest	1
Data-sharing resources	1
Telephone accessibility	1
HCPs	
Teamwork/interprofessional working	5
Joined-up approach across agencies	2
Adopting and encouraging best practice	2
Staff training/shared learning	6
Staff skills/competence	2
Access to first-contact health care	
Timeliness and frequency of appointments	1
Familiar environment	1
Personal greeting in waiting room	1
Begin consultation at once	1
Communication aid	1
Advance planning/preparation before consultation	6
Written care plans	1
Knowledge of the person and their routines	3
Respectful HCP–service user relationship/personal connection/patience/taking time/patient centred/empowering	8
Helping people with ID understand/learn skills/recognising and minimising treatment effects	3
Counselling (screening)	1
Education/information	5
Reassure/evaluate anxiety/pain	1
Continuing health care	
Signposting and appropriate referral	1
Continuity/communicate with people with ID/carer outside consultation	3

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Identified barriers were often accompanied by facilitators that were suggested or implemented to minimise the impact of the barriers; for example, an identified lack of communication skills in HCPs could be modified by training staff or by people with ID using communication aids.

Professional communication, knowledge, skills and attitudes appeared to be commonly reported barriers to people with ID seeking primary health care. This is mirrored by facilitators relating to the professional, including service user relationship, staff training, and planning before a consultation. Our adding up of the numbers of citations within these categories needs to be considered with caution; potentially it might not reflect the literature as a whole, as abstracts provide only partial information. It was intended that the information derived from characterising the literature in this way during the mapping review would assist us in prioritising the focus of the systematic review and considering where and how the research in this area had developed since the original review by Alborz *et al.*[21]

Chapter 4 Mapping review discussion

The mapping review identified a large number of studies on access to health-care services for people with ID. The evidence available for barriers to identification of need and continuing care appeared, from this review, to be less than for other domains of the Alborz *et al.*[21] model. Many barriers and facilitators identified in abstracts resonated with themes generated from the PPI discussions, particularly in arranging and attending health appointments, although less so at this point in identifying and communicating symptoms of ill health, and continuing access to services was also reported less often.

The Alborz *et al.*[21] review found that the evidence base on general practice was larger than those on many other areas of interest, and this mapping review found that studies specifying a role for the GP constituted the most common single HCP category. The 2003 review[21] found only one study on access to optometry services, and we similarly found only a small number considering the specific role of optometrists in screening and eye care, and some on the unmet eye care need of this population. A small number of studies were found on the organisation of dental services in the Alborz *et al.*[21] review, but no studies were found about entry point access. By contrast, we found a reasonably sized body of literature related to dentists, dental services and oral care.

Limitations of mapping review

Although mapping reviews use systematic methods to identify, screen and code studies, a mapping review is not a systematic review. Mapping reviews generally omit some standard features of systematic reviews, for example study quality assessment, and do not attempt to assess the effects of interventions. The role of mapping reviews is to provide a descriptive account of the published literature and this should be taken into account when assessing the findings of this part of the overall evidence synthesis. The strength of the mapping review is in identifying areas where opportunities for further research or review are either present or not present and not to support actionable practice. For this reason, quality assessment is usually reserved for detailed follow-up analysis using the full text of included studies.

Mapping reviews can be based either on the full text of a limited number of identified studies or, more typically, on the abstracts of a wider literature base. In this specific case, informed by the previous Alborz *et al.*[21] review and preliminary scoping, we decided that mapping on the basis of abstracts only was the preferred option for logistical reasons. This was particularly appropriate given that revisiting key studies would be necessary for the subsequent systematic review. We recognised that abstracts are of variable quality and may be either informative (e.g. containing a list of key barriers and facilitators) or indicative (e.g. stating that a list of barriers and facilitators is present in the full text of the study). In addition, there is some evidence that the contents of abstracts may not fully reflect the detail of the papers, as authors may omit to revise abstracts when the main body of the text undergoes manuscript revision.

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Chapter 5 Targeted systematic review methods

Aims and research questions

This targeted systematic review focused on evidence from the UK, building on the findings of the mapping review. The revised protocol for the targeted systematic review is provided in *Report Supplementary Material 2*.

The key elements of the targeted systematic review were:

1. development of the research questions based on the findings of the mapping review and information from PPI meetings
2. a focused systematic database search following inspection of the mapping review findings
3. a full data extraction of relevant studies
4. a quality assessment of included full peer-reviewed papers, and no formal quality assessment of conference abstracts or grey literature.

Research questions

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

Search strategy

The findings from the mapping review helped develop the search strategy for the targeted systematic review. Searches covered the period 2002–18. 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 SDO review) to September 2018. A validated filter[31] was used to identify UK studies. Further details of the database search, including a sample search strategy, can be found in *Appendix 5*. Further evidence was sought by contacting topic experts, people with ID and their carers. Broad searches for grey literature on ID (irrespective of setting) that were conducted during the mapping review provided the grey literature for the targeted review.

Selection of articles

Search results were uploaded to EPPI-Reviewer 4 for title and abstract screening. Screening was performed by a team of three reviewers, with a random sample of 10% of records from each reviewer double screened by one of the reviewers. Full papers were obtained for records that appeared potentially to meet the inclusion criteria (*Table 11*) and these were also uploaded to EPPI-Reviewer 4. Screening on full text followed a similar process to title and abstract screening. Any queries were resolved by discussion. The list of papers excluded at full-text review is available in *Appendix 6*.

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TABLE 11 Inclusion criteria for the targeted systematic review

Criteria	Eligibility
Population	• People with ID aged ≥ 16 years accessing health-care services directly or indirectly, in recognition of the fact that many people with ID rely on others to facilitate their access to services[32] • Carers of people with ID accessing health-care services on behalf of someone aged ≥ 16 years with ID. Carers could be family, friends and paid or unpaid carers • We anticipate that reported studies will include people identified as having ID because of their use of statutory services for this population and this may be used as a proxy definition for ID
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 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 to and facilitators of accessing and using services • Qualitative research on the acceptability of reasonable adjustments to services • Descriptive access research • Comparative access literature • Evaluation studies Systematic and non-systematic reviews were not included in the review but were considered as sources of additional references
Other limitations	English language only Evidence published since 2002. The Alborz *et al.*[21] review searched up to 2002

IAPT, Improving Access to Psychological Therapies.

Data extraction

Data extraction was completed in EPPI-Reviewer 4 using a mix of tick-box and open questions (see *Appendix 7*). We focused on extracting data relating to the barriers to and facilitators of service access, service acceptability and effectiveness of the implementation of reasonable adjustments to primary care services for people with ID. An example data extraction for one of the included studies is in *Appendix 8* and the data extraction table for the grey literature is in *Appendix 9*.

Quality assessment

Risk of bias was assessed using validated checklists published by the US National Heart, Lung and Blood Institute [URL: www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools (accessed 19 November 2018)] for quantitative study designs [controlled (randomised and non-randomised) intervention studies, observational cohort and cross-sectional studies, case–control studies and before-and-after studies with no control group]. Qualitative studies were assessed with the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies [URL: https://casp-uk.net/casp-tools-checklists/ (accessed 19 November 2018)]. Mixed-method studies were assessed using the appropriate checklist for the predominant methodology of the study.

Analysing and synthesising data

We performed a narrative synthesis of the evidence. The structure of the synthesis was determined by the themes that emerged from the included studies. We drew on a pathway of care model to explore evidence relating to the patient journey of care, including examination of the barriers and facilitators or influencing factors at each point in the pathway.

Patient and public involvement

Patient and public involvement in the development and conduct of the review is reported in *Chapter 2*. Further to this, we discussed the findings and recommendations from the review with a family carer representing the group of family carers ($n = 1$) and with a group of people with LDs ($n = 10$) 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, whether or not there was anything missing and whether or not there was anything they would like to add to the findings or recommendations.

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Chapter 6 Targeted systematic review results

Results of literature search

The 413 potentially relevant references from the mapping review were rescreened against the new inclusion criteria while the additional literature searches for the targeted review were being completed. The database search for the targeted review retrieved 9067 references. After de-duplication of the search results, 5957 additional unique records were available for screening (*Figure 6*), giving a total of 6370 to be screened.

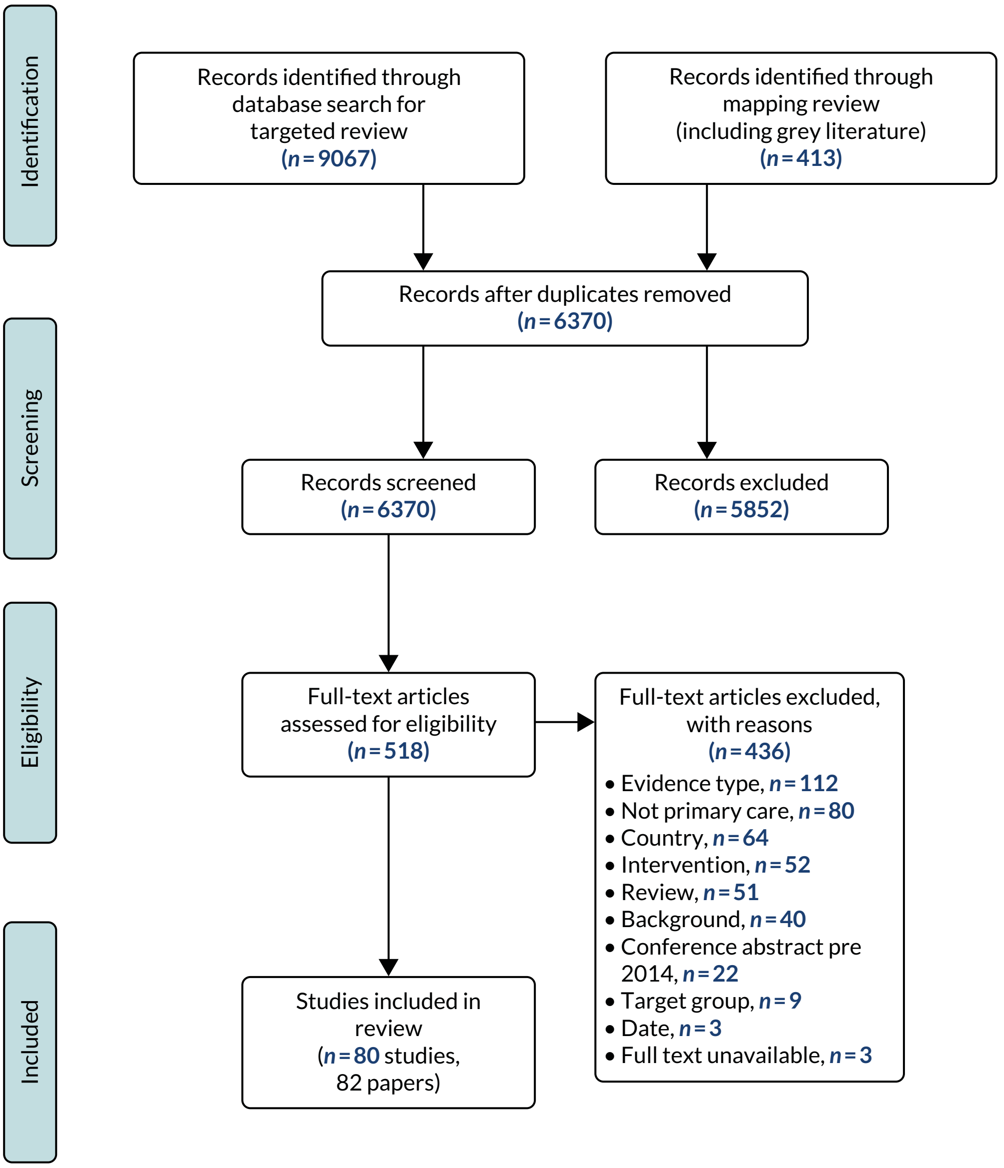

FIGURE 6 The PRISMA flow diagram for the targeted systematic review.

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Screening

The screening process was divided between three reviewers. A calculation of inter-rater agreement was made. A kappa coefficient was calculated that demonstrated excellent agreement between the reviewers ($\kappa = 0.933$, 95% CI 0.904 to 0.962). A total of 518 references were screened as 'include' based on a preliminary title and abstract screen. On further scrutiny of the full text, 436 of these were excluded. Common reasons for exclusion were that the study's setting was secondary not primary care, the study was about a different population, the study was not about access to health care and the study was not a research study. Eighty-two publications reporting 80 studies were included in the targeted systematic review.

Study characteristics

The review synthesised the evidence from 80 studies reported in 82 publications; an alphabetical list of the included studies is in *Appendix 10*. All of the included studies were conducted in the UK and investigated adults with ID and their carers (paid or family carers or primary care health professionals working with individuals with ID).

The synthesis was based around a pathway of care encompassing identifying need, accessing services and interaction during a consultation. The pathway model (*Figure 7*) was not prespecified but emerged from the examination of included study characteristics and was agreed by consensus among the review team. Included studies were grouped into the three clusters corresponding to the stages of the patient pathway. In addition, some studies evaluated innovations/interventions that aimed to improve access, which had an impact at different steps in the pathway model, and these formed a fourth cluster.

Influencing factors (barriers and facilitators) of access at each stage were also identified within the data. A common group of influencing factors that appeared to act at all stages was used to structure the narrative synthesis for each cluster of studies.

The evidence will thus be outlined within the following four clusters: identifying needs (14 studies), accessing services (24 studies), interaction during a consultation (19 studies) and interventions to improve access (23 studies).

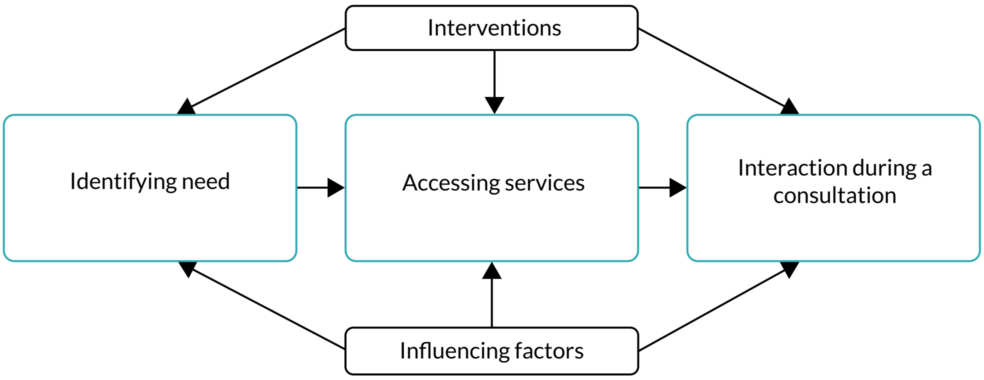

FIGURE 7 Pathway model.

Identifying need

Fourteen studies reported in 16 publications, published from 2003 to 2017, were included in this group (*Table 12*). Of these, three dealt with general practice,[44,45,48] three dealt with a range of primary care services,[36,37,49] three dealt with carers working at residential or supported living homes[33–35,43] and two dealt with formal and informal carers of people with ID in residential or family homes.[38,39] The other three studies dealt with audiology services,[42] cervical and cancer screening[40] and sexual health.[41] The majority of the studies included in this cluster had a qualitative design.

Accessing services

Twenty-four studies, published between 2003 and 2017, were included in this group (*Table 13*). Of these, six dealt with a range of primary care services,[50,55,58,62,66,67] six dealt with with general practice,[51–53,57,60,70] five dealt with cancer screening,[59,63,68,69,72] two dealt with dental services,[56,64] two dealt with mental health services,[54,61] one dealt with diabetic retinopathy screening[65] and one dealt with sexual health.[71] The majority of included studies used a cross-sectional (e.g. survey or audit) or qualitative (e.g. interviews or focus groups using qualitative methods for data analysis) design. Only two studies used a cohort or case–control design[63,69] and two were classed as mixed methods.[54,71]

TABLE 12 Studies included in the identifying needs cluster

First author and year of study	Type of service	Type of study
Beacroft 2010/11[33,34]	Residential and supported living homes in Surrey	Cross-sectional[33] Qualitative[34]
Bland 2003[35]	Nursing homes	Cross-sectional
Bollard 2017[36]	All services	Qualitative
Donovan 2002[37]	All services	Qualitative
Findlay 2014/15 (same study)[38,39]	Formal and informal carers	Qualitative
Hanna 2011[40]	Cervical screening and other cancer screening	Cross-sectional
McCarthy 2009[41]	Sexual health	Qualitative
McShea 2016[42]	Audiology	Qualitative
Northway 2017[43]	Supported living accommodation for people with ID in Wales	Qualitative
Turk 2012[44]	GP	Cross-sectional
Walker 2016[45]	GP	Very few data; mix of literature review; many relevant data linked to hospitals
Willis 2015[46]	Carers	Qualitative
Wilson 2010[47]	All services	Qualitative
Young 2012[48]	GP	Qualitative

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TABLE 13 Studies included in the accessing services cluster

First author and year of study	Type of service	Type of study
Ali 2013[50]	All services	Qualitative
Allgar 2008[51]	GP	Cross-sectional
Black 2004[52]	GP	Qualitative
Carey 2016[53]	GP	Cross-sectional
Chinn 2016[54]	IAPT	Mixed methods
Cooper 2011[55]	All services	Cross-sectional
Doshi 2009[56]	Dentist	Cross-sectional
Jones 2008[57]	GP	Qualitative
Lennox 2003[58]	All services	Cross-sectional
Lloyd 2014[59]	Cervical screening	Qualitative
Lodge 2011[60]	GP	Cross-sectional
McNally 2015[61]	Community mental health	Qualitative
Nicholson 2011[62]	All services	Cross-sectional
Osborn 2012[63]	Cancer screening	Cohort
Owens 2011[64]	Dentist	Qualitative
Pilling 2015[65]	Diabetic retinopathy screening	Cross-sectional
Raghavan 2007[66]	All services	Cross-sectional
Redley 2012[67]	All services	Qualitative
Rees 2011[68]	Cancer screening	Cross-sectional
Reynolds 2008[69]	Cervical screening	Case–control
Russell 2017[70]	GP	Cross-sectional
Starling 2006[6]	Eye care	Cross-sectional
Williams 2014[71]	Sexual health	Mixed methods
Wood 2007[72]	Cervical screening	Qualitative

IAPT, Improving Access to Psychological Therapies.

Interaction during a consultation

Nineteen articles, published between 2004 and 2017, were included in this group (*Table 14*). Six of these studies dealt with GP services,[75,79,82,83,91] four dealt with a range of primary services,[74,77,78,84] three dealt with palliative or end-of-life care service,[86,88,90] two dealt with sexual health services,[81,85] two dealt with diabetes services,[73,89] one dealt with dental services[80] and one study dealt with non-specific cancers in this population.[87] The majority of these studies had a qualitative design,[73–77,80,82,83,85,87,89,90] a few had a cross-sectional study design[78,79,81,84,85,88,91] and one was a case study.[86]

TABLE 14 Studies included in the interaction during a consultation cluster

First author and year of study	Type of service	Type of study
Brown 2017[73]	Diabetes	Qualitative
Gates 2011[74]	All services	Qualitative
Goldsmith 2013[75]	GP	Qualitative
Hames 2006[76]	GP	Qualitative
Hebblethwaite 2007[77]	All services	Qualitative
Heyman 2004[78]	All services	Cross-sectional
Jones 2007[79]	GP	Cross-sectional
Lees 2017[80]	Dental	Qualitative
McCarthy 2011[81]	Sexual health	Cross-sectional
Murphy 2006[82]	GP	Qualitative
Perry 2014[83]	GP	Qualitative
Powrie 2003[84]	All services	Cross-sectional
Thompson 2008[85]	Sexual health	Cross-sectional and qualitative
Tuffrey-Wijne 2002[86]	Palliative and end-of-life care	Case study
Tuffrey-Wijne 2009[87]	Cancer	Qualitative
Tuffrey-Wijne 2005[88]	Palliative and end-of-life care	Cross-sectional
Turner 2014[89]	Diabetes	Qualitative
Watchman 2005[90]	Palliative and end-of-life care	Qualitative
Williamson 2004[91]	GP	Cross-sectional

Innovations to improve access (including health checks)

Twenty-three studies evaluated innovations to improve access (*Table 15*). The majority of the studies investigated innovations within GP services.[19,93–101,103–105,107–109,111–113] The remaining studies reported innovations in eye health,[92] in Improving Access to Psychological Therapies (IAPT), in cardiovascular disease[106] and for staff in care homes.[110] One of the included studies was a cluster randomised controlled trial,[100] but most had a cross-sectional design.

Study quality

The results of the quality assessment for all included studies, classified by study design, are presented in *Appendix 11*, *Tables 27–32*. One case study[86] was included in the review but not assessed for quality. The methodological limitations of the included studies are discussed in this section. Overall, the studies in the review were rated as being at relatively high risk of bias. Only two were controlled intervention studies[92,100] and only one of these was randomised (by clusters).[100] The randomised trial appeared to be rated as being at low risk of bias, although blinding of outcome assessment was incomplete and the study did not meet the criteria for high adherence to the intervention (see *Appendix 11*, *Table 27*). The non-randomised study[92] had a number of weaknesses, including differences between groups at baseline, differences in background treatments (other than the intervention being evaluated) and lack of a sample size/power calculation (see *Appendix 11*, *Table 28*).

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TABLE 15 Studies included in the innovations to improve access cluster

First author and year of study	Type of service	Type of study
Adler 2005[92]	Eye health	Cross-sectional
Baxter 2006[93]	GP	Cross-sectional
Biswas 2005[94]	GP	Cross-sectional
Buszewicz 2014[95]	GP	Cohort
Cassidy 2002[96]	GP	Case control and qualitative
Chauhan 2010[97]	GP	Cohort
Chauhan 2012[98]	GP	Cohort and qualitative
Codling 2007[99]	GP	Cross-sectional
Cooper 2014[100]	GP	Cluster randomised controlled trial
Cooper 2006[101]	GP	Case–control
Dagnan 2018[102]	IAPT	Before and after
Felce 2008[19]	GP	Retrospective cohort (medical records scrutiny)
Ford 2015[103]	GP	Cross-sectional
Glover 2013[104]	GP	Retrospective cohort (routine data trends)
Harrison 2005[105]	GP	Before–after
Holly 2014[106]	Cardiovascular	Cross-sectional
Martin 2004[107]	GP	Cross-sectional
McConkey 2015[108]	GP	Cross-sectional
Romeo 2009[109]	GP	Case–control
Taylor 2014[110]	Care homes	Cross-sectional
Walmsley 2011[111]	GP	Qualitative
Webb 2009[112]	GP	Mixed methods
Webb 2009[113]	GP	Mixed methods

For quantitative (cohort and cross-sectional) observational studies, the main limitations identified were lack of a power calculation or justification of sample size, absence of blinded outcome assessment and not considering possible confounding factors in the analysis (see *Appendix 11*, *Table 29*). In the accessing services cluster, only two studies compared a sample of people with ID with a general population control group.[63,69] Studies involving people with ID and carers often had small samples recruited from specialist settings and hence were not necessarily representative. Other studies provided the perspectives of health professionals only, with little or no representation of people with ID. Only a few included studies were classed as case–control or uncontrolled before-and-after studies (see *Appendix 11*, *Tables 30* and *31*).

The included qualitative studies met most of the criteria on the CASP checklist for qualitative studies (see *Appendix 11*, *Table 32*). Some studies did not consider the relationship between researchers and participants, which is a major limitation in studies involving people with ID. Other studies reported few details of data analysis, so it was unclear whether or not the analysis was sufficiently rigorous.

Identifying need

There were 16 papers reporting 14 different studies in this cluster. Among these studies, health needs were identified by the person with ID,[34,36,38,41,44] family carers,[49,114] paid carers[33,35,39,40,42,48,73,114,115] and health professionals.[37,45,48]

Identifying health need depends on some knowledge of potential risks to health. Ten papers reporting eight studies looked at carers' awareness and knowledge of risks and potential health needs relating to cardiovascular disease,[48] hearing,[42] cancer,[40] men's health,[36] older people[35] and pain.[33,34,37–39] *Table 16* provides the key findings of the studies in the identifying needs cluster.

Influencing factors

Influencing factors in the framework were identified in the included studies as summarised in *Table 17*. The most commonly reported factors were uptake and relationships with staff. Individual factors are briefly discussed in the following sections.

Carer knowledge/skills

Many people with ID rely on those supporting them to recognise that they have a health need and that services are available to meet that need. Recognising unmet health need is an important step towards accessing appropriate care. Carers needed an in-depth knowledge of the client to be able to recognise

TABLE 16 Study findings in the identifying needs cluster

First author and year of study	Type of service	Key findings
Beacroft 2010/2011[33,34]	Residential and supported living homes in Surrey	Poor recognition and management of pain
Bland 2003[35]	Nursing homes	Screening rare; generally good access to GPs
Bollard 2017[36]	All services	Useful for GPs and other HCPs to actively promote the health of men with ID, who, with minimal nudging, are prepared to take on health promotion advice
Donovan 2002[37]	All services	Nurses find it hard to explore pain symptoms with people with ID. Ability to interpret non-verbal pain signals was crucial
Findlay 2014/2015 (same study)[38,39]	Formal and informal carers	Under-reporting of pain by people with ID
Hanna 2011[40]	Cervical screening and other cancer screening	Lack of professional carer knowledge about cancer and screening
McCarthy 2009[41]	Sexual health	Women's limited knowledge of contraception
McShea 2016[42]	Audiology	Lack of knowledge among support workers about hearing loss
Northway 2017[43]	Supported living accommodation for people with ID in Wales	Role of residential care staff in supporting older people with ID
Turk 2012[44]	GP	People with ID and carers under-report pain/problems
Walker 2016[45]	GP	Mostly descriptive, mentions QOF[116] coding
Willis 2015[46]	Carers	Carer role undefined in terms of health care
Wilson 2010[47]	All services	Majority of carers report good access to GPs and dentists but difficulties accessing allied health professionals
Young 2012[48]	GP	Move to engaging with services; suggests ways to improve self-management

QOF, Quality and Outcomes Framework.

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TABLE 17 Influencing factors by study, identifying needs

First author and year of study	Staff knowledge/ skills	Joint working with LD services	Service delivery model	Uptake	Appointment making	Carer/support role	Relationships with staff	Time	Accessible information	Communication
Beacroft 2010/2011[33,34]	✓					✓				
Bland 2003[35]			✓			✓				✓
Bollard 2017[36]						✓				✓
Donovan 2002[37]	✓					✓				
Findlay 2014/2015 (same study)[38,39]	✓					✓				
Hanna 2011[40]			✓			✓				
McCarthy 2009[41]			✓			✓				
McShea 2016[42]			✓			✓				
Northway 2017[43]						✓				✓
Turk 2012[44]	✓		✓							
Walker 2016[45]						✓				
Willis 2015[46]						✓				
Wilson 2010[47]										✓
Young 2012[48]						✓				

and interpret health-related changes in behaviour, whether acute or long term; recognising when someone is unwell or in pain is an important first step towards accessing primary care services. Five papers[33,34,37–39] reporting three studies explored pain recognition and management. One study was an audit exploring residential staff members' beliefs about pain, strategies for recognising and managing pain[33] and experiences of when people with ID had experienced pain.[34] Two qualitative studies explored the experience of pain for people with ID from the perspectives of people with ID and caregivers[38,39] and ID nurses.[37] They found that people with ID did not necessarily tell someone when they were in pain, although they relied on others to deal with their pain.[34,38] People with ID demonstrated pain through changes in verbal and non-verbal behaviour;[33,37] however, caregivers and residential staff did not always recognise that these were signs of pain.[33,39] Worryingly, some staff still believed that people with ID have a higher pain threshold than the general population, and those with more experience and qualifications were more likely to think that was the case, suggesting that training does not address pain recognition and management.[33] Pain recognition and communication tools were not widely used.[33,34,38] A further study carried out a secondary analysis of health information provided by people with mild to moderate ID and their carers to see how well the two sources corresponded. This study found some evidence that carers did not always recognise all health problems that were significant to the client, and clients reported a high frequency of unreported and untreated pain. Worryingly, some people with ID said that they did not have anyone to talk to about their health.[44]

Companion/carer/support worker role

Three studies[43,48,114] reported that tensions between services and uncertainty about roles and boundaries affected identification of and response to health needs.

One study used semistructured interviews with managers of supported living accommodation to explore how residential social care staff support older people with ID to meet their health needs.[43] This study found that residential social care staff often felt that their role in recognising, monitoring and meeting clients' health needs was not always understood by health professionals and that this had an impact on their ability to meet these needs.

One study carried out interviews with paid carers and unpaid family carers to explore views about their role in monitoring the health of people with ID.[114] This study found that there was uncertainty about who among residential care staff, day care services staff, welfare guardians and family members was responsible for recognising and managing health concerns. Relationships, and particularly communication between the different personnel and organisations, could be poor, and this lack of joined-up working contributed to delays and difficulties in identifying and addressing health needs.

These findings were echoed in the third study[48] that used qualitative interviews with people with ID, carers and health professionals to look at perceptions of self-management of cardiovascular disease. This study found that paid carers played a pivotal role in supporting health management because they were present regularly in the home and likely to have a trusting relationship with the person with ID. However, the authors raised concerns about poor knowledge about healthy lifestyle choices among social care staff, which could have an impact on their ability to recognise a health need.

Service delivery model

Access to services depends on someone identifying a need and being aware that services are available to address that need. A number of studies[35,40–42,117] explored knowledge of health risk and awareness of services to mitigate the risk.

A survey of residential staff carers found gaps in the knowledge of carers about the signs and symptoms of and risks and protective factors for cancer and, therefore, carers did not promote cervical screening or weight management services for cancer prevention.[40] This study also found that staff did not know about risk factors specific to the individual, for example their family history of diseases such as cancer or any previous screening or testing.

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A health needs assessment undertaken by the Lincolnshire Learning disabilities Health Needs Assessment steering group also found that the uptake of cervical screening was low among women with ID (28%) compared with women in the general population (71%). It also found that 48% of women with ID declined cervical screening or were 'exemption reported', compared with 12% of other women. Women who were exemption reported did not routinely receive future invitations for screening. This highlights the importance of care staff educating and supporting women to undergo screening. The authors speculate that as the Quality and Outcomes Framework (QOF) allows practices to omit exemption reported patients from the data on which their achievement scores are based, there might be a financial incentive to exemption report women who are more difficult to treat, such as women with ID.[45]

A survey of care staff working in accommodation for people with ID about health problems in those aged > 65 years and their perceptions about access to support found that many were unaware of the screening tests available and whether or not clients had undergone screening. The authors highlighted the need for staff training to raise awareness of health screening and the age at which screening is appropriate. This includes screening for hearing loss; the patient may be symptom free and it is therefore easy to miss.[35]

One study interviewed 20 residential and day care workers, focusing on their knowledge of hearing loss and use of hearing aids.[42] Care workers were aware that it was their responsibility to detect health problems in those unable to do so, but they lacked the skills to detect hearing problems and had reservations about the extent to which audiology services could verify and treat hearing loss in someone with ID. Carers also had negative perceptions about the use of hearing aids, the most common management option for hearing loss, and lacked the necessary skills to support their use in someone with ID.

One study interviewed 23 women with mild to moderate ID living in community-based settings about contraception use.[41] The study found that only 5 of the 23 women used family planning services, with the others preferring to consult their family doctor. Reasons for this may include lack of knowledge about family planning services among women and their carers and a preference for consulting someone familiar and trusted. The study concluded that family planning staff may have more time for consultations but may lack experience of working with women with ID.

Communication

One study[49] used semistructured questionnaires and two focus groups with informal family carers of children and adults with ID ranging from mild to severe to explore their perceptions of access to health and social care services. It found that family carers felt that they had to fight to get services and perceived that those that shouted loudest and fought most had better access to services.

Similarly, a study that interviewed men who had mild to moderate ID to explore the factors affecting their health and their capacity to act on health promotion messages found that a good relationship with a GP was important to ensure ongoing access to GP services and that people particularly valued the GP talking to them directly and then talking to the carer if there was a need to clarify information.[36]

Monitoring and record-keeping

It is important to record information to maintain an accurate medical history when clients are unable to do this for themselves. Bollard[118] found that men with ID in their study used health passports but not all health professionals filled them in on each visit. Residential care managers interviewed by Northway[43] raised concerns that some carers may not have the literacy and numeracy skills to maintain health records accurately.

Summary

All of the factors included in the framework were identified as having some influence on identifying need. The studies were mostly weak in design and some of the older studies are unlikely to represent current practice. The most commonly reported factors were uptake and relationships with staff.

Access to services

The access to services cluster comprised 24 studies; the types of services researched and the key findings of each study are provided in *Table 18*.

Influencing factors

Influencing factors in the framework were identified in the included studies as summarised in *Table 19*. The most commonly reported factors were uptake and relationships with staff. Individual factors are briefly discussed in the following sections.

TABLE 18 Study findings in the access to services cluster

First author and year of study	Type of service	Key findings
Ali 2013[50]	All services	Further improvement required in reasonable adjustments
Allgar 2008[51]	GP	Template useful for identifying people with ID in general practice
Black 2004[52]	GP	Many internal and external barriers to equal access
Carey 2016[53]	GP	Continuity of care and longer appointments are key improvements
Chinn 2016[54]	IAPT	Access involves negotiation between patients/carers and service, barriers and facilitators at many levels
Cooper 2011[55]	All services	Deprivation is not associated with worse access to services
Doshi 2009[56]	Dentist	Young Bangladeshi adults with ID have complex and unmet oral health needs
Jones 2008[57]	GP	Access issues identified by patients, social care staff or both
Lennox 2003[58]	All services	Many patients not accessing more specialised primary care (e.g. optician)
Lloyd 2014[59]	Cervical screening	Attendance at cervical screening facilitated by joint working between LD nurses and primary care
Lodge 2011[60]	GP	Relying on Read code searches to identify patients with ID may lead to underdetection
McNally 2015[61]	Community mental health	Mental health and LD specialists identified barriers to people with ID accessing mainstream mental health services
Nicholson 2011[62]	All services	Adults with ID living in rural areas were not disadvantaged compared with those in urban areas
Osborn 2012[63]	Cancer screening	People with ID less likely to be screened for cancer and situation not improving
Owens 2011[64]	Dentist	Improved model of access to dental care needed
Pilling 2015[65]	Diabetic retinopathy screening	National standards for access to screening are not currently being met. Reasonable adjustments (e.g. alternative screening method) could improve matters
Raghavan 2007[66]	All services	Participants accessed primary care services through their GPs. Barriers included lack of awareness, language difficulties and lack of culturally sensitive services
Redley 2012[67]	All services	Access depends on support from family and health professionals
Rees 2011[68]	Cancer screening	Limited awareness among health professionals of some screening programmes and recommended age limits for screening
Reynolds 2008[69]	Cervical screening	Need to improve training for staff taking smears and to improve communication between LD teams and GPs so that patients and carers can receive better support
Russell 2017[70]	GP	Advanced Read code search did not identify large numbers of new patients for register, suggesting other methods needed
Starling 2006[6]	Eye care	Need to monitor people with ID to ensure access to appropriate eye care
Williams 2014[71]	Sexual health	Most younger adults with ID wanted to attend mainstream sexual health services
Wood 2007[72]	Cervical screening	Many practices lacked robust methods to identify women with ID; most felt that there was a need for training and support to deliver cervical screening for women with ID

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TABLE 19 Influencing factors by study, accessing services

First author and year of study	Staff knowledge/ skills	Joint working with LD services	Service delivery model	Uptake	Appointment making	Carer/support role	Relationships with staff	Time	Accessible information	Communication
Ali 2013[50]				✓		✓	✓		✓	
Allgar 2008[51]			✓							
Black 2004[52]		✓			✓				✓	
Carey 2016[53]				✓			✓	✓		
Chinn 2016[54]		✓		✓			✓			
Cooper 2011[55]				✓						
Doshi 2009[56]				✓			✓			
Jones 2008[57]							✓	✓		✓
Lennox 2003[58]							✓	✓		
Lloyd 2014[59]	✓	✓	✓	✓	✓		✓	✓		
Lodge 2011[60]			✓							
McNally 2015[61]	✓		✓							
Nicholson 2011[62]				✓						
Osborn 2012[63]				✓						
Owens 2011[64]			✓	✓			✓			
Pilling 2015[65]		✓	✓		✓			✓	✓	
Raghavan 2007[66]				✓					✓	✓
Redley 2012[67]						✓				✓
Rees 2011[68]	✓									
Reynolds 2008[69]			✓							✓
Russell 2017[70]			✓							
Starling 2006[6]				✓						
Williams 2014[71]				✓						
Wood 2007[72]	✓		✓							

LD, learning disability.

Staff knowledge/skills

The importance of health professionals' knowledge and skills in relation to access was highlighted in several studies. In most cases, staff in mainstream services lacked confidence in their skills to deliver services to people with ID or at least expressed a need for further training. This was true for cervical screening[72] and mental health services.[61] In a study of sexual health services, young adults with ID in Scotland expressed a preference for accessing mainstream services and felt that staff in these services should be able to meet their needs.[71] In relation to cancer screening generally, Rees *et al.*[68] reported that community staff working with people with ID had low awareness of some national screening programmes and were unsure of age limits and recommended intervals for screening. Lloyd *et al.*[59] emphasised the importance of primary care staff skills and knowledge for conducting cervical screening, including investment of time in preparing women to be screened.

Joint working with learning disability services

Community learning disability (LD) teams offer specialist support and services to people with ID. Access to services is facilitated when community teams co-operate effectively with general practice, but the included studies revealed a mixed picture. In an early study,[52] many GP staff were unaware of the community team and what it could offer their patients. However, when there is awareness, there may still be confusion over the roles of different services and how they can best work together. Chinn *et al.*[54] identified this as a problem in the context of mental health and the respective roles of IAPT and specialist LD services.

Included studies identified a particular role for joint working between general practice and community services in promoting screening (e.g. for diabetic retinopathy in people with ID and diabetes[65] and supporting women with ID to attend cervical screening[59]).

Service delivery model

This topic overlaps *Joint working with learning disability services* and should be read in conjunction with it. The included studies identified a number of barriers to access associated with service delivery models. McNally *et al.*[61] reported that lack of resources limits access by people with ID to mainstream mental health services and it is important that services do not offer 'false hopes' about what they can provide. In another study, dental services were reported to not be available at suitable times, again limiting access.[64]

Service delivery by general practice is supported by practice registers of patients with ID; however, inaccuracies in registration constitute a barrier to accessing some services (e.g. screening). Three studies examined aspects of searching practice records using Read codes to identify people with ID. The findings were mixed; one study found a simple template useful[51] but two others suggested that searches based on Read codes may not identify all patients with ID and need to be supplemented with other methods.[60,70]

Pilling[65] found that ID was not always recorded for people with diabetes who were eligible for retinopathy screening, while cervical screening history was inadequately documented in another study.[69] Wood and Douglas[72] also reported that many general practices lacked robust methods to identify women with ID, which would have a bearing on service provision for cervical screening for this group. These cervical screening studies are more than 10 years old so it may be that they do not reflect current practice. As noted previously, a more recent study[59] highlighted the role of joint working across services in promoting cervical screening.

Uptake

This section covers studies reporting on use of services by people with ID (quantitative) and their attitudes to using services (qualitative or mixed methods). People with ID have a higher rate of GP consultations than the general population.[53] Uptake of services may vary across the UK but a study in Scotland found that people in rural areas had more primary care contacts than those living in urban areas, suggesting that living in a rural area is not a barrier to service uptake.[62] Another study[55] found no clear connection between the level of neighbourhood deprivation and the uptake of services by

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people with ID. However, people from minority ethnic communities with ID were reported to lack awareness of services and who was eligible for them.[50,66] In terms of specialist services, many people with ID were found to be receiving eye care below the recommended levels;[6] again, this is a relatively old study and may not represent the current situation.

Included studies identified patients' attitudes and perceptions as important factors influencing service uptake. Chinn and Abraham[54] reported an unwillingness to admit to mental health difficulties, while Lloyd and Coulson[59] found negative attitudes or apathy towards cervical screening among women with ID. Young Bangladeshi people with ID in Tower Hamlets, London, visited the dentist only when they experienced symptoms rather than regularly, suggesting that they and/or their carers might have had a negative attitude to screening.[56] However, another study[64] of dental services identified lack of availability of preferred provider as a barrier to uptake.

Only one study[63] compared people with ID with the general population and looked at changes in screening uptake over time. The authors found that differences in uptake between people with ID and control participants have reduced over time for cervical screening but not for breast screening.

In summary, uptake of services among people with ID is often lower than that among the general population and it is unclear whether or not the situation is improving. Initiatives to improve uptake are discussed in *Interaction during a consultation*, *Influencing factors*, *Uptake*.

Appointment making

Only three studies in this group dealt with the mechanics of making an appointment with a health professional. Black[52] identified that difficulties using the telephone was a barrier to access experienced by people with ID. Although the study was published in 2004, it is unlikely that the situation has improved as general practice and urgent care increasingly rely on the telephone for access and sometimes as an alternative to face-to-face appointments.

Offering pre-appointment visits to prepare people with ID for tests and other procedures has been recommended as a way of promoting access to cervical[59] and eye[65] screening but this depends on having the resources available and also on identifying patients with ID. This type of measure could be considered a 'reasonable adjustment' for the benefit of people with ID.

Companion/carer/support worker role

Two studies provided limited insight into the role of companions in helping people with ID to access services. Redley *et al.*[67] reported that GPs preferred people with ID to be accompanied as they felt that this helped to overcome communication problems; however, Ali *et al.*[50] noted a lack of support for and involvement of carers, although the study was small. Support for carers is closely linked to other issues (e.g. relationships with staff and communication), as discussed in the next section.

Relationships with staff

Evidence about relationships between people with ID and primary care professionals was mixed. Jones *et al.*[57] found that the attitudes and behaviour of general practice staff were generally positive, although there were some exceptions. By contrast, participants in Ali *et al.*'s[50] study reported some negative attitudes and behaviour from primary care staff, as did Owens *et al.*[64] from dental professionals.

Positive relationships between patients and staff are supported by continuity of care, which is not always easy to achieve for people with ID, as Owens *et al.*[64] reported for dental care. Better continuity of care was identified as a key area for improvement in a recent study of GP services,[53] while Lloyd and Coulson[59] noted that attendance at cervical screening was facilitated by long-term relationships between patients and LD specialist nurses. Patient preference was identified as a factor in a study of dental health in a Bangladeshi population in Tower Hamlets; for example, women preferred to see a female dentist from a similar background.[56]

Finally, a study of IAPT services used the concept of 'candidacy' to explore how people with ID and their supporters negotiate access to services.[54] This study used data from health and care professionals and concluded that there are barriers to access at many levels. As well as relationships between individual patients and staff, access to services was influenced by the culture of IAPT teams, specialist LDs mental health teams, managers and service commissioners.

The evidence on relationships with staff and its influence on access to services presents an unclear picture, with most studies being small and involving people from specific geographical areas or cultural groups. National, theory-based studies such as that of Chinn and Abraham[54] may offer a route towards better understanding this complex area.

Time

A number of studies highlighted that people with ID need longer appointments both with GPs[53] and for procedures such as diabetic retinopathy screening[65] or cervical screening.[59] Time pressure was identified as a particular barrier to cervical screening.[59] Longer appointments could be considered a 'reasonable adjustment' to facilitate access to primary care services.

Jones *et al.*[57] identified a different time-related issue, namely that excessive time waiting for appointments can be difficult for some people with ID. The authors recommended not to arrive too early for appointments to minimise this risk.

Accessible information

Accessible information is an additional reasonable adjustment for people with ID. More general communication issues are considered in the next section. Language barriers affect access to services by people with IDs, particularly those whose first language is not English.[50,66] Black *et al.*[52] noted in 2004 that practice information leaflets were too detailed for people with ID. Easy-read leaflets have been used to promote diabetic retinopathy screening[52] and as part of an intervention to improve general practice access for people with ID [see *Innovations to improve access (including health checks)*].

Communication

In addition to language barriers as mentioned above, included studies identified communication problems arising because people with ID were unable to express their problems clearly.[52] However, another study[57] of access to GP services found that communication was not a major problem. This issue is discussed in more detail in *Identifying need*.

Redley *et al.*[67] reported that GPs saw communication with people with ID as a problem, but most did not make special arrangements other than allowing extra time for appointments. From the point of view of patients and carers, professionals speaking to the carer rather than directly to the person with ID was highlighted as a problem.[58]

In general, health and care services aim to be 'colour-blind' rather than adapt to the needs of particular ethnic or religious groups. However, one included study highlighted that this may result in services lacking cultural knowledge or sensitivity.[66]

One included study found that communication problems can also arise when people with ID are invited to access services, in this case cervical screening, rather than seeking access themselves. A relatively robust case–control study[69] found that women with ID were less likely to respond to invitations and to be screened than those without ID. The authors' suggestions for improved communication include tailoring invitation letters and informing community LD teams when an invitation letter has been sent.

The included studies have thus identified communication problems as an influencing factor in access to services at different levels before and after an appointment.

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Summary

All of the factors included in the framework were identified as having some influence on access to primary care services in UK studies. The studies were mostly weak in design and some date back to the early 2000s and are unlikely to represent current practice. Topics highlighted in recent studies include the need for longer appointments and continuity of care,[53] the roles of mainstream versus specialist services[54,61] and the continuing need for 'reasonable adjustments'.[65]

Interaction during a consultation

Interaction during a consultation depends on the extent to which an individual can engage and interact with the health care provided. Nineteen papers were considered in this cluster and the majority focused on interactions with GPs and practice nurses, although one paper focused on dental services.[80] Among the papers focusing on general practice, studies considered the provision of palliative and end-of-life care,[86–88,90] sexual health and contraception[81,85] and diabetes management.[73,89] One study focused on the needs of people with ID who were homeless[77] and one focused on the needs of people with Down syndrome and dementia.[90] Details of the type of service investigated and the key study findings are provided in *Table 20*.

Influencing factors

Influencing factors identified in the innovations to improve access cluster are discussed below and shown in *Table 21*.

TABLE 20 Study findings in the interaction during a consultation cluster

First author and year of study	Type of service	Key findings
Brown 2017[73]	Diabetes	Limitations to providing diabetes services
Gates 2011[74]	All services	Importance of communication and interaction
Goldsmith 2013[75]	GP	Variable amounts of information and explanation given during blood tests. Variable attempts to elicit consent for blood tests. Consent process was rarely followed
Hames 2006[76]	GP	Limited knowledge of LD teams
Hebblethwaite 2007[77]	All services	Homeless people with ID require support in arranging appointments and additional provision
Heyman 2004[78]	All services	Concept of organisational simplification as a restriction to service access
Jones 2007[79]	GP	Appointments differ for people with Down syndrome; GP lack of confidence
Lees 2017[80]	Dental	General satisfaction with dentistry, problems with transition and communication
McCarthy 2011[81]	Sexual health	Challenges in providing contraception
Murphy 2006[82]	GP	Limitations of consultation experiences
Perry 2014[83]	GP	Contact with primary care: the experience of people with ID
Powrie 2003[84]	All services	Nurses require greater co-ordination with LD services
Thompson 2008[85]	Sexual health	Staff tend not to discuss sexual health. Study not specific to ID
Tuffrey-Wijne 2002[86]	Palliative and end-of-life care	Considerations for end-of-life care including consent and communication
Tuffrey-Wijne 2009[87]	Cancer	Challenges in cancer care including reliance on others to negotiate with services
Tuffrey-Wijne 2005[88]	Palliative and end-of-life care	Challenges in communication
Turner 2014[89]	Diabetes	Very limited data; makes suggestions for ways to improve access
Watchman 2005[90]	Palliative and end-of-life care	End-of-life care limitations
Williamson 2004[91]	GP	Provides useful list of recommendations to improve GP services

TABLE 21 Influencing factors by study, interaction during a consultation

First author and year of study	Staff knowledge/ skills	Joint working with LD services	Service delivery model	Uptake	Appointment making	Carer/support role	Relationships with staff	Time	Accessible information	Communication
Brown 2017[73]		✓						✓	✓	
Gates 2011[74]	✓						✓		✓	✓
Goldsmith 2013[75]	✓								✓	✓
Hames 2006[76]		✓								
Hebblethwaite 2007[77]					✓					
Heyman 2004[78]	✓						✓	✓		✓
Jones 2007[79]	✓							✓		
Lees 2017[80]	✓						✓	✓	✓	✓
McCarthy 2011[81]	✓								✓	
Murphy 2006[82]							✓	✓		✓
Perry 2014[83]	✓				✓			✓	✓	✓
Powrie 2003[84]	✓	✓								
Thompson 2008[85]	✓	✓								
Tuffrey-Wijne 2002[86]		✓								
Tuffrey-Wijne 2005[88]	✓									
Tuffrey-Wijne 2009[87]	✓					✓				
Turner 2014[89]									✓	
Watchman 2005[90]						✓				
Williamson 2004[91]	✓					✓		✓	✓	

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Making the appointment

A paper combining the findings of two studies that used focus groups of people with ID found that some patients found the telephone menu system used by general practices confusing and were frustrated by the time taken to get through to the surgery at busy times. Some people preferred to go to the practice to make their appointment. Triage systems were particularly problematic because people found it difficult to wait for a call back. Many of these problems are also experienced by people without ID; however, people with ID are unlikely to have the confidence or persistence of other patients and so are disproportionately affected by these issues and more likely to be disadvantaged by them.[83] A qualitative study[77] of people with ID who had experience of being homeless found that support to register at a practice close to any temporary accommodation was important because the distance to appointments was a factor that affected whether or not people attended.

Time needed

Seven studies[73,78–80,82,83] raised the issue of extra time to consult with people with ID. This caused problems for some during busy clinics,[73] whereas others routinely offered double appointments for people with ID.[79,82] Lees *et al.*[80] highlighted the importance of not rushing people with ID and Perry *et al.*[83] found that long waiting times increased anxiety for some people, which had an impact on the consultation. Williamson *et al.*[91] suggested that people with ID could be offered the first appointment of the clinic if waiting was difficult for them, whereas Perry *et al.*[83] highlighted the importance of offering flexible appointment times so that people did not miss day services that they might be paying to attend.

Consultation skills

Seven papers[74,75,78–81,83] discussed the interpersonal skills that were needed during a consultation with someone with ID. People with ID wanted to be treated with dignity and respect[74,78,80] and they wanted to feel that they could trust the person they were talking to. In a study of communication between general practice staff and patients with communication disabilities, including two focus groups comprising people with ID, Murphy[82] found that continuity and the opportunity to build a relationship with GP staff over time was important to the development of trust and rapport during consultations. Similarly, a qualitative interview study comprising people with ID and their carers about their experiences of using community dental services found that anxiety increased when people felt that they were not being listened to and that building long-term relationships with members of staff reduced this anxiety.[119] In a study using focus groups with people with ID and their parents and relatives, Gates[74] found that people with ID wanted all staff to have some training in working with people with ID so that everyone the patient came into contact with, including receptionists, porters and auxiliary staff, would treat them with respect. Three qualitative studies[74,78,83] using interviews with people with ID, family carers, and health and social care professionals all found that, when a carer accompanied a person with ID to a consultation, it was important that the health professional talked to the person with ID directly rather than to the carer. People with ID valued clear, verbal information tailored to their cognitive abilities, which included breaking explanations down into simple elements and using short sentences and simple, jargon-free vocabulary to explain concrete terms.[75,78]

Accessible information

Eight papers[73–75,80,81,83,89,91] discussed the provision and use of accessible information, tailored to individual abilities, to support verbal communication. In their study of practitioners supporting people with ID who had diabetes, Brown *et al.*[73] found that some practitioners made information about diabetes accessible by using 'Talking Mats' (Talking Mats Ltd, Stirling, UK), easy-read materials, and pictures and symbols, whereas others were not aware that these resources were available. Lees *et al.*[80] reported service user and carer perspectives on dental services and found that accessible information was important to support self-care and knowledge of what to do in a dental emergency. Perry *et al.*[83] found that the information sent with an invitation to a health check was confusing, particularly for people with mild ID who did not have access to support. They also found that information in the surgery was difficult for patients to understand; for example, some patients could not read signs and, therefore, were unable to find their way around the building. Two papers discussed the need to maintain accurate patient-held health records with accessible information tailored to the needs of the individuals.[89]

Using accessible information to support verbal communication, including pictures and symbols for those who could not read, was particularly important when information was needed to make a decision about whether or not to give consent, for example for a blood test.[75]

Support capacity to give consent

Ten papers discussed issues around capacity for people with ID to give consent or make other decisions about their health care,[75,84,89] cervical screening,[78,84] sexual health,[85] contraception[81] and end-of-life care.[86–88,90]

An ethnographic study[75] in which six people with ID were observed having a routine blood test in general practice found that information was not provided in an accessible format to support decision-making and that inconsistent levels of explanation were given for the procedure without checking for understanding. Instead, as patients were known to trust the nurse, their acquiescence was interpreted as consent. Similarly, in an ethnographic study of people with ID who had cancer, Tuffrey-Wijne *et al.*[87] identified that some health professionals did not seem to be aware that people with ID may have a tendency towards acquiescence and, therefore, the assumptions made about someone without ID may not apply to someone with ID. For example, when someone without ID offers an arm for a blood test it could reasonably be assumed that they are giving consent; however, they may be going along with this action because they are not confident or lack capacity to refuse the test. Turner[89] highlighted the importance of providing accessible information to support consent to blood tests and listening and responding to any fears in advance of any procedure. A survey of practice nurses[84] found that nurses were concerned about medical decision-making and consent in relation to invasive procedures such as cervical screening. A study[78] using focus groups with adults with ID to explore issues of autonomy and consent identified that adults with ID who are capable of giving informed consent are legally entitled to make their own decisions; however, they may not have the same agency and ability to choose as someone without ID because they may be unduly influenced by the views and preferences of carers or family members. The study reported that some health professionals felt that consent was obtained through negotiation with the individual and their relatives and social care staff.[78] A survey[81] of GP practice for women with ID attending for contraception found that GPs relied on discussions with carers when women could not consent to treatment. Most GPs felt that carers could facilitate communication between them and the woman with ID to maximise her capacity to consent; however, some respondents indicated that the purpose of this discussion was to gain the carer's consent, which has no legal basis in the UK. GPs said that they prescribed contraception on the basis of 'best interests' when women did not have the capacity to consent; however, the study's authors noted that it is sometimes difficult to separate the best interests of women with ID from the interests of their relatives and carers. The authors noted that relatively few GPs expressed concerns about whether or not a woman who could not consent to treatment could consent to sex, and it was not clear what those doctors did with their concerns or whether or not they reported them and, if so, to whom.

Four qualitative studies considered decision-making in relation to cancer,[87] dementia[90] and end-of-life care.[86,88] These studies found that relatives, carers and GPs were unsure about how to communicate with people with ID about terminal diagnoses, prognosis and death, and wanted to protect people with ID from distressing news. However, this led to people with ID feeling scared because they did not know what was happening to them. Doctors did not always give patients clear information about treatment decisions in a format they could understand, sometimes because carers asked them not to.[87] Emotional issues surrounding end-of-life and palliative care affected family and other carers' decisions, and situations arose where those close to the person with ID had conflicting views about the best course of action. This meant that people with ID were given conflicting information that caused anxiety and, in some cases, prevented them from making decisions about their care.[88]

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Role of carers

Family carers and paid social care staff clearly played an important role in facilitating communication and interaction during health consultations. However, a survey[90] of practitioners working in residential and palliative care settings with people with Down syndrome who had dementia raised the issue of a 'care culture clash'. This clash occurred when social care staff were employed to provide social care, which emphasised the rights of individuals to autonomy and an independent lifestyle, but their role subsequently changed to include monitoring deteriorating health and diminishing skills, which required more directive and structured services as well as medical and nursing care.[90] An ethnographic study of the experiences of people with ID who had cancer found that carers were committed to their patients but they found it hard to manage the practical and emotional demands of caring for someone with cancer without information and support from health professionals. In some cases, this support was not available because GPs did not explain the reason for a particular course of treatment action (or inaction), so carers did not understand some of the decisions that were made.[87] Similarly, Williamson *et al.*'s survey[91] of GPs about their interface with people with ID and their supports found that there was poor communication between GPs and social support providers.

Joint working

It was important for mainstream services to have good working relationships with specialist LD services so that they could access support and advice about how to interact with people with ID to meet their health needs.

In a qualitative study[85] using interviews with GPs and practice nurses, participants reported that they did not feel adequately trained to support people with ID to address their sexual health needs. A survey of general practice staff, including GPs, found varying levels of awareness of the role that community LD teams have in supporting people with ID to access mainstream health services. The study highlighted the role that these teams could have, particularly relating to screening and health checks, because of their knowledge of the patient's health needs and condition-specific risk factors.[76] A survey of practice nurses by Powrie[84] also suggested that primary care providers would benefit from closer working relationships with community LD teams to support them with dilemmas around autonomy and freedom of choice when discussing lifestyle issues such as overeating and alcohol abuse.

A qualitative study exploring perceptions of diabetes service provision among practitioners, including those delivering diabetes care in primary and secondary care, in ID services and in community care services found that positive working relationships between care providers in different settings were crucial to ensure person-centred care and effective diabetes management. Relatives and carers provided support to enact diabetes management plans but needed training in diabetes care. The study found that the high turnover of support staff meant that delivering this training was time and resource intensive. Diabetes practitioners noted that inconsistency of care by relatives and carers resulted in inaccurate communication with people with ID, leading to confusion and poor management, which highlighted the need for joined-up care between primary health care, specialist ID services, diabetes services and social care support services.[120]

Two further studies identified the problems caused by the high turnover of staff. Powrie[84] found that the high turnover of social care staff contributed to poor communication between primary and social care services and Tuffrey-Wijne[86] found that a reliance on agency staff put more pressure on permanent staff to provide consistency of care and meant that training for care staff was of limited value because of the constant turnover of staff.

Three studies focusing on cancer or end-of-life and palliative care found that mainstream service providers benefited from close working with staff from community LD teams.[86,87,90]

Staff uncertainty

Jones and Kemp[79] found that only 40% of GPs were confident about taking histories and gathering information from people with Down syndrome and that they valued working in close partnership with LD teams. Thompson *et al.*[85] found that GPs and practice nurses did not discuss sexual health with people with ID unless this was specifically requested, and they did not feel that they were adequately trained to support clients with ID to address their sexual health needs. Tuffrey-Wijne *et al.*[88] found that palliative care staff were unsure about how to communicate with and care for people with ID. Tuffrey-Wijne *et al.*[87] found that GPs and carers lacked confidence in breaking bad news to someone with ID and that sometimes they avoided doing so, which left patients feeling anxious and scared because they did not know what was happening to them. Similarly, Watchman[90] explored the experiences of practitioners working with people with Down syndrome and dementia and found that care staff as well as health professionals did not discuss end-of-life care or funeral arrangements with patients because they were unsure how to do so. Powrie[84] found that practice nurses were uncertain about how to manage consent or lack of consent for procedures such as blood tests, cervical screening and breast examinations with women with ID.

Summary

All of the factors included in the framework were identified as having some influence on interaction during a consultation. The studies were mostly weak in design and some of the early research is unlikely to reflect current practice. The most common factors were staff knowledge/skills, time, accessible information and communication.

Innovations to improve access (including health checks)

Twenty-three studies evaluated innovations developed to improve access. Fifteen of these studies[19,93,95–101,104,105,107–109,111] investigated health checks. Training for staff was investigated in five of the included studies.[92,102,106,110,112] A counselling intervention was evaluated in one study;[94] one cross-sectional study researched weekend opening and whom it would benefit[103] and one study investigated a training intervention for people with ID.[113] *Table 22* provides details of the key findings from studies in this cluster.

Health checks

Health checks were evaluated in 15 studies. These were found to help identify health needs,[93,101,107] improve the monitoring of people with long-term conditions,[121] reduce the long-term need for referral and interventions[96] and increase health promotion activities aimed at people with IDs.[19] Three studies[95,97,98] found that incentivisation schemes increased tests and checks and one study found health checks to be cost-effective.[109] A number of studies investigated the uptake of health checks and factors that could influence this.[104,107,108,111] One study[99] investigated the use of the ‘My Health’ booklet as part of health checks. Each of the studies will now be discussed in greater depth.

One of the included studies researched health checks carried out by practice nurses using a cluster RCT[121] to attempt to determine their clinical effectiveness and cost-effectiveness compared with standard care. The study investigated adults aged > 18 years with ID who were registered at one of the participating practices in Scotland. The practices were randomly assigned either to health checks in addition to standard care or to standard care, and participants were followed up for 9 months. The study found that more newly detected health needs were identified and met in the intervention group than in the control group, although the difference was not significant. The study was well conducted methodologically but was potentially underpowered to detect a significant difference for the outcome of health needs identified and met. Some of the participants disclosed their group to the outcome assessors. In many cases carers completed the measures with or for the individuals with ID and, because of staff turnover, different carers may have completed the measures and interpreted them differently.

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TABLE 22 Study findings in the innovations to improve access cluster

First author and year of study	Type of service	Key findings
Adler 2005[92]	Eye health	Training that incorporates clinical experience, and using real patients, is particularly effective, although there is still benefit in providing lecture-type courses. Whenever possible, courses provided should offer hands-on experience with real patients
Baxter 2006[93]	GP	Health checks help to identify health needs
Biswas 2005[94]	GP	Uptake of cervical screening in women with ID was found to be very low, but largely for appropriate reasons. Counselling made a small difference to uptake
Buszewicz 2014[95]	GP	Incentivisation schemes increase testing and checks
Cassidy 2002[96]	GP	Health checks reduce long-term need for onward referral and interventions
Chauhan 2010[97]	GP	Incentivisation increases recording of health data. Need for specific ID targeting of checks
Chauhan 2012[98]	GP	Incentivisation schemes increase checks and identification of disease. Fewer than half received the checks and a number of barriers were identified
Codling 2007[99]	GP	Evaluation of 'My Health' booklet – not always completed and information could be poor
Cooper 2014[100]	GP	Practice nurse health checks. No significant difference in health needs identified or SF-36 but better monitoring of long-term conditions, improved health (EQ-5D), quality-adjusted life-years and costs
Cooper 2006[101]	GP	Practice nurse health screening increased routine screening and immunisations, more health needs identified
Dagnan 2018[102]	IAPT	IAPT staff need specialist knowledge and confidence in dealing with people with ID. Outcome measures used by IAPT services are not standardised for people with ID
Felce 2008[19]	GP	Evaluation of health checks. No increase in consultations, but frequency of health promotion activities increased
Ford 2015[103]	GP	Weekend opening unlikely to benefit people with ID
Glover 2013[104]	GP	Number of adults receiving checks has increased (to around half). Obstacles remain
Harrison 2005[105]	GP	Targeted initiative improved uptake of health checks and health action plans
Holly 2014[106]	Cardiovascular	Evaluation of a training resource for coronary heart disease, initially promising but requires further evaluation
Martin 2004[107]	GP	Health check uptake 91%. Checks identified unmet need
McConkey 2015[108]	GP	In Northern Ireland, 64% received a check; variation in uptake; suggestions of barriers
Romeo 2009[109]	GP	Health check intervention is cost-effective
Taylor 2014[110]	Care homes	Evaluation of tool and training staff for pain reporting
Walmsley 2011[111]	GP	Describes reasons for slow implementation of health checks
Webb 2009[112]	GP	Training for GPs and practice staff can improve access for people with ID but releasing staff to attend training was a barrier
Webb 2009[113]	GP	12-week training programme improved knowledge and self-efficacy for accessing primary health care among people with ID, but implementing such programmes in practice would be difficult without additional funding

EQ-5D, EuroQol-5 Dimensions; SF-36, Short Form questionnaire-36 items.

Forty GP practices in Wales[93] identified adults with ID and then invited them for a structured health check. The practices identified 318 adults eligible for a health check; 190 health checks were conducted and data were available for 181 of these. An audit was undertaken 3 months after checks to determine any health needs identified and actions that had been taken. New health needs were identified in 51% of patients; 63% had one new health need recognised, 25% had two health needs and more than two new health needs were recognised in 12% of patients. New morbidity was discovered in 16 patients. At the 3-month audit, management had been initiated for 90% and treatment for 61% of the new health needs identified. For the 10% of new health needs for which management had not been started, the patient or carer had refused or there had been treatment delays. The study demonstrated that health checks can be an important tool for identifying health needs. The researchers felt that it was important to ensure that common hearing and visual conditions are identified, as they can have an impact on communication. The characteristics of the initially identified 318 people with ID and the final 190 that actually received a health check were similar for age, sex, abilities/disabilities, challenging behaviour and threshold indicators of mental illness. However, the final sample had more patients from staffed accommodations, meaning that the sample was not representative of the whole population of people with ID and potentially any findings might not be applicable. Furthermore, the paper was published in 2006 and, thus, might not be representative of current opinion.

A large cohort study[95] used data from The Health Improvement Network primary care database to investigate whether or not the NHS England opt-in incentive scheme to encourage practices to perform health checks for people with ID had improved care after 3 years. Complete data were available for 5256 people with ID; 4645 were registered with an incentivised practice and had received health checks during the study period. Blood tests to measure total cholesterol, health checks specifically for hearing and vision, medication reviews, action plans and referrals to secondary care were more likely to be offered at incentivised practices. Newly identified gastrointestinal, thyroid disorders, constipation rates and weight problems were higher at incentivised practices. People who chose not to attend health checks were younger and lived in more deprived areas. This evidence is important for demonstrating that health checks aimed at people with ID can have positive effects on health service provision, which potentially could contribute to a reduction in avoidable deaths. However, the study authors noted that it was difficult to ascertain which practices had opted into the learning disability direct enhanced service (LD-DES), which provided practices with a financial incentive, as the information was not available. In addition, the quality of the health checks was not assessed.

An analysis of QOF data[97] investigated the additional value of a health check for people with ID compared with that for a standard care control group. The study findings suggest that there is a high level of recording for processes that are directly incentivised through the QOF and further significant increases in the recording of information about people with ID. The study authors reported that focusing on health issues common to people with ID could potentially improve care more than the extensive health checks being performed. The study had only a small sample and was for a short time period (6 months). In addition, it was not possible to identify how many people with ID invited for a health check did not attend. Data that had been extracted for the LD-specific process might not be as reliable as QOF data, which are directly linked to GP payment.

A qualitative study[98] evaluated the impact of health checks on health professionals, patients and health services through interviews and analysing clinical data from GP clinical systems. Recording of health checks increased during the 2-year study period and the number of people with ID identified by practices increased. Health checks were associated with increased identification of QOF-incentivised conditions. Screening and health promotion activities that were associated with QOF-incentivised processes increased following health checks. There was still considerable variability between recording of data, and additional barriers to the introduction of health checks were identified in the recording of data by practices. The resources available to practices influenced how they introduced them. A facilitator for practices signing up to the LD-DES was the financial incentive and if this was removed then practices are potentially less likely to continue health checks. Reasonable adjustments introduced

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during the study, for example how appointments are booked, could potentially remain and become part of routine care. The study was potentially not representative of the whole population of people with ID, only one person cared for by their families who had refused a health check was recruited and no-one younger than 24 years was recruited.

A controlled study in GP practices in Scotland examined the service use and cost implications of health checks.[109] Costs considered were the costs of health checks, services, aids and adaptations, and carer costs. The study found that the mean cost of delivering a health check was £82. The 12-month costs of carers and services were lower in the group receiving health checks than in the control group (bootstrapped mean cost difference £22,272, 95% CI £37,657 to £6400); lower costs were mainly attributed to unpaid informal care. It is possible that health check interventions could offer value for money compared with standard care and hopefully benefit people with ID by reducing health inequalities. The study groups were not randomised and there was no information about previous health-care use. No data were provided to inform a sample size calculation, so the study could be underpowered. The study measured only costs; other possible benefits were inferred from the literature.

One study researched trends in health check provision from 2008–9 to 2011–12 using data collected by the Health and Social Care Information Centre from primary care trusts in England.[104] During the study period, uptake of health checks rose 5% from 48% to 53%. This increase in health checks is positive but the study found that a number of strategic health authority and primary care trust areas needed to improve to ensure that minimum standards are being met.

Another study researched the uptake of health checks across general practices in Northern Ireland over 3 years.[108] The study found that practices were identifying increasing numbers of people with ID but that the proportion who had received a check had fallen. There was also wide variation between practices in the number of people with ID receiving a check (6–100%); no differences were found between small and large practices in the number of patients being checked. The majority of identified people with ID (87%) were registered at a practice that performed annual health checks. Of those eligible, < 50% received the annual checks. The study did find that it was more likely that people living in nursing or residential homes and people living in more affluent areas would have had a check. The main reasons GPs gave for not doing health checks were a lack of demand, a desire to avoid extra paperwork and scepticism of their value. Trusts that employed more health facilitators for longer had greater numbers of practices that performed health checks. The total study sample size in this study was unclear and the data provided by GPs did not identify the people receiving the health check, so it was not possible to determine if people had had just one check or regular checks. This study did not evaluate the quality of health checks or their ability to detect health problems.

Trends in implementation of annual health checks in Oxfordshire were investigated in a qualitative study conducted during 2010.[111] The study considered GPs' experiences of conducting the health checks and any associated problems . The study also obtained perspectives on the checks from people with ID. The study found that the implementation of health checks was still in its infancy in Oxfordshire in 2010. Practices had different lists of people who might be eligible, making it difficult to determine whom to target for health checks. Six practices participated in the study but only two recorded any outcomes. Serious health conditions were identified through the checks, including heart disease and diabetes, and many less serious conditions were also identified and treated. One practice identified 90 health conditions from 65 checks. The practices found the following challenges to implementing health checks: difficult to define eligibility, costs, lack of training in working with people with ID and lack of awareness of 'reasonable adjustments'. There was limited access to or awareness about support from community LD teams, which could have provided much needed specialist support. The participating practices might not be representative of the whole country. The attitudes of GPs towards checks could have changed since 2010 and also the organisation of services could be different meaning that the findings from this study might not be reflective of the current situation.

A small study[19] in Wales investigated the impact of health checks on increased consultations with GPs or another member of the primary care team, increased health promotion activities and increased contact with specialists. Study participants had 5.4 primary care and 1.8 specialist consultations in 1 year. The rates before and after the study were not statistically different. The frequency of health promotion actions outside the health check increased significantly following the introduction of health checks. There was significant sample attrition during this study, one-third of practices declined to participate in the second stage of the study and a further one-fifth of participants chose not to continue in the study. The study authors acknowledge that the final sample did not represent an epidemiological cross-section, meaning that any findings need to be treated cautiously. In addition, the study was published in 2008 and therefore might not be reflective of current practice.

An audit study published in 2007[99] researched whether or not the 'My Health' booklet was being used effectively in practice and whether or not the format met the specific health needs of people with ID. The 'My Health' booklet was being used in practice but it was not always fully completed and some of the information recorded was inaccurate. The study was published in 2007 and is potentially not reflective of current practice. The study participants were from a residential home, mostly aged 51–60 years and over, with 60% being male, so any findings are potentially not reflective of the whole population of people with ID.

The introduction of a health screening programme for people with ID was implemented and health gains were investigated 1 year later.[101] The study demonstrated that the benefits of a screening programme were sustained for 1 year, when compared with standard treatment alone, and its routine implementation could potentially reduce health inequalities for people with ID. The study had a control and considered the longer-term impact of a health screening programme. However, the study was conducted prior to 2006 and might not reflect the current situation. The health screening intervention was introduced in isolation without any other changes to services.

A small uncontrolled service evaluation described a project designed to facilitate access to mainstream primary care services by people with ID in Warrington and the surrounding areas.[105] The project introduced a joined-up approach to working involving primary care and community staff and the project outcomes were uptake of health checks by people with ID and production of health action plans. When the study started, 14 of the 62 patients had accessed a health check in the previous year. At the end of the project, 60 had received a health check, with 46 being provided with a health action plan. This small uncontrolled study had promising findings but was conducted only in a single area and would need to be repeated with a larger sample in a range of areas to determine whether or not findings can be replicated.

A small survey conducted in 2002 evaluated a nurse-led health review for people with ID.[107] Fifty-three patients and carers attended health checks; 34 of these already had concerns and the checks identified an average of 1.49 required interventions per patient. In addition, the checks identified unmet health needs. However, the study found that it could be difficult to get patients to return for follow-up tests or interventions. The use of double appointments, a structured questionnaire and input from carers facilitated the health checks. The study used a small sample from one GP practice; a larger more robust study conducted in a number of GP practices would be needed to determine the true impact of the health checks. In addition, the research was conducted in 2002 and is potentially not reflective of current practice.

A small controlled study[96] investigated health checks for people with ID to detect, quantify and treat physical and mental health conditions in one Midlands market town. The health checks were performed by a consultant psychiatrist in LDs, a GP and a community LD nurse at the GP's surgery, and detected and treated a range of health conditions. The checks were performed twice, 1 year apart. At the second check, there were a reduced number of referrals and other interventions, but it was thought that it would still be useful to continue with annual checks. Generally, people with ID and carers were positive about the checks and how the consultations were conducted. A wider range of outcome

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measures would have helped to produce a fuller understanding of the quality of the consultations. The research was published in 2002 and is potentially not reflective of current practice.

Health checks were found to help identify health needs,[93,101,107] improve the monitoring of people with long-term conditions,[121] reduce long-term need for referral and interventions,[96] and increase health promotion activities aimed at people with ID.[19] Three studies[95,97,98] found that incentivisation schemes increased tests and checks and one study found health checks to be cost-effective.[109] A number of studies investigated uptake of health checks and factors that could influence this.[104,107,108,111] These studies found challenges to the introduction and uptake of health checks, including defining eligibility.[111] The included studies did not investigate the quality of the health checks.

Staff training

Five of the innovation studies investigated training of staff. Individual studies investigated training for staff in the following services or areas: eye health,[92] IAPT, general practice,[112] cardiovascular[106] and pain reporting.[110]

One controlled study investigated training for optometrists and student optometrists,[92] which included a series of lectures and then supervised practice at vision screening for at least 2 days. The results were compared with those of a control group who had received similar lectures but no practical experience. Both groups improved their self-reported knowledge of eye health for people with ID and their confidence in working with them. However, the study found that training that incorporated clinical experience and using real patients was particularly effective, although lectures can still be useful. Courses that provide practical experience should be offered where possible. The study findings were based on self-report data and the questionnaire used for attitude assessment had not been validated. Participants' actual knowledge would have been better assessed by a formal examination than by self-report data. In addition, the study participants had all volunteered to work at the Special Olympics so this is an area of possible bias as they potentially had a more positive attitude to people with ID than other optometrists.

Another study[112] evaluated a project that aimed to raise staff awareness, improve their training and adapt their working practices to improve the accessibility of their services to people with ID. The project was undertaken in three primary care practices in north Essex. The study found that GPs and practice staff were aware of their need for training in providing services to people with ID and training workshops were offered but only one of the three practices was prepared to release all of their reception and administrative staff to attend the training. Practice development plans were produced by all of the practices, which aimed to improve the accessibility of their services to people with ID. In addition, communication was improved between the practices and the community LD team. The study had only limited involvement of people with ID, it had a small sample size and its evaluation was only short term (3 months), so it is not possible to determine if the changes would be sustained.

One study investigated training for IAPT practitioners designed to prepare them for working with people with ID. The study participants, who were therapists working in an English IAPT service, completed measures of confidence, attitudes to people with ID using mainstream health services and their self-efficacy before and immediately after the training, and 3 months after the training. Following the training, there were positive changes in measures of confidence, attitudes to people with ID using mainstream IAPT services and their general therapeutic self-efficacy, which were maintained 3 months after the training. In addition, 12 of the practitioners were interviewed about how the training had affected their practice. The interviews highlighted that the referral and access process for IAPT can act as barriers to people with ID. The skill levels of practitioners can also be a barrier and specialist knowledge is needed to enable them to work effectively with people with ID. Furthermore, scales used at IAPT sessions have not been standardised for people with ID and this is a potential area for further research. The study was small and the training would need to be further evaluated in a larger study with a more robust study design.

A training package for professional carers, to train them to report and manage the pain of people with ID, was evaluated in a cross-sectional study.[110] The staff were from care homes in Kent. Out of 203 people who completed the training, 116 completed evaluations. The majority of staff (82.8%) who completed the evaluations found the training useful and 71.1% believed that they had gained new insights into pain assessment and management. The study authors reported that there was better reporting of pain following the training. However, the study provided data only on the training, not on the reported improvements in recording. The study was based on self-report data, which are open to bias.

One small pilot study[106] investigated a training resource for coronary heart disease. The programme trained 17 staff from community support organisations in Scotland about heart disease. Following the training, staff had increased their knowledge of heart disease and felt more confident about improving the health of people with ID. This was an initial study to test the training package and would need to be evaluated with a larger number of staff using a stronger study design to conclusively determine its impact.

Other innovations

A small cross-sectional study[94] investigated whether one-to-one counselling improved uptake of cervical screening in eligible women with ID in one primary care trust area in Lancashire. At the start of the study only 16% were having regular screening compared with the national target of 80%. The counselling was time-consuming and uptake was low for mainly appropriate reasons. Following counselling, an extra nine women had cervical screening for the first time, which was a small increase in uptake to 22% and the counselling revealed that the remaining 96 women (60%) had appropriate reasons (e.g. medical reasons, not sexually active, etc.) for not having cervical screening. Counselling provided an opportunity for women with ID to discuss their reasons for not attending cervical screening, which is potentially a discussion that could take place with a patient's GP or practice nurse. Women included in the study had mild ID and, therefore, were not representative of the whole ID spectrum, meaning that the findings were not applicable to the whole ID population.

A small mixed-methods study developed, implemented and evaluated a teaching programme to empower people with ID to better access health care.[113] The study assessed participants' knowledge, skills and self-efficacy related to accessing health care and improvements were seen compared with scores before the training. Data from the qualitative interviews suggested that the programme has improved decision-making, symptom awareness, understanding of medical procedures, knowledge of how to access primary care, self-efficacy, ability to plan health care and how to formulate health goals. The project was funded by a research grant and it would be difficult to find the money to implement the programme in normal practice. The findings from this pilot project were promising but the sample size was small and there was no follow-up done. Further larger studies would be necessary to determine if the findings were as a result of the project.

An analysis of the general practice patient survey[103] investigated which patient groups were more likely to benefit from weekend opening. Patients with ID were found to be less likely to utilise or want weekend opening, so this innovation would be unlikely to improve GP access for this population. The survey had a low response rate of 33%, meaning that it is not reflective of the whole population and potentially has a degree of participation bias; people who felt strongly that they wanted weekend opening hours could potentially have been more likely to reply. The survey was based on self-report data meaning that potentially the population of people with ID could have been higher but individuals might not have reported that they have ID. In addition, the survey included only patients registered with a GP so that patients who did not have a GP or had recently moved practices would not have been invited to participate, meaning that the views of certain populations (e.g. immigrants, people without a permanent home) might not have been considered. Furthermore, the survey was based on self-report data about people's perceptions of the usefulness of weekend opening not their actual use.

Influencing factors

Influencing factors identified in the innovations to improve access cluster are discussed below and shown in *Table 23*.

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TABLE 23 Influencing factors by study, innovations to improve access

	Factor									
First author and year of study	**Staff knowledge/ skills**	**Joint working with LD services**	**Service delivery model**	**Uptake**	**Appointment making**	**Carer/support role**	**Relationships with staff**	**Time**	**Accessible information**	**Communication**
Adler 2005[92]	✓									
Baxter 2006[93]				✓						✓
Biswas 2005[94]								✓		
Buszewicz 2014[95]			✓	✓						
Cassidy 2002[96]			✓	✓						
Chauhan 2010[97]			✓							
Chauhan 2012[98]			✓	✓	✓		✓			
Codling 2007[99]										
Cooper 2006[101]										
Cooper 2014[100]										
Dagnan 2018[102]	✓				✓					
Felce 2008[19]										
Ford 2015[103]			✓							
Glover 2013[104]										
Harrison 2005[105]		✓	✓							
Holly 2014[106]	✓									
Martin 2004[107]						✓		✓		
McConkey 2015[108]				✓						
Romeo 2009[109]										
Taylor 2014[110]						✓				
Walmsley 2011[111]	✓		✓	✓						
Webb 2009[112]	✓	✓	✓					✓	✓	
Webb 2009[113]				✓						

Staff knowledge/skills

The importance of health professionals' knowledge and skills in working with people with ID was apparent in several studies. Staff involved in mainstream services lacked confidence in their skills to effectively deliver services to patients with ID or were aware of the need for further training. This was the case for staff in mainstream IAPT services, general practice staff[106,111,112] and optometrists.[92] Training to develop the knowledge and skills of health professionals working with people with ID was found to be more effective when it incorporated clinical practice.[92]

Joint working with learning disability services

Joint working with LD services was highlighted in three studies. A project to improve access involved practices producing a practice development plan that included reasonable adjustments for people with ID, which was developed by the practices working with the community LD team.[112] One study investigated a joined-up approach involving primary care and community and specialist LD team staff, which improved access to mainstream health care for people with ID.[105] An older study introduced health checks performed by a consultant psychiatrist in ID, a GP and a community intellectual disability nurse at the GP's surgery. They detected health conditions and were favourably received by people with ID and their carers.[96]

Service delivery model

One influencing factor highlighted in this topic was the challenge of identifying who was actually eligible for health checks.[111] A project to improve service access for people with ID introduced a LD register as part of a practice development plan.[112] Read codes were used for specific conditions to help identify patients.[95] However, another study found that there could be variation in coding and coding could be based on social assessment not medical need with no clarity about purpose or value.[98]

Another important influencing factor for practices in introducing health checks was financial incentivisation.[95,97,98]

Uptake

The uptake of health checks was affected by uncertainty about who was actually eligible.[111] Read codes in GP records for specific conditions could help to identify patients eligible for checks.[95] Two studies[93,108] considering uptake found that people in nursing or residential homes were more likely to have health checks, which could be because their eligibility for checks was easier to determine than that for people living in family homes.

Poor uptake could also be associated with problems making an appointment; potential issues were the way patients were invited, poor interagency communication and patients' individual communication difficulties.[98] The study attempted to make reasonable adjustments for people with ID, including telephoning to arrange an appointment, offering health check appointments at home and telephoning to remind patients of their appointment.[98]

One training programme improved the knowledge and confidence of people with ID to access primary care, which could potentially lead to increased uptake of services.[113]

Appointment making

As discussed in *Uptake*, a telephone call to arrange an appointment, the option of an appointment at home and a telephone call reminder about the appointment can help make the appointment process easier.[98]

Making appointments to attend other services could also be problematic; the referral and access process for IAPT could be challenging for people with ID.

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Companion/carer/support worker role

Input from carers to health review was important.[107]

Staff working in care homes need knowledge about pain assessment and management.[110]

Relationships with staff

For people with ID, continuity of health professionals was important.[98]

Time

Flexible GP appointments could also be introduced as a reasonable adjustment; in one study flexible appointments included offering the first appointment of the clinic to reduce waiting time and offering double-length appointments.[112] Booking double appointments for health reviews ensured that people with ID were not rushed.[107] Providing a quiet waiting area could help people with ID and stop them from getting anxious.[112]

One-to-one counselling provides time for discussion and helps identify reasons for low uptake of cervical screening and improved actual uptake by a small percentage.[94]

Accessible information

Accessible information is important to people with ID. Reasonable adjustments introduced in one study included a board with staff photographs, visual aids in consultation rooms and an easy-to-read practice leaflet.[112]

Communication

Communication can be difficult for people with ID; therefore, if health checks can identify common hearing and visual problems that can affect communication, and if these are treated, this could help people with ID to communicate with primary care health professionals.[93]

Grey literature

The mapping review grey literature searches identified 28 reports; following full-text inspection, three reports were included. Of these, only one report comprised a research study,[30] using mixed qualitative methods. The remaining two reports, published by Public Health England and using quantitative methods[29] and case studies,[122] provide only short sections that are relevant to this review.

The Mencap-led Pharmacy Project[123] aimed to identify issues reported by pharmacists, people with disabilities and their professional and family carers in accessing pharmacy services. A significant limitation of this study for our review is that the scope was broader than ID, including any disability. This suggests that caution should be used in interpreting the findings as some reported barriers to access, for example, physical barriers, may not be specific to people with ID. Issues that were identified within pharmacies included unclear signage in the pharmacy and lack of a quiet room. One-third of respondents stated that pharmacists could be more patient, and that some attitudes about disabled people were negative. There were reported limitations in pharmacists' knowledge about disabled people. Health information was reported as too complex or difficult to read. Disabled people may also be unable to adequately describe their symptoms. Pharmacists reported that health review medication may not be checked by a GP and therefore may go unchanged for a considerable time. There was a reported lack of communication between GPs and pharmacists, which leads to communication gaps between the pharmacist and families and/or other service providers. Pharmacists reported that they need to build up trust, assist families' understanding of the situation and provide information.

Making reasonable adjustments to encourage the uptake of screening for cervical, breast and bowel cancer[122] provides a number of innovative case studies. As cervical cancer screening is the only screening programme relevant to this review (being carried out in primary care), the data we have included from the report are limited. One intervention provides resources to help women with ID make informed choices about cervical screening, including a 20-page, easy-to-read guide and a 'smear test' film. Another innovation is the introduction of a screening liaison nurse to work with GPs to identify eligible women with ID and also to ensure that they receive the appropriate information. This role is not confined to cervical screening and as yet there are no reported outcomes relating to changes in cervical screening uptake. The role does, however, appear to have made a positive impact on the uptake of breast screening. A Quality Innovation Productivity and Prevention Plan has resulted in statistically significant (no figures supplied) increases in the use and recording of mental capacity and best interest assessments across a range of GP practices; however, there are currently no data on the effects on screening rates. Similarly, implementation of the 'screening uptake for vulnerable groups' cluster of the Accelerate, Coordinate, Evaluate (ACE) programme (60 projects, eight clusters) as yet has no reported outcomes.

Initiation and uptake of health checks[29] is discussed briefly using quantitative data. The report highlights the increase in registration of people with ID in GP practices from 2008 to 2015, when 252,446 people of all ages were on LD registers. A total of 197,451 of those registered were eligible for an intellectual disability health check and 124,785 were reported to have been carried out (63%) compared with 25,000 in 2008.

Summary

A very small body of data has been identified from grey literature that provides evidence relevant to this review. Only one report comprises a research study and it is limited by its broader disability scope. However, it does provide some insight into the views and experiences of people with disabilities accessing pharmacies as well as pharmacists' views of their own potential to make adjustments. Further adjustments are being made across a range of conditions and screening programmes, although outcomes are generally not yet reported. One exception is for cervical screening, in which there is limited evidence for initiatives that specifically aim to identify women with ID and ensure that they are made aware of the programme and its implications in an appropriate format. Finally, there is evidence that GP registration for people with ID and uptake of annual health checks, initiated in 2007, are both increasing each year.

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Chapter 7 Discussion

Main findings

The literature search identified 82 publications describing 80 studies that met the reviews inclusion criteria. The included studies were published between 2002 and 2018. Three items of grey literature were included.[29,30,122]

The overall strength of the evidence base is weak. The methodological quality of the included studies was generally poor, which limits the strength of any findings from the review. The studies generally had small sample sizes and reported short-term outcomes.

The majority of studies focused on studies about access to services provided in or by general practices, a small number of studies referred to IAPT services, optical services, and those provided by sexual health clinics[71] and dental clinics. No studies explored access to pharmacy services, NHS 111, and out-of-hours or walk-in general practice centres. Individual studies explored particular settings, including rural health, deprived communities and temporary accommodation for the homeless.

Given the variation and changes in service provision over the time period covered by this review and across different geographical areas, it is difficult to get a clear picture about service provision nationally.

The review found very little new high-quality evidence to add to the review by Alborz *et al.* in 2003.[21] Some innovations, such as annual health checks, have increased access to and uptake of some health services but not all of those who are eligible for the checks receive them and there is some evidence that actions taken are preferentially directed towards those services that bring financial benefit to the service provider. Some high-profile innovations that have taken place across primary care, since the review by Alborz *et al.*,[21] have been widely publicised, such as extended opening hours; however, these have not benefited people with ID.[103]

The review conceptualised access in three stages: (1) identifying need, (2) accessing services and (3) interacting during a consultation. These three stages reflect a simple pathway to access; however, factors identified from the literature that influenced these stages were common to more than one stage and, in most cases, relevant to all three stages. Influencing factors are considered below.

The review identified the following key factors that influenced access and were cross-cutting across the stages of access reported in the literature:

- availability of support – from social service providers, relatives and other paid and unpaid supporters
- consistent person or people providing care or support – enabled a long-term relationship between the person with ID and their supporters, and communication between social service providers, relatives, other supporters and health professionals
- adequate training for supporters – training for social service providers and all paid supporters to identify health needs
- effective communication within services – close teamworking, sharing knowledge of the client, and consistency of staff team
- effective communication between services – mainstream health services, specialist ID services, day services and residential services, family carers, and other formal carers and supporters (e.g. personal assistants, advocates)

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- accurate record keeping
- communication skills of all who come into contact with people with ID – value, respect, ability to tailor information to the abilities of the individual with ID
- appropriate use of accessible resources – including use of pain recognition and communication tools
- time – to communicate and work effectively with people with ID.

Availability of support from a consistent person or people with adequate training in monitoring and addressing the health needs of people with intellectual disabilities

The role of carers and supporters is pivotal and studies reported the importance of long-term relationships to enable staff and supporters to recognise and monitor health-related changes in verbal and non-verbal behaviours. Supporters needed an awareness of health needs relevant to the general population regardless of intellectual disability, as well as those related to any underlying cause of ID, associated comorbidity or polypharmacy. In addition, they needed knowledge of the health needs of a particular individual, for example related to family history of disease, living environment and lifestyle. Several authors reported that high turnover of staff meant that training was time-consuming and of limited value.[86,120] Lack of knowledge about potential health risks and services available leads to unmet health needs and untreated ill health. Powrie[84] found that the high turnover of social care staff contributed to poor communication between primary and social care and Tuffrey-Wijne[86] found that reliance on agency staff put more pressure on permanent staff who were able to provide consistency of care.

The evidence base demonstrated that people with ID and their carers also valued being able to see the same health professional, and this led to trusting relationships that built up over time. However, health professionals needed greater awareness of the needs of someone with ID and of communication strategies and aids to facilitate good communication during consultations.[110] The opportunity to see the same health professional over time can help reduce anxiety for the person with ID and help the health professional to develop knowledge of an individual, their living circumstances and health needs and the communication skills to work with them effectively. Training can develop health professionals' specialist knowledge of ID and potentially improve their skills in working with people with ID. Training that includes clinical practices may be more beneficial.[92]

Studies found that carers and supporters experienced tension between their role in promoting the autonomy of an individual with ID and promoting good health or, in some cases, safeguarding when a decision had the potential to be harmful to health.[84,90] In some cases, the decision was referred to as a 'best interest' decision but there was little clarity about how these decisions were made and some concern that decisions were influenced by the interests of carers or relatives as well as the interests of the individual. This was of particular concern in relation to contraception and to end-of-life care when there are significant emotional and practical consequences for carers and relatives. Clarity about the process and monitoring of best interest decisions is needed.

People are long-term users of services and their past experience has an impact on access. The PPI showed that adults and, particularly, their carers feel that they have to fight for the services that they are accessing. In addition, there is a fear of health professionals making blood tests or dental procedures difficult.

Effective communication within and between services

Communication within services was particularly important to monitor and identify health-related changes in verbal and non-verbal behaviour when people with ID were unable to communicate their health needs verbally. There was evidence that people who use verbal communication did not necessarily disclose health needs and so monitoring is important. There was some uncertainty about whose role it is to monitor health between day and residential care services as both clearly have a role in monitoring and communicating any health concerns when an individual is unable or unlikely to do so for themselves.

Communication between mainstream health services and specialist ID services is important to enable mainstream services to meet the needs of people with ID. The evidence base contained limited evidence of joint working between health professionals and specialist ID staff, and health professionals were not always aware that there was support available from the community LD teams. Similarly, it was important to have good communication between social care and health services and to include informal carers and relatives in this. There was evidence that in some cases families and carers felt that their knowledge of the individual with ID was undervalued or disregarded by health professionals. There was also evidence that cultural differences between organisations had an impact on communication and care for people with ID and that families had to negotiate these differences to access health care.

Accurate record-keeping

Studies highlighted the importance of maintaining accurate health records[43,89,99,118] to facilitate communication within and between services when appropriate. One study[43] highlighted that some care staff may lack the literacy and numeracy skills to maintain accurate health records. A small number of studies discussed patient-held records such as health passports but there were concerns about how these are used and that they are not completed accurately by all health professionals.

Communication skills including use of accessible information

There was some evidence that communication was important to enable people to make appointments.[52,69,83,98] Sometimes information provided in letters inviting patients to attend for health checks or screening appointments was not understood by the recipient. Some people did not communicate over the telephone and so visited the service to make an appointment instead. Telephone triage appointments were difficult for some patients.

There was considerable evidence highlighting that people with ID want to be treated with dignity and respect by everyone they come into contact with at a service, and that this is not always the treatment they receive.[73,79,80,82,83,91,107,112] The literature suggests that this means talking to the individual first rather than anyone accompanying them to the appointment, although clearly the accompanying person may facilitate this communication. People want clear verbal information tailored to their abilities and supported by information in a format that is accessible to them. There was evidence that some service providers were not confident to communicate with people with ID and joint working with community ID teams could facilitate this. Being able to see the same person at repeat appointments was important to practitioners to develop person-specific knowledge of communication abilities and preferences, and to patients and carers because it reduced anxiety and fostered relationship building and the development of trust. The literature found that to help people with ID interact during a consultation, health professionals needed to give the patient adequate time. Some clinics offered double appointments for people with ID.

Many of the studies discussed the importance of accessible information for people with ID and highlighted that some service providers were not aware of accessible resources that are widely available.[50,52,66,73–75,80,81,83,89,91,112] Provision of accessible information tailored to the abilities of the individual was particularly important to support decision-making, including consent to procedures such as blood tests and cervical screening. There was evidence that consent is a particularly contentious issue and that there is a lack of clarity about actions to support capacity, the process of assessing capacity and the correct action to take when an individual is deemed to lack capacity.[75,78,81,84–90] The evidence suggests that there is a tension between promoting individual autonomy and the right to make decisions, and safeguarding, when people may make choices that are detrimental to their health possibly because they lack accessible information and/or capacity to weigh the future implications of their choices, and that staff were uncertain about how to manage this tension. There was some evidence to suggest that health professionals were basing best interest decisions on the interests of relatives and carers when they should be based on the best interests of the individual alone.

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Patient and public involvement contribution to the review

The PPI consultation raised some issues that were not covered in the literature. Formal support staff spoke about the difficulties of supporting people with milder ID who lived independently and had limited support. They spoke about the difficulty in supporting access to services, for example when screening invitations or text appointment reminders were sent to the client who ignored them and did not inform the support staff. They spoke about the difficulties clients had in responding to automated text appointment reminders and said that these created anxiety because clients did not know if they had responded correctly and so were not sure whether an appointment was confirmed or not. The literature did not refer to text reminders, but our PPI work suggests that these have created a further barrier to access for people with ID. They also discussed pharmacy services. None of the included studies referred to pharmacy services but formal carers talked about the difficulties and the danger posed when clients had the ability to go to a pharmacy themselves to request a prescription but did not explain about other medications they were taking or could not understand the instructions they were given about the new medication. This is clearly an area that warrants further exploration. PPI consultations on the findings and recommendations from the review are included in *Chapter 8*.

Considering these results in relation to the recommendations made in the Learning Disabilities Mortality Review Programme Second Annual Report and the UK government response to this review

Since the Alborz *et al.* review,[21] there has been increasing attention to the preventable deaths of people with ID. The scale of these deaths led to a confidential inquiry into premature deaths of people with LDs [*Confidential Inquiry into premature deaths of people with learning disabilities* (CIPOLD)], which reported that deaths from causes amenable to good-quality health care were significantly more common for people with ID than for those in a comparator group.[13] The inquiry was across all health services and did not specifically focus on direct access; however, the findings have implications for all those who have a role in ensuring that people with ID can access high-quality health care. The confidential inquiry led to an annual Learning Disabilities Mortality Review (LeDeR). The *Learning Disabilities Mortality Review (LeDeR) Programme Annual Report December 2017*[124] (the second annual LeDeR report) listed nine recommendations, which resonate closely with the influencing factors identified from the literature. The influencing factors identified in this review of the literature have been mapped to the recommendations from the second annual LeDeR report[124] and the actions proposed in the UK government's response to the recommendations in the LeDeR report[125] (*Table 24*).

Strengths and limitations

The review process

We conducted two large searches for the mapping and targeted review and extensive grey literature searching. However, time constraints meant that it was not possible to do all of the reference checking of reviews described in the protocol (see *Report Supplementary Material 2*). However, a recent *Health Services and Delivery Research* review[129] found that searching reviews for UK studies was time-consuming because of poor reporting and tended to find only older relevant studies.

There was no agreed pre-existing framework for analysis of the studies and the clusters developed from the literature. The clusters were reflective of the patient pathway and enabled us to focus on the different steps in the pathway. In addition, the clusters being reflective of the patient pathway would make them familiar to the readers. A disadvantage of the clusters is that it imposed a structure that was arbitrary and could mean that issues across the different clusters were not considered.

The evidence base

The methodological quality of the included studies was generally poor, which limits the strength of any findings from the review. The studies generally had small sample sizes and short-term outcomes.

TABLE 24 Influencing factors and overlap with the recommendations from the LeDeR programme second annual report

Influencing factors	LeDeR recommendation	Action proposed in UK government's response to LeDeR
• Effective communication with services • Effective communication between services	1. Strengthen collaboration and information sharing, and effective communication, between different care providers or agencies	1. Report on accessible information in LD services in NHS trusts 2. NHS England to report annually to the Department of Health and Social Care on progress made on the learning into action workstream regarding improvements in interagency communication achieved through local action
• Accurate record-keeping	2. Push forward the electronic integration (with appropriate security controls) of health and social care records to ensure that agencies can communicate effectively, and share relevant information in a timely way	1. Update to the Department of Health and Social Care on progress made in flagging and SCR development work 2. Once testing is complete, NHS England and NHS Digital to develop clear guidance on how the 'flagging system' will support clinical practice. NHS England to continue to support the use of additional information in the SCR through the annual health check programme 3. NHS England to review how LHCREs could better integrate the approach to sharing of pertinent information between health and care providers for people with a LD
• Effective communication within services • Effective communication between services	3. Health action plans developed as part of the LDs annual health check should be shared with relevant health and social care agencies involved in supporting the person (either with consent or following the appropriate MCA decision-making process)	1. NHS England to report progress on uptake of annual health checks to the Department of Health and Social Care via CCG IAF
• Availability of support • Consistent person or people providing care or support	4. All people with LDs with two or more long-term conditions (related to either physical or mental health) should have a local, named health-care co-ordinator	1. Disseminate the evaluation of the named social worker model 2. Undertake a rapid review of best practice in care co-ordination/key working for people with a LD, focused on health and well-being, to inform guidance for the NHS on care co-ordination
• Accurate record-keeping • Appropriate use of accessible resources • Time	5. Providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required and regularly audit their provision	1. (Repeated) once testing is complete, NHS England and NHS Digital to develop clear guidance on how the 'flagging system' will support clinical practice. NHS England will continue to support the use of additional information in the SCR through the annual health check programme 2. Publish update to the Department of Health and Social Care on progress made in adding a reasonable adjustment flag to the SCR application 3. Implement NHS Digital reasonable adjustment project roll-out and as part of this align with the LHCREs to ensure that the same information is being used in both

continued

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TABLE 24 Influencing factors and overlap with the recommendations from the LeDeR programme second annual report (*continued*)

Influencing factors	LeDeR recommendation	Action proposed in UK government's response to LeDeR
• Adequate training for supporters • Accurate record-keeping • Communication skills of all who come into contact with people with ID • Appropriate use of accessible resources	6. Mandatory LD awareness training should be provided to all staff, delivered in conjunction with people with LDs and their families	1. The Department of Health and Social Care, in conjunction with partners, will complete a consultation on proposals for mandatory LD awareness training 2. NHS England and the Department of Health and Social Care to write to providers and employers promoting the *Learning Disability Core Skills Education and Training Framework*[126] and reminding them of responsibilities in respect of training 3. Health Education England to develop and publish a tier 1 training offer 4. Health Education England to audit provision of LD training 5. NHS Improvement to implement and then monitor adherence to trust LD standards 6. The Department of Health and Social Care to commission Skills for Care to undertake a comprehensive skills and training audit of the social care workforce based on the LD core skills framework 7. Care Quality Commission to monitor uptake of mandatory training (see action point 1) through regulatory and inspection processes, and update the Department of Health and Social Care on progress (subject to consultation)
• Adequate training for supporters to identify health needs	7. There should be a national focus on pneumonia and sepsis in people with LDs, to raise awareness about their prevention, identification and early treatment	1. NHS England to publish *RightCare Pathways*[127] for dysphagia, epilepsy, sepsis and constipation 2. NHS England to report annually to the Department of Health and Social Care on progress made on the learning into action workstream regarding work on pneumonia, sepsis, constipation early warning scores and other identified themes that require action 3. Public Health England to improve uptake of the flu vaccine for people with a LD
• Communication skills of all who come into contact with people with ID • Appropriate use of accessible resources	8. Local services strengthen their governance in relation to adherence to the MCA, and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role	1. The Department of Health and Social Care to update on progress regarding the National Mental Capacity Forum 2. NHS England to distribute additional best practice guidance on the MCA, LDs and urgent care situations 3. The Care Quality Commission to further develop inspection expertise to assess the quality of MCA application and practice

TABLE 24 Influencing factors and overlap with the recommendations from the LeDeR programme second annual report (*continued*)

Influencing factors	LeDeR recommendation	Action proposed in UK government's response to LeDeR
Not applicable	9. A strategic approach is required nationally for the training of those conducting mortality reviews or investigations, with a core module about the principles of undertaking reviews or investigations, and additional tailored modules for the different mortality review or investigation methodologies	

CCG IAF, Clinical Commissioning Groups Improvement and Assessment Framework; LHCRE, local health and care record exemplars; MCA, Mental Capacity Act 2005;[128] SCR, summary case report.

The body of literature included in the review was heterogeneous in nature. Studies researched adults across the whole spectrum of ID, adults living in their own home cared for by formal or informal carers or in residential homes. The differences in study populations made comparing results from different studies difficult and findings from individual studies are therefore potentially not applicable to all adults with ID.

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Chapter 8 Conclusions

Implications for health care

The review has identified a number of potential implications for health care or service delivery. The methodological quality of the included studies was generally poor, which limits the strength of any findings from the review.

Consistency of care is important and staff retention is a key aspect of this. Adults with ID are looked after by family or paid carers in their homes or in residential homes. There is a high turnover of paid carers, meaning that it can be difficult for carers to develop a relationship with adults with ID that can enable them to realise when adults with ID are ill or in pain and when they need to access services. Carers who know the adult with ID well can help them in consultations with their GP or other HCPs by providing background health information and helping the adult explain themselves. Improving the retention of paid carers working with people with ID, for example, by fostering a culture that values the quality rather than the speed of care, has the potential to improve access to primary and community health care.

Training of health professionals is important to improve their knowledge of the needs of people with ID and their skills in working effectively with this population. This training could usefully include an awareness of the availability and role of specialist LD services and of the need to make reasonable adjustments to ensure that people with ID receive equitable care. Health professionals need to be able to fulfil the requirements of the Mental Capacity Act 2005 (MCA)[128] in relation to consent.

Employers have a responsibility to promote and prioritise staff training to ensure that social care staff and other paid carers have an up-to-date knowledge of health needs and services available to address those needs.

Action is needed to improve collaboration and joint working across funding and organisational boundaries. The failure of services to work together has been a factor contributing to the preventable deaths of people with ID.

Communication with someone with ID needs to be appropriate to their abilities. This may mean using accessible materials and resources to augment verbal communication and allowing extra time to communicate and to assess whether or not information has been understood. Appointments with the same health professional can facilitate communication over time and the opportunity to develop trusting relationships with health professionals may facilitate discussions about health needs and possible actions to take to maintain or improve health. Improved communication also includes ensuring that all information, including signs and notices, is clear and that any materials are available in an accessible format. Written communication, for example invitations to attend for screening, is particularly important and where possible information sent by post will include some mechanism to check that it has been received and understood to the extent of an individual's capabilities, while ensuring patient confidentiality.

Action is needed to improve compliance with the MCA.[128] This includes practice guidance about how to adhere to the MCA in situations where capacity to consent is lacking, and monitoring to ensure that practices adhere to this guidance. Similarly, guidance about the process of determining best interest and monitoring of this process is needed.

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Accurate record keeping at many different levels is important to ensure that information is available within services and between services. Comprehensive and up-to-date practice registers of people with ID facilitate access to annual health checks and enable recording of any reasonable adjustments needed to access care. Accurate health records held by residential care staff facilitate identification of health need and access to services, for example routine dental health screening. Action to improve recording and use of this information in practice is needed.

Patient and public involvement feedback on the implications for health care

Discussions about the implications for health care raised in the report were wide-ranging and energetic. The findings and suggested implications resonated with participants who agreed that they were relevant and important. A summary of key points from the discussions is given below.

- Improving retention of carers in order to provide consistency of care is important. There should be a career structure for carers. This should recognise when carers have undergone training and are experienced. These carers should be able to earn more money because they have been trained and are more experienced than other carers. Caring should be valued more highly, which means paying carers more for the work they do.
- People with LDs should be involved in delivering training to HCPs. When this happens the training is stronger and more effective.
- When talking to someone with LDs, check that the person has understood the information. For example someone with LDs may not understand how often to take their medication if they are told to take it daily. It is important to check that the person understands that this means they should take it once a day.
- Communication within and between services is important because some people with LDs have multiple health problems and they should be treated holistically taking into account all their health problems and their living arrangements. There has to be someone who knows them well who can communicate between services and organisations, and co-ordinate all their care.
- Families feel they have to fight for services when services should be proactive in offering services to people who need them.

Recommendations for research

The UK government's response to the LeDeR Programme Second Annual Report, published in September 2018, details actions to address recommendations from the LeDeR report, and these actions also resonate with the recommendations for practice from this literature review (see *Table 24*). However, research is needed to evaluate whether these actions are effective at improving access to health care for people, to understand the barriers that prevent actions from being implemented and used in practice and to develop effective interventions to improve staff training and retention, communication skills, collaboration and joined-up working and record-keeping. Recommendations for research are based on the evidence reviewed and are therefore limited by the availability of research. Given the paucity and the poor quality of research available, these recommendations are prioritised pragmatically according to their potential impact on the future health of people with ID rather than by the strength of the evidence supporting them. Fifteen years after the original review by Alborz *et al.*,[21] the evidence remains patchy and of poor quality because of the complexity of the population, the settings and the interventions under scrutiny and the ethical, logistical and financial challenges these present for randomised controlled designs, seen as the 'gold standard' for evaluating health care.[130]

1. Creative study designs that are feasible and ethical to implement and that meaningfully include people with ID are needed to address the complex issues highlighted in this review. The value of these designs should be recognised rather than seen as diminishing the quality of the study.

2. Given the range of abilities, living circumstances, support and other resources available within the population of people with ID, future studies should provide greater clarity about participants, including their abilities and circumstances relevant to the subject of the research. Further research is needed to identify how to support access for people in different circumstances with different abilities and with different levels of support and other resources, and across the population. For example, people with mild ID who live independently with little or no support are likely to have different abilities and, therefore, require different support to those people with moderate or severe ID living with higher levels of support. All studies should describe participants, perhaps in terms of living circumstances and relevant support needs, to enable practitioners to determine the extent to which findings are likely to be transferable to another population and for researchers to make meaningful comparisons across different studies.
3. Studies are needed to develop and evaluate solutions aiming to improve communication within services and across funding and organisational boundaries.
4. Studies are needed to explore how training can involve people with ID and improve the knowledge, attitudes and skills of those who work with and for people with ID, and to evaluate this training in terms of the difference it makes to the health of people with ID.
5. Research is needed to analyse the barriers to effectively implementing the MCA and to identify potential solutions to overcome these in order to improve compliance with it.
6. Research is needed to develop and evaluate interventions to improve the retention of care staff in order to provide consistency of care.
7. Interventions are needed to support carers to negotiate the tension between promoting autonomy and safeguarding against risk of harm when supporting individuals who have some capacity to make autonomous decisions. This might include frameworks to support decision-making or theoretical work. People with LDs should be involved in developing these interventions.
8. The majority of included studies addressed GPs' services; therefore, we recommend that research studies investigate access to other primary care services, for example nurses, pharmacists, opticians, NHS 111 and IAPT, with the aim of developing reasonable adjustments, interventions and service innovations to improve access.
9. Limited research was identified around other axes of difference [lesbian, gay, bisexual, transgender, and queer (or questioning) (LGBTQ), Black, Asian and minority ethnic (BAME), homelessness, etc.], further research is needed into access to health care for people with ID from communities that are already marginalised.

This review focused on access to mainstream primary and community care services and, therefore, did not include specialist community health-care teams for people with learning disabilities (CTALDs) and similar services for young people (aged 16–25 years). These specialist services accept referrals directly from people with ID and their carers and, therefore, a future systematic review of access to these services is needed to provide a full picture of access to community services for people with ID.

Patient and public involvement feedback on the recommendations for research

Discussions about the recommendations for future research centred on the importance of involving people with LDs in all training about working with people with LDs. This may reflect the fact that the PPI group included self-advocates who regularly contributed to training for people working with people with LDs. They also expressed frustration at the lack of progress made despite the research that has been undertaken since the Alborz *et al.*[21] review in 2003. The recommendations have been changed to reflect this feedback.

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Contributions of authors

Anna Cantrell (https://orcid.org/0000-0003-0040-9853) (Research Associate in Health Economics and Decision Science) was responsible for project co-ordination, protocol development for the mapping and targeted systematic review, study selection for the mapping and targeted systematic review, data extraction for the mapping and targeted systematic review, quality assessment for the targeted systematic review and report writing for the mapping and targeted systematic review.

Elizabeth Croot (https://orcid.org/0000-0002-3666-6264) (Senior Research Fellow in Health Services Research) was responsible for protocol development for the mapping and targeted systematic review, study selection for the mapping and targeted systematic review, data extraction for the mapping and targeted systematic review, quality assessment of the targeted systematic review, report writing for the mapping and targeted systematic review and subject expertise.

Maxine Johnson (https://orcid.org/0000-0003-0850-234X) (Research Fellow in Public Health) was responsible for the protocol development for the mapping and targeted systematic review, study selection for the mapping and targeted systematic review, data extraction for the mapping and targeted systematic review and report writing for the mapping review.

Ruth Wong (https://orcid.org/0000-0002-4536-4794) (Information Specialist in Health Economics and Decision Science) was responsible for information retrieval for the mapping and targeted review.

Duncan Chambers (https://orcid.org/0000-0002-0154-0469) (Research Fellow in Public Health) was responsible for data extraction for the targeted systematic review, quality assessment for the targeted systematic review and report writing for the targeted systematic review.

Susan K Baxter (https://orcid.org/0000-0002-6034-5495) (Senior Research Fellow in Public Health) was responsible for data extraction and quality assessment for the targeted systematic review and co-ordinated the PPI meetings.

Andrew Booth (https://orcid.org/0000-0003-4808-3880) (Reader in Evidence-based Information Practice) was responsible for protocol development for the mapping and targeted systematic review, report writing for the mapping review and methodological expertise.

All authors commented on drafts of the report.

Data-sharing statement

No new data have been created in the preparation of this report and, therefore, there is nothing available for access and further sharing. All queries should be submitted to the corresponding author.

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Appendix 1 Search strategy for mapping review

Epub Ahead of Print, In-Process & Other Non-Indexed Citations, MEDLINE® Daily and MEDLINE®

Date searched: 4 May 2018.

Date range: 2002–18.

Records retrieved: 1090.

#	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 deficien*)).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'

Web of Science

Date searched: 4 May 2018.

Date range: 2002–18.

Records retrieved: 2023.

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#	Searches
#1	TS = ((learning NEAR/1 (disab* or disorder* or difficult*)))
#2	TI = (((developmental* or intellectual*) NEAR/1 disab*))
#3	TI = ((mental* NEAR/1 (retard* or handicap* or subnormal* or deficien*)))
#4	TITLE: (intellectual* impair*)
#5	#4 OR #3 OR #2 OR #1
#6	TI = ((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*))
#7	TI = ((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'))
#8	TS = (('reasonable adjustment*' or 'equality act' or 'disability discrimination act' or 'mental capacity act' or 'care act'))
#9	#8 OR #7 OR #6
#10	(#9 AND #5) AND LANGUAGE: (English) Timespan = 2002-2018

The Cochrane Library

Date searched: 4 May 2018.

Date range: 2002–18.

Records retrieved: 666.

#	Searches
#1	(learning near/1 (disab* or disorder* or difficult*)):ti,ab
#2	((developmental* or intellectual*) near/1 disab*):ti
#3	(mental* near/1 (retard* or handicap* or subnormal* or deficien*)):ti
#4	intellectual* impair*:ti
#5	#1 OR #2 OR #3 OR #5
#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):ti,ab
#9	#6 OR #7 OR #8
#10	#5 and #9 Publication Year from 2002 to 2018

Cumulative Index of Nursing and Allied Health Literature

Date searched: 4 May 2018.

Records retrieved: 1117.

#	Searches
S1	TI ((learning N1 (disab* or disorder* or difficult*))) OR AB ((learning N1 (disab* or disorder* or difficult*)))
S2	TI ((developmental* or intellectual*) N1 disab*)
S3	TI (mental* N1 (retard* or handicap* or subnormal* or deficien*))
S4	TI ‘intellectual* impair*’
S5	S1 OR S2 OR S3 OR S4
S6	TI (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*)
S7	TI (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)
S8	TI (‘reasonable adjustment*’ or ‘equality act’ or ‘disability discrimination act’ or ‘mental capacity act’ or ‘care act’)
S9	S6 OR S7 OR S8
S10	S5 AND S9 Limiters - Published Date: 20020101-20181231; English Language

PsycINFO

Date searched: 4 May 2018.

Date range: 2002–18.

Records retrieved: 1646.

#	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 deficien*)).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/

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#	Searches
13	11 not (11 and 12)
14	10 not 13
15	limit 14 to english language
16	limit 15 to yr = '2002 -Current'

Applied Social Sciences Index and Abstracts

Date searched: 4 May 2018.

Date range: 2002–18.

Records retrieved: 596.

#	Searches
S1	(((ti((learning disab* OR learning disorder* OR learning difficult*)) OR ab((learning disab* OR learning disorder* OR learning difficult*))) OR ti((developmental* disab* OR intellectual* disab*)) OR ti((mental* retard* OR mental* handicap* OR mental* subnormal* OR mental* deficien*)) OR ti(intellectual* impair*)) AND (ti((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*)) OR ti((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)) OR ti(('reasonable adjustment*' OR 'equality act' OR 'disability discrimination act' OR 'mental capacity act' OR 'care act')))) AND (la.exact('ENG') AND pd (20020101-20181231))

Education Resources Information Center

Date searched: 4 May 2018.

Date range: 2002–18.

Records retrieved: 920.

#	Searches
S1	TI ((learning N1 (disab* or disorder* or difficult*))) OR AB ((learning N1 (disab* or disorder* or difficult*)))
S2	TI ((developmental* or intellectual*) N1 disab*)
S3	TI (mental* N1 (retard* or handicap* or subnormal* or deficien*))
S4	TI 'intellectual* impair*'
S5	S1 OR S2 OR S3 OR S4
S6	TI (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*)
S7	TI (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)
S8	TI ('reasonable adjustment*' or 'equality act' or 'disability discrimination act' or 'mental capacity act' or 'care act')
S9	S6 OR S7 OR S8
S10	S5 AND S9 Limiters - Date Published: 20020101-20181231; Language: English

Grey literature search

Terms used in the grey literature search in include 'learning disab*', 'learning disorder*', 'learning difficult*', 'access*', 'primary care' and 'community'.

- Association of Chartered Physiotherapists for People with Learning Disabilities – http://acppld.csp.org.uk/ (accessed 10 May 2018).
- British Institute of Learning Disabilities (BILD) – www.bild.org.uk (accessed 10 May 2018).
- Dimensions – www.dimensions-uk.org/ (accessed 10 May 2018).
- Disability Rights UK – www.disabilityrightsuk.org/ (accessed 10 May 2018).
- Foundation for People with Learning Disabilities – www.mentalhealth.org.uk/learning-disabilities (accessed 10 May 2018).
- IHaL - The Learning Disabilities Public Health Observatory – www.ndti.org.uk/our-work/our-projects/peoples-health/improving-health-and-lives-ihal (accessed 10 May 2018).
- Learning Disability Wales – www.ldw.org.uk/ (accessed 10 May 2018).
- Mencap – www.mencap.org.uk/ (accessed 10 May 2018).
- Mind – www.mind.org.uk/ (accessed 17 May 2018).
- Scope – www.scope.org.uk/ (accessed 17 May 2018).
- The Hearing and Learning Disabilities Group – www.hald.org.uk/ (accessed 17 May 2018).
- British Academy of Childhood Disability (BACD) – www.bacdis.org.uk/ (accessed 17 May 2018).
- British Society for Disability and Oral Health (BSDH) – www.bsdh.org/ (accessed 17 May 2018).
- Focus on Disability – www.focusondisability.org.uk/ (accessed 17 May 2018).
- Sexual Health and Disability Alliance (SHADA) – http://shada.org.uk/wp2/ (accessed 17 May 2018).
- Voluntary Organisations Disability Group (VODG) – www.vodg.org.uk/ (accessed 17 May 2018).

Citation search

Citation searches were carried out in Google Scholar on 21 June 2018 on three key publications:

1. Alborz A, McNally R, Swallow A, Glendinning C. *From the Cradle to the Grave: A Literature Review of Access to Healthcare for People with Learning Disabilities Across the Lifespan*. London: National Coordinating Centre for the Service Delivery and Organisation; 2003. (44 citations.)
2. Alborz A, McNally R, Glendinning C. Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. *J Health Serv Res Policy* 2005;**10**:173–82. https://doi.org/10.1258/1355819054338997. (111 citations.)
3. McNally R, Alborz A. 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 Info Libr J* 2004; **21**:182–92. (19 citations.)

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Appendix 2 Data extraction components for mapping review

Study identification number.

Study design:

- quantitative
- qualitative
- mixed methods
- review
- unclear.

Setting: country

HCP:

- GP
- dentist
- optometrist
- pharmacist
- other community staff.

Specialist topic:

- sexual health
- palliative care
- mental health
- other.

Study population.

Sample size.

Needs assessment.

Study outcomes.

Tools used to measure outcomes.

Study results.

Barriers.

Facilitators.

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Appendix 3 Data extraction mapping review example

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TABLE 25 Example data extraction from mapping review

Study identification number	Study design	Setting: country	HCP	Specialist topic	Study population	Sample size	Needs assessment	Study outcomes	Tools	Study results	Barriers	Facilitators
Burton (2013)[131]	Qualitative	Australia	GP Other community staff: practice nurse		In-depth interviews were conducted with 18 participants including people with ID, carers/support workers and rural doctors	18				Seven themes were identified: (1) health-care barriers in rural areas, (2) cohesion of rural communities, (3) the way rural doctors practice, (4) lack of knowledge/understanding, (5) venturing into new territory, (6) the role of the practice nurse and (7) the health communication triangle	Lack of services in rural areas. Distance to specialists in rural Australia	Increased social cohesion. Community connectedness

Appendix 4 Information from the patient and public involvement meetings

Consultation meeting at Mencap Sheffield, Norfolk Lodge with group of members who had been working on Royal Mencap's 'Treat Me Well' campaign on 6 June 2018 (EC/AC)

Themes arising from discussion:

- someone else decided when an appointment was necessary
- someone to take them to appointments
- someone to go into appointments with them
- not having to wait too long (people laughing at me in the waiting area)
- staff using correct name (not shortening names without asking first)
- seeing same doctor each time who knows them
- one member took photos of pills taken so Mum can check correct
- parents receive any appointment letters or text reminders
- letters are confusing and use long words
- knowing where to go – related more to hospital care.

Question – eye tests for people with intellectual disabilities. (URL: www.seeability.org/eye-tests-explained; accessed 30 November 2018).

Showed video they had done about visit hospital – letters confusing, big words, cannot read it, how to get to hospital, where to go, signs confusing, worry late, so many different big words, open wide fear not explained.

Letters – Dad read.

Dad talks to doctor.

Tell parents ears sore, they phone and make appointment wait too long. Happened before so point to ear, know need to go to doctors, Mum or Dad takes, not comfortable asking questions.

Dentist – parents make appointment and take them, parents ring dentist, take them, go in on own.

Opticians – new glasses, need someone to go with. Regular check-ups told need new glasses, do not know what letters are? Parents help choose glasses.

Pain.

Check-ups letters arrive not strange.

Like dentist, nice lady, injections 'no pain, no gain' easy to understand.

Optician sends letter, Mum reads, makes appointment, had eye test chose new glasses.

Mum decides need go to doctors, asks if ill, rings doctors to make appointment.

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Doctors – do not want to wait too long, get agitated think people laughing. Want staff at doctors to use correct name not shorten.

Seeing same doctor helpful as understanding, knows patient, Mum goes too, Mum talks first then doctor to patient. Does not get upset if sees same doctor.

Important someone to take and go in with, see same Dr.

Takes medicine himself, if Mum not there take photo of medicine taken so she can check correct. Explains medicines when take, colours, size tablets. Pill organiser so in days.

One group member uses diary and Mum writes appointments in.

One group member had ears syringed to clear wax before so was confident to go to hospital himself. Mum decides when need ears syringed.

Consultation meeting with two formal carers employed by national organisation. 18 July 2018 (MJ/EC)

Barriers may be structural – cost and organisation of services, or they may relate to a person's preferences and priorities, their knowledge, cultural beliefs and attitudes.

General practitioner

Barriers

- Appointment systems.
- Receptionists.
- Confidentiality when someone has reduced capacity but practice are not aware that they have not understood the consultation.
- Poor communication: not at the level the person can understand.
- People may not want to talk about their problems or may over/under emphasise relevant symptoms.
- Patients may make a nuisance of themselves by visiting often for no reason.
- If patients refuse to go no one can make them attend.
- Variation in the extent to which GPs will share patient information with carers (fluctuating mental capacity of patient).

Enablers

- Good provider–patient communication: understanding that it takes time to listen, talking to the person and ensuring that they have understood, making sure the proposed treatment is understood and is acceptable to the person.
- Seeing the same doctor/nurse so that they build a relationship and get to know the person.
- Health checks done in the home by a nurse from the practice.

Pharmacy

Barrier/enabler

- Knowledge of the individual's capacity.

Optician

Barriers

- Can be frightening to go to a strange place and do something you do not normally do.

Enablers

- Able to do home visits if necessary.
- Suitable methods for testing eyes when someone cannot read.

Dentist

Enabler

- Formal carers keeping records to track check-ups and ensure that they are not missed.

General

Barriers

- Person's understanding and willingness to attend an appointment somewhere unfamiliar.
- Person's willingness to attend for unpleasant treatment: cervical screening, vaccination.
- Negative past experiences.
- Seeing a different, unfamiliar or unexpected doctor without advanced explanation that this would happen.
- Person's inability to flag up a health problem at an early stage (e.g. blister that became badly infected without staff knowing about it).
- Person who goes to the GP regularly although there is nothing wrong.
- Person might not attend appointment because they are worried about the outcome (e.g. fear of diabetes diagnosis).
- Person might appear as though they have capacity to understand but actually not be able to understand or pass on the information they are given.
- People might not know what information is relevant to tell the doctor.
- Difficult to identify some health problems that arise over several days or that might not be obvious to a support worker who is only there for short periods at a time (e.g. constipation).
- Support workers often having to 'fight' (advocate) for several people at any one time.
- Letters/texts appointment reminders go to person and may be ignored.
- Voicemail messages can cause alarm: from surgical team when no surgery planned.
- Fragmented service where individual services pass the person between them with no one taking ownership to follow through until the problem is resolved.
- Lack of understanding of life world of person with disability (support worker) 'they do not see it from our side'.
- Different agencies attending patient (risk of missing appointments if patient not ready in time).

Enablers

- Having support staff who can attend with the person.
- Having consistent support staff who know the person so can recognise when something is not right.
- Good lines of communication between support staff and health service providers.
- Time.
- Listening to what is needed.
- Getting to know the person (e.g. their preferences).

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- Talking to the person with ID but then also to the carers to ensure that the information will be acted on.
- Sending appointment letters and reminders to support workers as well as patients.
- Someone willing to coordinate care between different services to ensure that the health need is met.
- Recognising where system/approach requires adjustment to accommodate patient needs.

Patient and public involvement meeting 5 July 2018

Present at the meeting were five members (two male and three female) of the FLASh carers group (all parents of adults with ID).

Introductions were made and discussion followed the guide adapted from the Alborz *et al.* review.[21]

The notes of the discussion points follow.

Identifying/communicating symptoms of ill health

- Difficulty communicating (e.g. pain; parents used to call for help at every suspicion of pain or other symptom, but then no signs when they see HCP).
- Can sometimes read facial expressions; have to ask what it means.
- Not sure if person with ID is giving 'correct' response to HCP's questions.
- Cannot leave signs/symptoms in case it becomes serious.
- Example of paramedics saying observations were fine but could not read person with ID's expression of pain.
- Communicate in the way people with ID is used to or through stories (example of using 'Mr Diabetes').
- Patient's views may differ from parent's views; HCP has to listen to patient.
- Patient may not understand reason for symptoms (e.g. 'ageing' the reason for aches and pains).
- Pain may be recognised suddenly rather than gradually.
- People with autism do not like to talk about personal things so may make, for example, depression worse if they are encouraged to do so.
- People with ID may expect others to be able to 'know' what is wrong ('be psychic').
- People with ID not the same all the time.
- People with ID may get ideas stuck in their heads about certain things (e.g. antidepressants are for bad people).
- Difficulty understanding that 'silent symptoms' (e.g. high blood sugar) are serious whereas obvious symptoms (e.g. painful foot) may be less serious – link between severity of symptom and severity of problem not always helpful.

Arranging and attending health consultations

Barriers

- Appointments difficult to obtain (discussion of different systems at GP practices including morning triage, afternoon drop in).
- Cannot always get transport to other services such as walk-in centre (need to book transport in advance).
- People with ID cannot explain their symptoms to the doctor, they need an advocate.
- Waiting in the waiting room can raise anxiety for people with ID.
- A 10-minute consultation time is not enough – need 15 minutes.

- Some people with ID (e.g. with autism) express more concern about small things than larger ones, so time needed to explore.
- HCPs not always aware of how ID affects family members.
- GP practices (and secondary care) do not always share the same computer system, so not easy to share information.
- Not all practices are linked to out-of-hours service.
- Late diagnosis of ID.
- Dentist – paperwork not always clear (ticking wrong boxes could affect funding).
- Cutting pharmacy support – having to wait for medication – not dealing with patients as too many prescriptions.

Facilitators

- GP listens to the patient.
- Quiet area away from waiting room to sit until can see GP.
- Able to ask for a double appointment.
- Suggestion – add red flag to patient notes so that the HCP is aware that this is a person with ID.
- Doctors discussing/sharing best practice, not doing things a certain way because that is how it has always been done.
- Important role of support worker (triangle: patient–support worker–HCP).
- Practice receptionists get to know patient and situation after a while.
- Home visits (GP, dentist, optician).
- Hospital passport (personal to people with ID, lets staff know needs and requirements), good idea but HCPs do not always read it.
- Parents involved in HCP training sessions.

Continuing access

- Take on board patient feelings/fears (e.g. patient with autism may panic over seemingly small things).
- Patient feeling safe.
- Knowing patient (e.g. carrying backpack around all the time can lead to chest pains).
- Continuity – patients like familiarity.
- Patient story does not always follow patient around from one service/HCP to another.

Other

- Parents need respite as care is 24/7 and do not get privacy if care is at home.
- Budget cuts have affected ability to employ support workers (increase in hourly rate/use of agency staff).
- What will happen when parents no longer there – concern.
- LD Care Act 2014[132] not implemented – clinical commissioning group not bound by it.
- No support worker cover for holidays – could ask trainees/volunteers to cover?

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Appendix 5 Search strategy for targeted systematic review

Adapted from the searches conducted for previous SDO review (i.e. McNally and Alborz[25]).

- Strategy informed by the findings from the mapping review.
- Multiple limits applied: humans, English language, date limits (2002–18), UK filter (Ayiku *et al.*[31]).
- Seven databases to search.

i. MEDLINE
ii. The 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)
iii. Web of Science (Science Citation Index Expanded; Social Sciences Citation Index)
iv. CINAHL (Cumulative Index to Nursing and Allied Health)
v. ASSIA (Applied Social Science Index)
vi. PsycINFO
vii. ERIC (Educational Resources Index).

MEDLINE

Date of search: 7 September 2018.

Date range searched: 2002–18.

Search strategy

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.

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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 6 List of excluded studies

Ahmad F, Roy A, Brady S, Belgeonne S, Dunn L, Pitts J. Care pathway initiative for people with intellectual disabilities: impact evaluation. *J Nurs Manag* 2007;**15**:700–2.

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Alborz A, McNally R, Glendinning C. Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. *J Health Serv Res Policy* 2005;**10**:173–82. https://doi.org/10.1258/1355819054338997

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Anonymous. GP registration moving too slowly. *Community Care* 2004:7.

Anonymous. HSJ awards 2005. Primary care innovation. Winner: PCT and council set up integrated commissioning for mental health, substance misuse and learning disability. *Health Serv J* 2005;**115**(Suppl.):42–3.

Anonymous. Open forum. *Community Care* 2007:19.

Anonymous. Threat to learning disability nursing. *Nurs Times* 2007;**103**:3.

Anonymous. Second equality report slams DH. *Nurs Times* 2007;**103**:3.

Anonymous. Chance to improve learning disability care must be taken. *Nurs Times* 2008;**104**:1.

Anonymous. Step change Ian McMillan Step change is a Freelance journalist. *Nurs Stand* 2012;**26**:18–20.

Anonymous. NHS strategy for learning disability. *Nurs Stand* 2015;**29**:10.

Anonymous. Appropriate care for people with learning disabilities. *Nurs Stand* 2016;**30**:66.

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Antaki C, Finlay WML, Walton C, Sempik J. Communicative Practices In Staff Support of Adults with Intellectual Disabilities. In O'Reilly M, Lester JN, editors. *The Palgrave Handbook Of Adult Mental Health: Discourse and Conversation Studies*. New York, NY: Palgrave Macmillan; 2016. pp. 613–32.

Atkinson D. Editorial. *Br J Learn Disabil* 2006;**34**:1–2.

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Bailey M, Doody O, Lyons R. Surveying community nursing support for persons with an intellectual disability and palliative care needs. *Br J Learn Disabil* 2016;**44**:24–34.

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Bains H, Bonell E, Speight P. Carer satisfaction with telephone consultations in a community intellectual disability unit. *J Intellect Disabil* 2010;**14**:259–65. https://doi.org/10.1177/1744629510390450

Bakker-van Gijssel EJ, Olde Hartman TC, Lucassen PL, van den Driessen Mareeuw F, Dees MK, Assendelft WJ, van Schrojenstein Lantman-de Valk HM. GPs' opinions of health assessment instruments for people with intellectual disabilities: a qualitative study. *Br J Gen Pract* 2017;**67**:e41–e48. https://doi.org/10.3399/bjgp16X688585

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Appendix 7 Data extraction components for targeted systematic review

Study details.

Study design:

- quantitative
- qualitative
- mixed methods
- conference abstract 2015 onwards.

Study population.

Sample size.

Setting.

Study aim.

Reasonable adjustment.

HCP:

- GP
- dentist
- optometrist
- pharmacist
- IAPT service staff
- audiologist
- disability liaison nurse
- practice nurse
- other GP staff
- other community staff.

Specialist topic:

- audiology
- cardiovascular
- cervical screening
- dental health
- diabetes
- eye health
- gastrointestinal
- health checks
- IAPT
- mental health
- palliative and end-of-life care
- respiratory
- sexual health
- transition
- other.

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Study outcomes.

Study results.

Study conclusions.

Barriers.

Facilitators.

Limitations.

Appendix 8 Data extraction targeted systematic review example

Findlay L, Williams AC, Scior K. 'Exploring experiences and understandings of pain in adults with intellectual disabilities'. *J Intellect Disabil Res* 2014;**58**:358–67. Study details:

- Study design: qualitative (semistructured interviews).
- Study population: adults with ID – 15 participants (eight men and seven women) with mild to moderate LD took part in the study.
- Sample size: 15 adults with ID.
- Setting: participants were invited to participate by professionals working in a community service for people with ID in the London area.
- Study aim: to explore the experiences that adults with ID have had of being in pain, and what meaning they attribute to both acute and chronic pain.
- Specialist topic.
- Other pain.
- Barriers: people may hide pain or fail to tell people they are in pain because they do not think they will be believed or they will be ignored, or because they think they might be stopped from doing something they enjoy. Someone who can communicate verbally will not necessarily communicate pain.
- Facilitators: development of a widely accessible checklist of questions to ask could help with the task of assessing pain and its potential causes.
- Limitations: the recruitment method may have introduced unknown biases, for example two participants did not speak English as their first language and may not have properly understood the question or answered fully. The study relied on service providers to approach potential participants; this poses the risk that not everyone meeting the inclusion criteria had the same chance of being invited to participate. The interviews used pictures and this might have limited the different pains discussed.

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Appendix 9 Grey literature data extraction

TABLE 26 Grey literature data extraction

Data topic	Details
***Hatton* et al. *2016*[30]**	
Study design	Qualitative
Setting	Pharmacist
Specialist topic	General
Study population	PwLD Professional support staff Family carers Pharmacists
Sample size	597
Study results	57% thought that signage was not clear in the pharmacy < 10% used a quiet room to communicate to staff and 48% did not think that their pharmacy had a quiet room at all 30% wanted their pharmacist to be more patient The average frequency for visits to pharmacists was monthly 15% stated that they did not know why they took their medication Survey work shows that negative experiences of pharmacy services are not the norm but some barriers exist
Barriers	For people with disabilities: Access to information – information presented in ways that were too small, too wordy, too complex, or not suitable Physical barriers – poor accessibility to health-care facilities Administrative barriers – short appointments and long waiting times Communication barriers – inability to describe symptoms, with differential diagnosis difficult and diagnostic overshadowing possible Attitudinal barriers – negative assumptions and attitudes about disabled people Knowledge barriers – limited theory and practice experience of the health needs of disabled people For pharmacists: Health reviews often completed by practice nurses so medication not being checked by a GP and, therefore, can go years without being changed Lack of communication between GP and pharmacy, and then to service providers or families Fear among families of reducing medication, especially if bad experiences in the past and have finally got the situation to a manageable point, they can be scared to alter it

continued

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TABLE 26 Grey literature data extraction (*continued*)

Data topic	Details
	Community pharmacists do not have the skills or confidence to support better communications between HCPs Families do not want to have to deal with too many professionals, so there needs to be decision-making and co-ordination at a local level
Facilitators	Pharmacists feel they need to build up trust, help the families' understanding of the situation and give them information
Limitations	Not restricted to learning disabilities
Public Health England 2016[29]	
Study design	Quantitative
Setting	GP (section of report)
Specialist topic	Health checks (section of report)
Study population	People with LD
Sample size	N/A
Study results	At the end of March 2015, there were 252,446 people of all ages on LD registers In 2014 to 2015, GP practices reported that there were 197,451 patients eligible for a LD health check (registered with their GP as having a LD and aged $\geq$ 14 years). There were 124,785 checks reported, giving an overall apparent coverage of 63.2%. The number of people with LD registered at a GP, eligible for a health check and having a health check has risen each year from 2008/9 when around 25,000 checks were carried out (no data for eligibility in 2013/14)
Barriers	Not reported
Facilitators	Not reported
Limitations	Not reported
Marriott and Turner 2016[122]	
Study design	Case studies 1. Jo's Cervical Cancer Trust (London, UK): resources to help women with LD make informed choices 2. The screening liaison nurse role: work with GPs to identify women with LD eligible for screening and ensure they have sufficient information 3. Quality Innovation Productivity and Prevention Plans 4. Accelerate, Coordinate, Evaluate (ACE) programme (60 projects, eight clusters). One cluster is 'screening uptake for vulnerable groups'
Setting	GP/community
Specialist topic	Cervical screening (2 and 3 also include breast and bowel screening)
Study population	Women with LD
Sample size	Not reported
Study results	1. Production of a 20-page, easy-read guide to cervical screening, and The Smear Test Film 2. No data on cervical cancer but improved uptake of breast screening 3. Statistically significant increases in use and recording of mental capacity and best interest assessments across all three screening programmes in a range of GP practices, although no increase in screening rates as yet 4. No outcomes to date
Barriers	Not reported
Facilitators	Not reported
Limitations	Not reported

N/A, not applicable; PwLD, people with a learning disability.

Appendix 10 Alphabetical list of included studies

Adler P, Cregg M, Duignan A, Ilett G, Woodhouse JM. Effect of training on attitudes and expertise of optometrists towards people with intellectual disabilities. *Ophthalmic Physiol Opt* 2005;**25**:105–18.

Ali A, Scior K, Ratti V, Strydom A, King M, Hassiotis A. Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PLOS ONE* 2013;**8**:e70855. https://doi.org/10.1371/journal.pone.0070855

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Baxter H, Lowe K, Houston H, Jones G, Felce D, Kerr M. Previously unidentified morbidity in patients with intellectual disability. *Br J Gen Pract* 2006;**56**:93–8.

Beacroft M, Dodd K. Pain in people with learning disabilities in residential settings – the need for change. *Br J Learn Disabil* 2010;**38**:201–9. https://doi.org/10.1111/j.1468-3156.2009.00593.x

Beacroft M, Dodd K. 'I Feel Pain' – audit of communication skills and understanding of pain and health needs with people with learning disabilities. *Br J Learn Disabil* 2011;**39**:139–47. https://doi.org/10.1111/j.1468-3156.2010.00640.x

Biswas M, Whalley H, Foster J, Friedman E, Deacon R. Women with learning disability and uptake of screening: audit of screening uptake before and after one to one counselling. *J Public Health* 2005;**27**:344–7.

Black D. Improving access to care for the learning disabled. *Pract Nurs* 2004;**15**:38–40.

Bland R, Hutchinson N, Oakes P, Yates C. Double jeopardy? Needs and services for older people who have learning disabilities. *J Learn Disabil* 2003;**7**:317–38.

Bollard M. Health promotion and intellectual disability: listening to men. *Health Soc Care Community* 2017;**25**:185–93. https://doi.org/10.1111/hsc.12291

Brown M, Taggart L, Karatzias T, Truesdale M, Walley R, Northway R, *et al.* Improving diabetes care for people with intellectual disabilities: a qualitative study exploring the perceptions and experiences of professionals in diabetes and intellectual disability services. *J Intellect Disabil Res* 2017;**61**:435–49. https://doi.org/10.1111/jir.12369

Buszewicz M, Welch C, Horsfall L, Nazareth I, Osborn D, Hassiotis A, *et al.* Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: a longitudinal cohort study. *Lancet Psychiatry* 2014;**1**:522–30. https://doi.org/10.1016/S2215-0366(14)00079-0

Carey IM, Shah SM, Hosking FJ, DeWilde S, Harris T, Beighton C, Cook DG. Health characteristics and consultation patterns of people with intellectual disability: a cross-sectional database study in English general practice. *Br J Gen Pract* 2016;**66**:e264–70. https://doi.org/10.3399/bjgp16X684301

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Cassidy G, Martin DM, Martin GH, Roy A. Health checks for people with learning disabilities: Community learning disability teams working with general practitioners and primary health care teams. *J Learn Disabil* 2002;**6**:123–36.

Chauhan U, Kontopantelis E, Campbell S, Jarrett H, Lester H. Health checks in primary care for adults with intellectual disabilities: how extensive should they be? *J Intellect Disabil Res* 2010;**54**:479–86. https://doi.org/10.1111/j.1365-2788.2010.01263.x

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Felce D, Baxter H, Lowe K, Dunstan F, Houston H, Jones G, *et al.* The impact of checking the health of adults with intellectual disabilities on primary care consultation rates, health promotion and contact with specialists. *J Appl Res Intellect Disabil* 2008;**21**:597–602. https://doi.org/10.1111/j.1468-3148.2008.00432.x

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Appendix 11 Quality appraisal of included studies

For the one randomised study the risk of bias was assessed using the checklist produced by the US National Heart Lung and Blood Institute for controlled intervention studies. The checklist can be accessed at URL: www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools (*Table 27*).

For the one non-randomised study the risk of bias was assessed using the checklist produced by the US National Heart Lung and Blood Institute for controlled intervention studies. The checklist can be accessed at URL: www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools (*Table 28*).

For the observational, cohort and cross-sectional studies, risk of bias was assessed using the checklist published by the US National Heart, Lung and Blood Institute for observational cohort and cross-sectional studies. The checklist can be accessed at URL: www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools (*Table 29*).

For the case–control studies risk of bias was assessed using the checklist published by the US National Heart, Lung and Blood Institute for case–control studies. The checklist can be accessed at URL: www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools (*Table 30*).

For the before-and-after studies, risk of bias was assessed using the checklist published by the US National Heart, Lung and Blood Institute for before-and-after studies with no control group. The checklist can be accessed at URL: www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools (*Table 31*).

Qualitative studies were assessed with the CASP checklist for qualitative studies, which can be accessed at https://casp-uk.net/casp-tools-checklists/ (*Table 32*).

TABLE 27 Quality assessment of randomised intervention study

	Cooper *et al.* 2014[100]		
Criteria	**Yes**	**No**	**Other**
1	Y		
2	Y		
3	Y, statisticians blinded to group		
4			Not possible
5			Partial, some compromise
6	Y		
7	Y		
8			
9		N, 76% received	
10	Y		
11	Y		
12	Y		
13			Unclear
14	Y		

N, no; Y, yes.

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TABLE 28 Quality assessment of non-randomised intervention study

	Adler *et al.* 2005[92]		
Criteria	**Yes**	**No**	**Other**
1		N	
2			NA
3			Not possible
4			Not possible
5			Unclear
6		N	
7	Y		
8	Y		
9	Y		
10		N	
11		N	
12		N	
13			Unclear
14			NA

N, no; NA, not applicable; Y, yes.

TABLE 29 Quality assessment of observational cohort and cross-sectional studies

Reference (first author and year of study)	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Allgar 2008[51]	Y	Y	U	Y	N	N	NA	NA	NA	N	Y	U	NA	N
Baxter 2006[93]	Y	Y	U	N	N	Y	Y	NA	Y	N	Y	U	Y	N
Bland 2003[35]	Y	Y	Y	Y	N	NA	Y	NA	NA	N	Y	N	NA	NA
Buszewicz 2014[95]	Y	Y, existing database	Y	U	N	N	NA	NA	Y	N	Y	U	NA	N
Carey 2016[53]	Y	Y	NA	Y	Y	Y	Y	Y	Y	N	Y	N	NA	N
Chauhan 2010[97]	Y	Y	U	Y	N	N	Y	N	Y	N	Y	U	U	N
Chauhan 2012[98]	Y	Y	U	Y	N	N	Y	NA	Y	N	Y	U	U	N
Codling 2007[99]	Y	Y	Y	Y	N	N	Y	NA	Y	N	Y	N	Y	N
Cooper 2006[101]	Y	Y	Y	Y	N	N	Y	NA	Y	N	Y	U	N	N
Cooper 2011[55]	Y	Y	U	Y	N	N	NA	Y	Y	N	Y	U	NA	Y
Doshi 2009[56]	Y	Y	Y	Y	N	Y	Y	N	Y	N	Y	N	NA	N
Felce 2008[19]	Y	Y	U	U	N	N	Y	NA	Y	N	Y	U	Y	N
Ford 2015[103]	Y	N	U	N	Y	Y	Y	U	Y	Y	Y	U	Y	Y
Glover 2013[104]	Y	Y	Y	Y	N	N	Y	NA	Y	N	Y	U	Y	N
Hanna 2011[40]	Y	Y	N	Y	N	NA	Y	NA	NA	N	Y	N	NA	NA

TABLE 29 Quality assessment of observational cohort and cross-sectional studies (*continued*)

Reference (first author and year of study)	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Hames 2006[76]	Y	Y	N	Y	N	N	NA	NA	NA	N	N	U	NA	N
Heyman 2004[78]	Y	Y	N	Y	N	N	NA	N	Y	N	Y	U	NA	N
Holly 2014[106]	Y	Y	U	Y	N	N	Y	Y	Y	Y	Y	N	Y	N
Jones 2007[79]	Y	Y	N	Y	N	N	NA	N	N	N	Y	U	NA	N
Lennox 2003[58]	Y	Y	Y	Y	N	Y	Y	Y	Y	N	Y	N	NA	Y
Lodge 2011[60]	Y	Y	NA	Y	N	N	NA	NA	N	N	Y	N	NA	NA
Martin 2004[107]	Y	Y	Y	Y	N	N	NA	NA	Y	N	Y	U	Y	N
McCarthy 2011[81]	Y	Y	N	U	N	N	NA	NA	N	N	N	N	NA	N
McConkey 2015[108]	Y	Y	Y	Y	N	N	NA	NA	Y	N	Y	U	Y	N
Melville 2005[133]	Y	Y	Y	Y	N	N	NA	NA	N	N	Y	N	NA	N
Nicholson 2011[62]	Y	Y	N	Y	Y	Y	Y	Y	Y	N	Y	N	NA	Y
Osborn 2012[63]	Y	Y	NA	Y	Y	Y	Y	N	Y	N	Y	N	U	Y
Pilling 2015[65]	Y	Y	Y	Y	N	Y	Y	N	Y	N	Y	N	NA	N
Powrie 2003[84]	Y	Y	Y	Y	N	N	NA	NA	Y	N	Y	N	NA	N
Raghavan 2007[66]	Y	Y	NR	Y	N	Y	Y	N	Y	N	Y	N	NA	N
Rees 2011[68]	Y	Y	Y	Y	N	NA	NA	NA	NA	NA	NA	NA	NA	NA
Reynolds 2008[69]	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	N	NA	N
Russell 2017[70]	Y	Y	NA	Y	N	N	NA	NA	NA	NA	N	N	NA	N
Starling 2006[6]	Y	Y	Y	Y	N	Y	Y	Y	U	N	Y	N	NA	Y
Taylor 2014[110]	Y	Y	U	Y	N	N	Y	N	N	N	N	N	NA	N
Tuffrey-Wijne 2005[88]	Y	Y	N	U	N	N	NA	NA	N	N	NA	N	NA	N
Turk 2012[44]	Y	Y	N	Y	Y	NA	Y	NA	NA	N	Y	N	NA	NA
Walker 2016[45]	Y	Y	NA	Y	N	NA	Y	NA	NA	N	Y	N	NA	NA
Williams 2014[71]	Y	Y	N	Y	N	NA	NA	NA	NA	NA	NA	NA	NA	NA
Williamson 2004[91]	Y	Y	Y	Y	N	N	NA	NA	N	N	N	N	NA	N

N, no; NA, not applicable; U, unclear; Y, yes.

TABLE 30 Quality assessment of case–control studies

Reference (first author and year of study)	1	2	3	4	5	6	7	8	9	10	11	12
Cassidy 2002[96]	Y	Y	N	Y	Y	Y	N	N	Y	Y	U	N
Romeo 2009[109]	Y	Y	N	Y	Y	Y	NA	Y	Y	Y	U	N

N, no; NA, not applicable; U, unclear; Y, yes.

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TABLE 31 Quality assessment of before-and-after studies with no control group

Reference (first author and year of study)	1	2	3	4	5	6	7	8	9	10	11	12
Dagnan 2018[102]	Y	Y	Y	U	Y	Y	N	U	Y	Y	N	NA
Webb 2009[112]	Y	NA	Y	Y	N	N	Y	N	NA	N	N	NA
Webb 2009[113]	Y	Y	Y	U	N	Y	N	U	Y	Y	N	NA
Biswas 2005[94]	Y	Y	Y	U	Y	Y	N	U	Y	N	N	NA

N, no; NA, not applicable; U, unclear; Y, yes.

TABLE 32 Quality assessment of qualitative studies

Reference (first author and year of study)	1	2	3	4	5	6	7	8	9	10
Ali 2013[50]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Beacroft 2010/2011[33,34]	Y	Y	Y	Y	Y	N	Y	U	Y	Y
Bollard 2017[36]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Black 2004[52]	Y	Y	Y	Y	Y	N	U	U	Y	Y
Brown 2017[73]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Chinn 2016[54]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Donovan 2002[37]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Findlay 2014/2015[38,39]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Gates 2011[74]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Goldsmith 2013[75]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Hebblethwaite 2007[77]	Y	Y	Y	Y	Y	U	U	U	Y	Y
Jones 2008[57]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Lees 2017[80]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Lloyd 2014[59]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
McCarthy 2009[41]	Y	Y	Y	Y	Y	N	Y	U	Y	Y
McNally 2015[61]	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
McShea 2016[42]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Murphy 2006[82]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Northway 2017[43]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Owens 2011[64]	Y	Y	Y	U	Y	Y	Y	U	Y	Y
Perry 2014[83]	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Redley 2012[67]	Y	Y	Y	U	U	N	Y	U	Y	Y
Thompson 2008[85] (mixed methods)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Tuffrey-Wijne 2009[87]	Y	Y	Y	Y	Y	N	Y	y	y	y
Turner 2014[89]	Y	Y	Y	U	U	N	U	U	Y	Y
Walmsley *et al.* 2011[111]	Y	Y	Y	Y	Y	N	N	N	Y	Y
Watchman 2005[90]	Y	Y	Y	U	U	N	U	U	Y	Y
Willis 2015[46]	Y	Y	Y	U	Y	N	Y	Y	Y	Y
Wilson 2010[47]	Y	Y	Y	Y	Y	N	Y	U	Y	Y
Wood 2007[72]	Y	Y	Y	Y	Y	N	U	U	Y	Y
Young 2012[48]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

N, no; U, unclear; Y, yes.

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