


BMJ Open Improving access to primary care and annual health checks for people who have a learning disability: a multistakeholder qualitative study

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ABSTRACT

Objectives To investigate key stakeholders' views on how to improve access to primary care in general practice settings for people with learning disabilities (or intellectual disabilities). Further to explore how inequalities and barriers in specific areas including annual health checks might be addressed.

Design A qualitative study design was used with data collected during focus groups, interviews and open-response surveys; data analysis was thematic and informed by stakeholder consultation. Processes to facilitate quality included triangulation of stakeholder perspectives, triangulation of data collection methods and checking interpretation of findings with participants.

Setting UK regional services including learning disability organisations, primary care general practitioner (GP) clinical practice networks and supported housing organisations.

Participants Sixteen people participated in the study: four people with learning disabilities participated in a focus group; four relatives completed an interview or survey; eight GPs, practice nurses and supported housing managers participated in interviews.

Results Five overarching themes describing approaches to improve primary care access for people with learning disabilities were identified including: prioritisation, proactivity, innovation and improvement, personalisation and prevention and follow-up. Definitions of themes were described and illustrated with quotes. Ten recommendations informed by the thematic analysis, stakeholder consultation, research and primary care guidance were codeveloped with people with learning disabilities.

Conclusions All stakeholders identified problems, with primary care interfaces being misaligned with the needs of people with learning disabilities. The recommendations informed by all stakeholders can be used to guide development of service provision to better meet the needs of people with learning disabilities in primary care. Future research should explore professionals' understanding of reasonable adjustments.

INTRODUCTION

People with learning disabilities experience higher burden of chronic disease and were at

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Qualitative data were collected from 16 key stakeholders (people with learning disabilities, relatives, general practitioners, practice nurses and sheltered housing managers) on ways to improve primary care access for people with learning disabilities.
- ⇒ Stakeholder consultation informed study design and interpretation of research findings and recommendations were codeveloped with people with learning disabilities.
- ⇒ We used convenience sampling and the number of participants was small though this is appropriate for qualitative designs.
- ⇒ Different methods of data collection were used, perspectives were triangulated across key stakeholders and interpretation of the research findings was checked with research participants.

increased risk of hospitalisation and mortality during the COVID-19 pandemic compared with the general population.¹⁻⁴ Given these health vulnerabilities, prioritising the health needs of people with learning disabilities is crucial.⁵ Guidance addressing this includes standards of care published in Canada^{6,7}; and UK recommendations encompass annual health checks, learning disability registers, reasonable adjustments and champions to share good practice.⁸⁻¹⁰

Annual health checks can uncover previously unknown conditions,¹¹ reduce preventable emergency hospitalisations,¹² allow monitoring treatments and foster continuity of care.⁷ Annual health checks are structured assessments conducted by general practitioners (GPs) and practice nurses who facilitate access for people with learning disabilities into healthcare services.¹³

Learning disability registers, and diagnostic codes for clinical terms ('READ' or SNOMED (Systematised Nomenclature of Medicine) codes) used in the UK National Health Service

(NHS) facilitate identifying people attending primary care who may have a learning disability (NHS Digital). However, people may be uncoded or incorrectly coded; without correct coding for learning disability they cannot gain access to appropriate healthcare and adjustments. Methods of identifying people with learning disabilities in primary care are required.^{14 15}

Despite initiatives and financial incentivisation for annual health checks,¹⁶ barriers in primary healthcare persist for people with learning disabilities. Examples include low uptake of health checks,¹⁷ and women with learning disabilities being less likely than those without to have cervical cancer screening or physiotherapy.^{18 19} Further, while prevalence of long-term conditions in primary care (eg, diabetes), is higher among people with learning disabilities, best-practice condition-management indicators are lower relative to the general population.²⁰ In a study examining barriers to improving primary care for people with learning disabilities in Canada, services in which leadership only passively supported innovation were less likely to implement care improvements.²¹

Other barriers in primary care for people with learning disabilities, include fear, carer unawareness of health problems²² and lack of evidence-based lifestyle interventions (eg, obesity prevention).²³ People with learning disabilities may lack assertiveness, communication skills and carers to support primary care attendance, and have difficulties self-managing health needs.^{17 22 24 25} In the USA, adults with learning disabilities living unsupported had more emergency hospital visits compared with other residency types.²⁶ Reviews of service user and carer perspectives on barriers to accessing primary care, identified time, knowledge, awareness, training, communication, embarrassment and active involvement in healthcare decision-making as factors.^{24 27}

Access to primary care for people with learning disabilities can be facilitated by individualised easy-read information,^{28 29} health questionnaires,³⁰ longer appointments,¹⁷ assisting those living unsupported²⁶ and having a proactive,⁷ flexible approach to suit the person.³¹ Practitioner and direct support staff training can also reduce barriers.^{32–34} Practitioners may lack confidence working with people with learning disabilities,³⁵ and experiential learning was found beneficial for physicians in Canada.³⁶

While research into primary care for people with learning disabilities is growing, coproduced research across different stakeholders is sparse. This study aimed to elicit key stakeholder views on ways to improve GP primary care access for people with learning disabilities and coproduce recommendations.

METHODS

The study was qualitative. Data were collected during focus groups, interviews and surveys, from June to December 2021 by the first and second authors. Analysis

was thematic with an inductive experiential framework informed by stakeholder consultation.

Participants

Recruitment was purposive to capture a range of stakeholder perspectives. Inclusion criteria were adults (>18 years of age) with mild to moderate learning disabilities, defined as having capacity to consent to participate in the research. People with learning disabilities were recruited via a UK regional charity who distributed accessible study information to people with learning disabilities and informed the research team of those meeting inclusion criteria and interested in participating. Prior to meeting the researcher accessible study information was read with people with learning disabilities by an advocate. Following this the information was read with people with learning disabilities by the first author who also asked questions about the information to assess understanding and capacity to informed consent. Relatives of adults with learning disabilities were recruited via a regional charity and contacts network who distributed study information and researcher details.

GPs, practice nurses and sheltered housing managers were recruited through regional clinical and practitioner networks.

Data collection

Online data were collected using Microsoft Teams after completion of informed consent. An online focus group was conducted with people with learning disabilities and supported by an advocate who facilitated online access. Data collection from relatives was by online interview or survey depending on their preference. The survey comprised the same open-response questions as the interview schedule. During focus groups and interviews, prompts were used to elicit detail, for example: can you tell me more about that? Key points from the focus group with people with learning disabilities were summarised by the researcher and read back to the group to check accuracy. Interviews with relatives were audiorecorded and transcribed. The focus groups, interview and survey topic schedules are shown in online supplemental materials.

Online semistructured interviews conducted with GPs, nurse practitioners and sheltered housing managers were audiorecorded and transcribed. The interview schedule (online supplemental material 2) comprised five sections: annual health checks, learning disability inclusion tools, barriers to accessing primary care, reasonable adjustments and COVID-19. Data on inclusion tools are reported elsewhere.³⁷ All participants were sent a debrief email.

Patient and public involvement

Study documents (consent, information sheets, focus group topic guides) were developed in consultation with a research advisory group led by people with learning disabilities. Feedback included to add content, edit wording, and create a debrief document. GPs were consulted regarding the interview topic schedule, and

Table 1 Ten recommendations: cocreated suggestions for improving annual health checks for people with learning disabilities

R1	Call them 'yearly' health checks	The health check should take place every year, 'yearly'. People should know that this does not stop them from seeing a doctor at other times if they have a health problem
R2	Create a supportive practice	Creating a supportive practice involves making accommodations and prioritising the needs of people with learning disabilities and may require adjusting practice. 'Personalisation' and making reasonable adjustments can make a big difference to helping the checks work well for people, and creating a supportive practice. Sharing examples of good practice can improve how support is given. Having a practice champion can help with this.
R3	Use a screening tool	Screening tools (learning disability inclusion tools) can be used to help understand what people's needs are and show if they might have a learning disability. Keeping registers up to date is important.
R4	Be proactive!	Contact people to attend, and follow-up if they do not attend. People need to know why they are being asked to get a health check and what will happen. Check people have information in a way they can understand.
R5	Offer personalised appointments	Ask if the check is a good time for them, and if it is somewhere they can get to. Offer longer appointments so checks are not done in a hurry. Find out what support people might need.
R6	In the appointment speak to the person directly	Speak to the person with a learning disability first, it's their health, even if they have someone supporting them. Let the person know what will happen and ask questions, even if it takes a bit longer.
R7	Provide easy-read information or picture-questionnaires	Make codeveloped easy-read information the same for all practices. Give information about what will happen before the appointment. Use easy-read questionnaires to collect details or for health action planning. Give people information about their health to take away with them.
R8	Make public health and health promotion information accessible	Provide online easy-read public health and health promotion resources (eg, on diet and exercise). These can be printed and handed to the person, posted, or emailed. It does not matter where you live, if the same easy-read information is being used across the country.
R9	Support transfer and access to other health services where needed	If people need to be seen by another health service after their check, they may need accessible information about this. They may need support to access follow-up services successfully. A learning disability nurse could help with this.
R10	Have an accessibility champion	Have a named team member who keeps up to date with information about working with and caring for people with learning disabilities. They should link to a regional lead person who shares good practice and training opportunities.

advised on wording and content. Initial review of data indicated living arrangements impact primary care access; this was discussed with a GP and informed our decision to recruit sheltered housing managers. An online presentation of preliminary findings was made to a research advisory group led by people with learning disabilities. Study findings were presented to a GP practice meeting.

Analysis

Thematic analysis was conducted manually by the first and last authors (an experienced clinician and researcher in the field of learning disabilities) in iterative phases following anonymisation: (1) data familiarisation, (2) coding, (3) developing a coding framework, (4) identifying themes, (5) reviewing, revising and confirming themes and definitions, and (6) identifying illustrative quotes.^{38 39} Informed by thematic analysis findings, research, primary care guidance and consultation with key stakeholders, recommendations were coproduced with people with learning disabilities (table 1). In accordance with qualitative analysis best-practice, trustworthiness

was ensured by: checking interpretation of findings with participants, triangulating perspectives and important aspects of the topic by collecting data from different stakeholders using different methods, and by inviting participants to comment on a summary of findings.^{38 39}

RESULTS

Sixteen people participated comprising four people with learning disabilities (one male, three female); four relatives (all female) and eight GPs, practice nurses and supported housing managers (seven female, one male). GPs, practice nurses, supported housing managers and one relative completed interviews, four people with learning disabilities took part in a focus group and three relatives completed surveys. Five themes with subthemes were identified from the focus group, interviews and survey data: prioritisation, proactivity, innovation and improvement, personalisation, prevention and follow-up (figure 1).

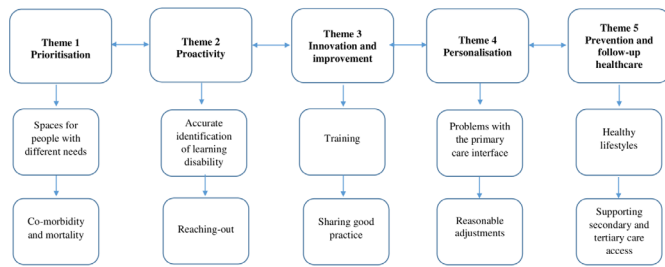


Figure 1 Structure of themes and subthemes

Figure 1 Structure of themes and subthemes.

At the time of the study primary care services were still under considerable pressure from the impact of COVID-19, and participants described changes to healthcare delivery including use of virtual technology: ‘*there was lots of Facetime consultation*’ (sheltered housing manager: SHM) and ‘*we had to put them (health checks) all on hold*’ (GP). Some changes worked well and were adopted longer-term: ‘*Now we’ve got the technology in place, it allows patient choice if somebody finds it more comfortable with consultation by video or phone*’. However, this wasn’t always suitable: ‘*There are bits of health checks that need to be done face-to-face; you can’t do a breast or testicle check over the phone or video*’ (GP).

Theme 1: prioritisation

This theme described the rationale for prioritising people with learning disabilities in primary care, and how to support this (Recommendation: R2), and comprised two subthemes: spaces for people with different needs, and comorbidity and mortality.

Subtheme 1: spaces for people with different needs

Participants indicated that waiting rooms may put people off attending and suggested the benefits of spaces for people with learning disabilities: ‘*He doesn’t like to go because of how busy it can get...loads of noises... distractions... he has anxiety...if he’s making noises and he’s aware of people looking at him*’ (SHM). Participants also valued being seen promptly ‘*sometimes the GP will see my daughter on time, this has happened more recently as I’ve explained my daughter’s inability to wait and her anxiety*’ (relative). A participant with a learning disability said ‘*you don’t know how long they (the GP) are going to be, it’s not always 5 min, then you get flustered because the doctor wasn’t on time*’.

Subtheme 2: comorbidity and mortality

Given prevalence of multiple health conditions and high mortality among people with learning disabilities relative to the general population, participants said unless they are prioritised health conditions may be missed: ‘*If any of the people on this [learning disability] list, ring for help, they go to the top of the queue. So that’s the culture we’re trying to develop in our practice, to minimize the risk of stuff being missed*’ (GP).

Primary care checks were viewed as being key to identifying preventable health conditions, and important as people with learning disabilities may find it difficult to manage multiple-health conditions: ‘*We have patients at*

high risk of avoidable illness and preventable mortality, have another long-term condition to manage, which is really difficult and puts them at higher risk of death’ (GP).

Prioritisation required allocating resources; participants described offering longer appointments and allowing enough time for thorough health checks for patients with learning disabilities (R5): ‘*People who are enthusiastic [about annual health checks] and see their value, do them more thoroughly. Some people will just put a few biometric results into a template...a health check needs to be a multi-system review, taking into context biological, psychological, sociological circumstances and needs to act on what it finds*’ (GP).

Theme 2: proactivity (R4)

A recurring theme described by participants was the importance of proactively encouraging people with learning disabilities to attend primary care. The theme comprised two subthemes: accurate identification and reaching-out.

Subtheme 1: accurate identification (R3)

In order to prioritise people, practices need to know which patients have a learning disability: ‘*we know people with learning disabilities have premature avoidable mortality. The only way we can do something about that is to proactively identify them and bring them in*’ (GP). Identification of patients with learning disabilities required the correct diagnostic codes, use of registers, screening, and multi-agency working: ‘*We need to work together, general practice, paediatrics and hostels*’ because ‘*if you don’t have the right code, you don’t get the [appropriate] health-care*’ (GP).

Subtheme 2: reaching-out

Participants explained that it was important to reach-out to people with learning disabilities who may be unaware of health service entitlements. While participants with learning disabilities could see the value of health checks: ‘*they are important, and can tell you if things are getting worse*’ and ‘*there’s no reason I wouldn’t want one*’, one person with a learning disability said there was ‘*no sign saying you’re allowed a health check, I didn’t know I could get one*’. A relative described inconsistent service provision: ‘*health checks have been hit-and-miss*’, while a sheltered housing manager said ‘*sometimes the people we support don’t know what an annual health check is*’.

Participants said that ‘*people decline them [health checks], and we have to chase around for them*’ (GP). Reasons included ‘*fear of health professionals and settings from past experiences*’ (relative), or feeling they don’t need a health assessment and have no-one to advocate for them: ‘*If a person is living independently, they may feel they don’t want to bother the GP... a lot of people with mild learning disabilities tend not to go to the GP so things can be missed*’ (SHM). Participants described the importance of reaching-out to people without an advocate: ‘*If people don’t have wrap-around support, they probably fall through the cracks*’ (SHM).

Participants highlighted that people with learning disabilities may have atypical symptoms, and they and

carers may not understand symptom significance: *'It's hard to know if there's health issues, when my son is non-speaking and unable to communicate pain or feelings'* (relative). A GP said *'unless we provide proactive healthcare to people that might not present typically, we risk their health'*. Methods of reaching-out included extra phone-calls, texts, offering flexibility, follow-up of non-attenders and those unsupported, and supporting follow-up healthcare arising from primary care visits (R4 & R9).

Theme 3: innovation and improvement

Theme three focused on service development and comprised two subthemes: training and sharing good practice.

Subtheme 1: training

Participants described how training improves primary care staff skills and awareness; a GP commented: *'education of staff is really important, so they're aware these patients might be phoning up'*. This was emphasised by a participant with a learning disability: *'people on reception don't give you enough time, they rush you and you can make mistakes...if they know you've a learning disability, they can talk to you in a different way'*. A relative suggested training on behaviours viewed as challenging would be helpful: *'receptionists should have training to understand'*.

Subtheme 2: sharing good practice

Participants described how sharing good practice can improve quality: *'there are various suboptimal [annual health check] templates being used. Our CCG [clinical commissioning group] has been ensuring everybody uses the national template. We demonstrated how to do annual health checks using the template'* (GP). Sharing good practice also included supporting less experienced practices: *'there was a strategic approach from our CCG to share data monthly, about how each practice network was doing with annual health checks, whether they were on target or not. There was help to practices with poorer uptake'* (GP).

Participants described the importance of a named person supporting development and good practice: *'I'm the learning disability lead...so it's my responsibility to make sure they're all done [health checks]'* (R10) and *'the practice could have a designated lead, that everybody recognises as the learning disability doctor or nurse'* (practice nurse) (R10).

Theme 4: personalisation (R2, R5)

A personalised service was valued, including for continuity of care, participants with learning disabilities said: *'I know the nurses quite well, that's helpful'* and *'seeing the same GP, so they get to know you a bit'*. Sub-themes included primary care interface problems and reasonable adjustments.

Subtheme 1: primary care interface problems

It was evident across all stakeholders that the primary care interface was challenging to people with learning disabilities, including automated telephone response options when phoning the surgery: *'A patient ringing-up with a mild learning disability, might not be able to wait in a phone*

queue, and struggle with phone numbers...if it says press '1'. Those things haven't been thought about for people with learning disabilities' (GP). A participant with a learning disability said they: *'might not be able to use the check-in machine and put in a date of birth'*. A GP described how: *'We only book four weeks ahead. If I say I need to see you in six weeks, they can't book that appointment and need to ring closer to the time. Someone who hasn't got a carer, will probably not remember'*.

Subtheme 2: reasonable adjustments

A GP described how offering flexibility around health checks improved uptake: *'We went from 49% uptake of annual health checks to 98%'*. A relative suggested *'ask if patients need any reasonable adjustments, and what would make the visit easier'* (R2 and R5), for example booking appointments at times to suit the person with a learning disability and carer who could attend with them. A participant with a learning disability said: *'they could talk for me if I didn't know the answer'*. However, direct communication from GPs or nurses was key, one participant with a learning disability saying: *'It's important to speak to the person; it's not nice to be talked over the top of'* (R6).

Other examples were provision of accessible information and avoiding jargon (R7 and R8); a participant with a learning disability said: *'They should be called yearly health checks...yearly is clearer than annual'* (R1). Clear information before and during appointments was found helpful by people with learning disabilities: *'Some people might be frightened so letting people know what to expect at their appointment makes it less scary'* and *'I liked that I could watch on You-tube what a health check is'* (R7). A participant with a learning disability described receiving a postal picture-questionnaire and said: *'you can fill in a form, if you're afraid of needles'* and *'I filled it in with help from my support worker'*.

Participants described gaps in awareness of accessible resources: *'It would be really helpful to have a website that has all the common health conditions. If you've got asthma I can print something off. There's a lot of medical terminology in leaflets we give people'* (GP) (R7). Limitations in reasonable adjustments provision was evident, a GP said: *'I'm rolling out the idea of coding that patients need a reasonable adjustment. When I talk to practices they're not really doing it; it's in their heads but they're not making it visible'*. A GP explained staff may lack awareness: *'I think we need to talk about reasonable adjustments in a more accessible way, even for professionals. They've got reasonable adjustments written on their notes; that assumes our staff know what reasonable adjustments are'*.

Theme 5: prevention and follow-up healthcare

This theme focused on supporting any follow-up resulting from primary care consultation and comprised two subthemes including healthy lifestyles and supporting secondary and tertiary care access.

Subtheme 1: healthy lifestyles

Participants alluded to primary care's role supporting people with learning disabilities in preventative approaches to healthcare, accessing public health



promotion campaigns, and supporting healthy behaviours and choices (eg, diet, exercise) (R2). A GP said: *'To understand that making healthy choices around food is really important. People without learning disabilities struggle on that. People with learning disabilities end-up with diabetes and struggle to manage it'* (R8).

Subtheme 2: supporting secondary and tertiary care access (R9)

Participants described the importance of planning follow-up to primary healthcare: *'some people may need a named individual to support them booking appointments, or accessing test results and follow-up appointments'* (relative) and *'sometimes they rely on carers to remind them that they have follow-up. I don't necessarily think they would remember'* (SHM). This sometimes required referral into another service for support and care coordination: *'It's thinking about practical safety nets, that will allow them not to become lost to follow-up'* (GP) and sharing health action plans with relevant health professionals to facilitate follow-up support (R9).

Recommendations informed by the thematic analysis, research, primary care guidance and consultation with key stakeholders, were coproduced with an advisory group led by people learning disabilities (table 1).

DISCUSSION

Five themes were identified and ten recommendations codeveloped, describing approaches to improve primary care access for people with learning disabilities. Aligned with previous research, participants emphasised prioritising people with learning disabilities, given their susceptibility to health inequalities, high mortality and comorbidity.^{15 17} Previous research supports health checks for identification of treatable health conditions,^{11 12} however in this study the quality of health checks varied. Primary care practices where development of services for people with learning disabilities is passively endorsed, may be less likely to proactively implement service improvements.²¹ Aligned with this the current study found proactive prioritisation of people with learning disabilities was facilitated by champions who supported initiatives including more thorough health checks and time for longer appointments.

In common with previous research, incorrect coding for learning disability was a challenge to prioritising people with learning disabilities.^{14 15} When participants were unaware someone had a learning disability, this was a barrier to prioritising them and offering appropriate healthcare and adjustments. Participants indicated a proactive approach to addressing this is required, including accurate and reliable methods of identification as described in previous research.^{5 7 14} Previous research describes barriers to people with learning disabilities accessing primary care including difficulty understanding and communicating symptoms, lack of an advocate, lack of assertiveness and living in unsupported settings.^{22 24 26} In this study, the importance of primary care proactively reaching-out to encourage attendance

at health checks and facilitate follow-up healthcare was clear. People with learning disabilities were sometimes unaware they could have a health check, and aligned with previous research this highlights the role of direct support staff and importance of training on the health needs of people with learning disabilities.³⁴ Training and experiential learning have been found effective in reducing barriers to primary care for people with learning disabilities.^{32 33 36} In accordance with this, training the broader primary care team including receptionists, sharing good practice via demonstrating annual health checks and targeted support for practices, were found to contribute to increasing health checks and service improvement in this study. UK national guidance¹⁰ highlights the value of learning disability champions, and in this study practitioners with the role were key to driving primary care improvement and innovation, through training, data collection and support for practices less experienced in the care of people with learning disabilities (R10). Important training topics identified in this study included learning disabilities coding, reasonable adjustments, and national guidance initiatives.

In accordance with research on improving comprehensibility of health questionnaires, participants valued receiving accessible information before, and during primary healthcare appointments, especially when they were afraid of attending.^{22 30} However, previous research highlighted accessible information is not always available and needs to be individualised^{28 29}; this was reflected in our fourth theme of personalisation. A bespoke, flexible and personalised service (eg, the receptionist knowing your name), went some way to addressing barriers faced by people with learning disabilities in primary care. However, it was clear more innovation is required with consideration of accessibility and service to service-user alignment in broader contexts. These included automated telephone and check-in systems, embedding relevant easy-read information into long-term condition management templates and health checks, and facilitating staff awareness of reasonable adjustments (some participants reporting limited understanding). Aligned with previous research promoting a more active role for people with learning disabilities in healthcare interactions,²⁷ participants in this study valued communication directed to the person with a learning disability when attending with a supporter.

Participants highlighted the importance of accessible health promotion, public health information and resources, and primary care services who planned ahead, considering support for people with learning disabilities and families along pathways into secondary or tertiary care. A care coordinator or learning disability nurse may be required, for example, to support hospital admission, so people with learning disabilities do not get lost to follow-up. In accordance with previous research on preventative healthcare,²³ bridging agencies and providers onwards from primary care requires a proactive organisational-level approach.

A strength of the study is exploring the views of four stakeholder groups, and using the information gathered to coproduce recommendations informed by stakeholder consultation. A regional inner-city GP practice affirmed utility of the recommendations (saying all seemed practical and could be implemented within practice); and indicated the key to change was a named practice lead, linked through regional primary care networks who could implement the recommendations. The study has a number of limitations; online data collection may have impeded establishing rapport, we collected limited demographic characteristics, and use of convenience sampling in the North East UK may have limited representativeness. At the time of the study primary care services were still being impacted by COVID-19, and under other circumstances, perceptions regarding primary healthcare may have differed. Changes in practice were described including more virtual consultations; in accordance with previous research this format for consultation was found acceptable.⁴⁰

In conclusion, all stakeholders highlighted misalignment in the primary care interface with the needs of people with learning disabilities. Improvements in primary care services to best meet the needs of people with learning disabilities continue to be required. The coproduced recommendations can be used immediately, as a complement to existing guidance and as a summary to guide training and service development. Future research should explore standardised methods of identifying and coding reasonable adjustments, and innovation to improve access to the primary care interface, including automated phone and check-in systems. The study findings accord with the crucial role of learning disability leads, providing strategic support to prioritise the healthcare needs of people with learning disabilities and drive service improvements and innovation.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by Newcastle University Faculty of Medical Sciences Research Ethics Committee (Ref. 2102/10380) Participants gave informed consent to participate in the study before taking part.

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REFERENCES

- Heslop P, Blair PS, Fleming P, *et al*. The Confidential inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet* 2014;383:889–95.
- Hirvikoski T, Boman M, Tideman M, *et al*. Association of intellectual disability with all-cause and cause-specific mortality in Sweden. *JAMA Netw Open* 2021;4:e2113014–e14.
- Carey IM, Shah SM, Hosking FJ, *et al*. 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.
- Williamson EJ, McDonald HI, Bhaskaran K, *et al*. Risks of covid-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform. *BMJ* 2021;374:n1592.
- Courtenay K, Cooper V. *Covid 19: people with learning disabilities are highly vulnerable*. British Medical Journal Publishing Group, 2021.
- Sullivan WF, Diepstra H, Heng J, *et al*. Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Can Fam Physician* 2018;64:254–79.
- Casson I, Broda T, Durbin J. Health checks for adults with intellectual and developmental disabilities in a family practice. *Can Fam Physician* 2018;64:S44–50.
- NICE. *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*. National Institute for Health and Care Excellence, 2015.
- NICE. *Mental health problems in people with learning disabilities: prevention, assessment and management*. National Institute for Health and Care Excellence, 2016.
- NICE. *Care and support of people growing older with learning disabilities*. National Institute for Health and Care Excellence, 2018.
- Robertson J, Hatton C, Emerson E, *et al*. The impact of health checks for people with intellectual disabilities: an updated systematic review of evidence. *Res Dev Disabil* 2014;35:2450–62.
- Carey IM, Hosking FJ, Harris T, *et al*. Do health checks for adults with intellectual disability reduce emergency hospital admissions? evaluation of a natural experiment. *J Epidemiol Community Health* 2017;71:52–8.



- 13 RCGP. Royal College of General Practitioners. Health checks for people with learning disabilities toolkit. Available: <https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/health-check-toolkit.aspx>
- 14 Russell AM, Bryant L, House A. Identifying people with a learning disability: an advanced search for general practice. *Br J Gen Pract* 2017;67:e842–50.
- 15 Emerson E, Glover G. The “transition cliff” in the administrative prevalence of learning disabilities in England. *Tizard Learning Disability Review* 2012;17:139–43.
- 16 Buszewicz M, Welch C, Horsfall L, 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.
- 17 Slowie D, Martin G. Narrowing the health inequality gap by annual health checks for patients with intellectual disability. *Br J Gen Pract* 2014;64:101–2.
- 18 Maltais J, Morin D, Tassé MJ. Healthcare services utilization among people with intellectual disability and comparison with the general population. *J Appl Res Intellect Disabil* 2020;33:552–64.
- 19 Brown HK, Plourde N, Ouellette-Kuntz H, et al. Brief report: cervical cancer screening in women with intellectual and developmental disabilities who have had a pregnancy. *J Intellect Disabil Res* 2016;60:22–7.
- 20 Cooper S-A, Hughes-McCormack L, Greenlaw N, et al. Management and prevalence of long-term conditions in primary health care for adults with intellectual disabilities compared with the general population: a population-based cohort study. *J Appl Res Intellect Disabil* 2018;31 Suppl 1:68–81.
- 21 Selick A, Durbin J, Casson I, et al. Barriers and facilitators to improving health care for adults with intellectual and developmental disabilities: what do staff tell us? *Health Promot Chronic Dis Prev Can* 2018;38:349–57.
- 22 Hanlon P, MacDonald S, Wood K, et al. Long-Term condition management in adults with intellectual disability in primary care: a systematic review. *BJGP Open* 2018;2:bjgpopen18X101445.
- 23 Taggart L, Doherty AJ, Chauhan U, et al. An exploration of lifestyle/obesity programmes for adults with intellectual disabilities through a realist lens: Impact of a 'context, mechanism and outcome' evaluation. *J Appl Res Intellect Disabil* 2021;34:578–93.
- 24 Doherty AJ, Atherton H, Boland P, et al. Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review. *BJGP Open* 2020;4:bjgpopen20X101030.
- 25 McConkey R, Taggart L, Kane M. Optimizing the uptake of health checks for people with intellectual disabilities. *J Intellect Disabil* 2015;19:205–14.
- 26 McDermott S, Royer J, Mann JR, et al. Factors associated with ambulatory care sensitive emergency department visits for South Carolina Medicaid members with intellectual disability. *J Intellect Disabil Res* 2018;62:165–78.
- 27 Gregson N, Randle-Phillips C, Hillman S. People with intellectual disabilities' experiences of primary care health checks, screenings and GP consultations: a systematic review and meta-ethnography. *Int J Dev Disabil* 2022;336:1–17.
- 28 Chinn D. An empirical examination of the use of easy read health information in health consultations involving patients with intellectual disabilities. *J Appl Res Intellect Disabil* 2020;33:232–47.
- 29 Chinn D, Homeyard C. Easy read and accessible information for people with intellectual disabilities: is it worth it? A meta-narrative literature review. *Health Expect* 2017;20:1189–200.
- 30 Bakker-van Gijssel EJ, Lucassen PLBJ, Olde Hartman TC, et al. "Constructing a health assessment questionnaire for people with intellectual disabilities: A cognitive interview study". *J Appl Res Intellect Disabil* 2020;33:345–53.
- 31 Lunskey Y, Bobbette N, Selick A, et al. "The doctor will see you now": Direct support professionals' perspectives on supporting adults with intellectual and developmental disabilities accessing health care during COVID-19. *Disabil Health J* 2021;14:101066.
- 32 Melville CA, Cooper S-A, Morrison J, et al. The outcomes of an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary health care services. *J Intellect Disabil Res* 2006;50:11–17.
- 33 Billon G, Attoe C, Marshall-Tate K, et al. Simulation training to support healthcare professionals to meet the health needs of people with intellectual disabilities. *Adv Ment Health Intellect Disabil* 2016;10:284–92.
- 34 Selick A, Durbin J, Salonia C, et al. The nuts and bolts of health care: evaluating an initiative to build direct support professional capacity to support the health care of individuals with intellectual disabilities. *J Appl Res Intellect Disabil* 2022;35:623–32.
- 35 Durbin J, Selick A, Casson I, et al. Improving the quality of primary care for adults with intellectual and developmental disabilities: value of the periodic health examination. *Can Fam Physician* 2019;65:S66–72.
- 36 Selick A, Durbin J, Casson I, et al. Improving capacity to care for patients with intellectual and developmental disabilities: the value of an experiential learning model for family medicine residents. *Disabil Health J* 2022;15:101282.
- 37 McKenzie K, Wigham S, Bourne J, et al. Exploring the views of UK regional primary care practitioners on the use and role of screening tools for learning disabilities in their services. *Br J Learn Disabil* 2022.
- 38 Braun V, Clarke V. *Successful qualitative research: a practical guide for beginners*. sage, 2013.
- 39 Nowell LS, Norris JM, White DE, et al. Thematic analysis: Striving to meet the trustworthiness criteria. *International journal of qualitative methods* 2017;16:1609406917733847.
- 40 Selick A, Bobbette N, Lunskey Y, et al. Virtual health care for adult patients with intellectual and developmental disabilities: a scoping review. *Disabil Health J* 2021;14:101132.