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# Exploring the views of UK regional primary care practitioners on the use and role of screening tools for learning disabilities in their services

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## Accessible summary

- Many people with learning disabilities have poor health and die younger compared to the general population so having regular health checks is very important.
- Sometimes doctors (general practitioners or GPs) and nurses do not know a person has a learning disability so cannot offer them a suitable health check.
- We asked GPs and a nurse for their views on ways they can find out who has learning disabilities and whether those ways of finding people work
- We found that the doctors and the nurses did not use ways to find out who has learning disabilities very often, but thought they were a good idea.
- Finding people with learning disabilities meant they could be offered support to attend appointments more easily.

## Abstract

**Background:** People with learning disabilities are at increased risk of physical health conditions and mortality compared to the general population. Initiatives to address these health inequalities include the introduction of learning disability registers, through which people with learning disabilities can be identified and offered annual health checks and reasonable adjustments in their healthcare provision. A barrier to offering such initiatives to people with learning disabilities is that practitioners/providers may be unaware of the presence of a learning disability, and people who meet criteria may not be entered onto general practice learning disability registers. Screening tools can be used to help identify people with learning disabilities in order that they can be offered appropriate health services and reasonable adjustments. This study aimed to explore the awareness and views of UK primary care staff about the existence and role of screening tools for learning disability in their services.

**Methods:** A qualitative approach was used; semistructured online interviews were conducted with a purposive sample of primary care staff recruited via a

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regional professional network of primary care practitioners. Five general practitioners and one nurse practitioner, representing five primary care practices in the North-East of England, participated. Interview transcripts were analysed using thematic analysis.

**Findings:** Two themes and associated subthemes were identified. Within Theme 1 ('I haven't had anything much to do with them') two subthemes related to reasons why screening tools were not routinely used. Theme 2 ('I think they're great that they exist') comprised two subthemes that explored the benefits of screening tools, for example, for those practitioners less experienced with people with learning disabilities, and also explored potential reluctance to use them. The study found that most practitioners had some knowledge of screening tools and the general consensus was that they are beneficial. However, the tendency of participants was not to use screening tools in a consistent and/or systematic way, instead relying on informal approaches or other services for identifying the presence of learning disabilities.

**Conclusions:** The study findings highlight the need for changes in practice to support primary care staff to access and systematically use evidence-based effective and efficient screening tools for learning disability.

#### KEYWORDS

learning disability screening, primary care

## 1 | INTRODUCTION

Learning disability (often referred to as intellectual disability) is defined as significant impairments in learning and adaptive functioning, with childhood onset (American Psychiatric Association, DSM-5, 2013), and is associated with health conditions that are often comorbid, significant and complex, such as cancer, diabetes and obesity (Emerson et al., 2016). People with learning disabilities continue to die at a younger age than the general population, and of different types of conditions. In both 2018 and 2019, the leading underlying causes of death for people with a learning disability aged between 5 and 49 years were epilepsy, cerebral palsy and bacterial pneumonia (NHS England and NHS Improvement, 2021b). The Covid-19 pandemic further highlighted the health inequalities experienced by this group of people, with 2020 figures estimating that the death rate from Covid-19 for people with learning disabilities was between 3.1 and 3.6 times greater, compared to the general population (Public Health England, 2020).

The recognition of the long-standing and significant health inequalities which are experienced by people with learning disabilities has resulted in a number of healthcare initiatives (e.g., NHS England, 2018). Within primary care services, these have included the introduction of learning disability registers for those aged 14 years and older. The aim is to identify people within the practice with a learning disability, offer them an annual health check and

ensure that they receive 'reasonable adjustments' in their healthcare provision.

Such reasonable adjustments have included initiatives, in conjunction with specialist services, to increase the uptake of both Covid and flu vaccinations, and to reduce avoidable deaths from causes such as respiratory conditions, cardiovascular disease, sepsis, diabetes, cancer and epilepsy. These have commonly been based on the development of accessible information for use with people with a learning disability, and targeted training, awareness raising and resources for clinicians (NHS England and NHS Improvement, 2021a). There is some cause for optimism, that such initiatives are having a positive impact, with the latest learning disability mortality review (LeDeR) Annual Report (The LeDeR Team, 2021) indicating an overall fall in the proportion of avoidable deaths due to medical causes among adults with a learning disability from 54% to 50% since 2018. There was, however, no change for children and overall people with a learning disability were found to still be three times more likely to have an avoidable medical cause of death than those in the general population.

A key challenge for healthcare initiatives for people with a learning disability is that they may not be identified as having a learning disability in the first place. Figures suggest that many people, and the majority of those with a mild learning disability, go unrecognised (Emerson & Glover, 2012) and that learning disability can be missed, even in specialist services (McKenzie et al., 2019a). Staff who would be

expected to be well placed to identify those who are likely to have a learning disability, such as teachers (Rae et al., 2011) and healthcare staff (Emerson et al., 2012) may lack knowledge about this group of people and their support needs. As such, people may not be entered onto the General Practice learning disability register and receive the health care that they need.

This issue was recognised in NHS England's recent specification (2018) that people who are in need of reasonable adjustments should be clearly identified, the required adjustments recorded and their provision audited on a regular basis. Previous attempts to identify those in primary care practices who are likely to have a learning disability from existing practice records are, however, considered to have overlooked many people (Allgar et al., 2008). A more recent system, based on diagnostic codes and a 'Learning Disability Register Inclusion Tool' checklist (NHS England and NHS Improvement, 2019), also has limitations. The checklist is relatively long, comprising 21 items, and has no cut-off score; therefore, the user is left to interpret what the scores might indicate, with the only guidance being that 'Several "yes" answers could indicate the presence of a Learning Disability.' Important information is also lacking about the extent to which it meets the psychometric requirements for a screening tool (Glascoe, 2007). As Iragorri and Spackman (2018) note screening tools and checklists that are not valid, reliable and accurate may lead to misidentification, with the potential for associated negative impacts on health.

There are evidence-based screening tools for learning disability in existence, which are used widely, if not systematically, in healthcare and other services, where it is important to identify and support people with a learning disability. The Learning Disability Screening Questionnaire [LDSQ] and Child and Adolescent Learning Disability Screening Questionnaire [CAIDS-Q] are available in an online format for practitioners to use (see <https://learningdisabilitymatters.co.uk/tools/>), are brief, and provide automatic scoring and immediate feedback on whether the person is likely to have a learning disability or not (McKenzie, Murray, Thompson et al., 2020).

Such tools are, however, likely to be of limited widespread benefit if the staff and patients are unaware of them, do not engage with them or they do not lead to (or are perceived not to lead to) benefits (Iragorri & Spackman, 2018). Research suggests that identifying an issue and the associated solution may only result in change if staff are willing and motivated to adopt new ways of working in practice (Rutherford et al., 2018). Factors that have been found to influence the adoption of new clinical measures include their perceived usability, usefulness, benefit and acceptability (e.g., Callahan et al., 2017; Richardson et al., 2017). There has, however, been limited research exploring the extent to which these factors may influence the adoption of screening tools for learning disability in primary care services.

The present study aims to explore the awareness and views of UK primary care staff on the use and role of screening tools for learning disability in their services.

## 2 | METHOD

The study is part of a larger project on access to primary care for people with learning disabilities in which data were gathered from people with learning disabilities, relatives, general practitioners, practice nurses and sheltered housing managers. Data collected covered annual health checks, learning disability inclusion/screening tools, barriers to people with learning disability accessing primary care, reasonable adjustments and COVID-19. The findings pertaining to learning disability inclusion tools are reported here; findings pertaining to the other aspects of the larger study are reported elsewhere (Wigham et al., in review).

### 2.1 | Design and ethics

A qualitative approach was used, with semistructured interviews being conducted with a purposive sample of primary care staff, between June and December 2021. The context of the study was an exploration of the use of learning disability screening tools as one means of addressing health inequalities for this group of people. Ethical approval for the study was provided by Newcastle University Research Ethics Committee (Ref: 2102/10380).

### 2.2 | Participants

We recruited a convenience sample of six people, who represented five primary care practices in the North-East of England. The inclusion criteria were consenting to take part and being employed in a clinical capacity in a primary care service as a general practitioner (GP). Discussion with a GP on the primary care of people with learning disabilities, identified primary care nurse practitioners as also playing a key role and this informed our decision to include them in recruitment. Having experience of using learning disability screening tools was not a criterion for inclusion in the study.

### 2.3 | Procedure

Participants were recruited via a regional professional network of GPs with an interest in learning disability. Information about the study with contact details of the research team was initially distributed to GP practices throughout the region by a GP and learning disability lead. Potential participants were asked to contact the research team if they were interested in taking part. If they consented to take part, a suitable time was arranged to complete the interview which was conducted online by the second author who was unknown to participants before the study.

### 2.4 | Data collection

An interview topic schedule was developed in consultation with the wider research team. We consulted GPs regarding the interview topic schedule

and received advice on content and wording. The interview questions pertaining to screening tools are shown in Table 1; a copy of the full interview topic schedule from the larger study can be found in the Supporting Information: (OS 1). The aim of the interview topic schedule was to enable some consistency in the main topics that were included in the interview, while still providing the flexibility for issues relevant to the participants to be included. The interview topic schedule covered the topics of: awareness/knowledge and use of screening tools for learning disability in primary care; important characteristics of such tools; and their benefits and drawbacks. Before the interview participants were sent a copy of the Learning Disability Screening Questionnaire as an example of a screening tool; however, during the interview questions covered learning disability screening tools in general/more broadly. All of the interviews were conducted, recorded and subsequently transcribed by the second author (an experienced researcher in the field of learning disability). Potentially identifying information was removed at this stage and participants were allocated a pseudonym. Interviews were between 31 and 43 min long (on average 36 min).

## 2.5 | Data analysis

The transcripts were analysed by the first author (an experienced clinical psychologist and researcher in the area of learning disability)

**TABLE 1** General/nurse practitioner interview topic schedule

We would like to ask you some questions about screening/inclusion tools and how they might be used to improve the health of people with a learning disability (e.g., LDSQ).

1. Are you using this tool/another inclusion tool? If so, what are the benefits/drawbacks?  
If not, would it be useful? If so, how?
2. What do you think the impact of using inclusion tools might be (both positive and negative)?
  - (a) ...on you? (e.g. increased awareness of learning disability, increased confidence in identifying it, increased workload)
  - (b) ...on your service? (e.g. identifying people who weren't previously known to have a learning disability, support that is needed/provided, on GP learning disability registers, on annual health checks, waiting times, referrals to specialist services)
  - (c) ...on people with a learning disability/without a learning disability? (e.g. changes in health and wellbeing, increased understanding, stigma, waiting times for specialist assessment)
3. What do you think the main benefits of inclusion tools would be (and main drawbacks)?
4. How could use of inclusion tools be improved in the future to help identify people with a learning disability? (when, how, where and by whom should they be used as part of the inclusion/assessment pathway—if at all?)
5. Do you think that inclusion tools can help meet government guidance including that people with a learning disability be prioritised for a COVID-19 vaccination?
6. How would staff in your practice usually know that a person has a learning disability?
7. When do you think is the best time for doctors to use a questionnaire to help identify a person who has a learning disability?
8. Any other comments?

using thematic analysis (Braun & Clarke, 2006) and adopting a constructivist perspective. This method offers a flexible approach that is suitable for integrating the perspectives of different participants (Nowell et al., 2017). Clear guidance is available on the approach, which was followed during the data analysis process (Braun & Clarke, 2006, 2020). Each transcript was read on multiple occasions and specific sections relevant to potentially relevant themes were grouped under initial codes. These codes were combined across all transcripts to develop themes and related subthemes, and illustrative quotes were chosen to support these. These results were then shared with the wider research team as a means of checking their internal consistency and relevance. A summary was provided to the participants, to check if the researchers' interpretation was consistent with their perspectives. They were asked to give feedback if they wished. No requests for changes were received.

### 2.5.1 | Stakeholder involvement

Preliminary results from the overall project were presented to a research advisory group led by people with learning disabilities and 10 recommendations for improving access to primary care were co-produced including one specific to screening tools (Wigham et al., in review). The 10 recommendations were presented to a regional inner city GP practice meeting, and the recommendations were endorsed by the practitioners present.

## 3 | FINDINGS

Six participants were recruited into the study; five participants were females and one male (see Table 2 for further details). The data yielded two themes with associated subthemes as outlined below and in Table 3.

### 3.1 | Theme 1: 'I haven't had anything much to do with them [screening tools]'

This first theme highlighted the limited awareness about, and limited systematic use of, screening tools for learning disability in general

**TABLE 2** Characteristics of the participants

	Gender	Role
P1	Female	Nurse practitioner
P2	Female	GP
P3	Female	GP
P4	Male	GP
P5	Female	GP
P6	Female	GP

**TABLE 3** Summary of themes, related subthemes and illustrative quotes

Theme	Description	Related subthemes
Theme 1: 'I haven't had anything much to do with them'	This theme explores the limited awareness and use of learning disability screening tools by practitioners in primary care services. Also the perceived barriers to the routine and systematic use of screening tools, and the current methods used to identify people with a learning disability	<p>'I've never used a tool with anybody'.</p> <p>This subtheme shows that while practitioners were mostly aware of the existence of screening tools many were unfamiliar with them and/or not using one, rather relying on other methods e.g. clinical judgement and informal systems</p> <p>'This is a work in progress'</p> <p>Heavy workloads were described but also willingness to incorporate a screening tool into practice that benefitted patients. The introduction of screening tools into practice was viewed as part of service development/innovation requiring a proactive approach</p>
Theme 2: 'I think they're great - that they exist'	This theme explores the perceived benefits of using learning disability screening tools in primary care, and wider, contextual issues to consider in their use	<p>'It looked quite helpful when I had a quick look at it today'</p> <p>While many practitioners were unfamiliar with screening tools, they were viewed positively, including as a guide for when unsure how to broach the possibility of the presence of a learning disability; plus, the structured approach was considered helpful</p> <p>'Ooh I don't like to deal...'</p> <p>This subtheme explored reservations regarding the use of screening tools including medicalisation of learning disability, and subsequent barriers to accessing secondary care for people who have a learning disability</p>

practice, and some of the reasons why this was perceived to be the case.

### 3.1.1 | Subtheme 1: 'I've never used a tool with anybody'

In general, there was limited evidence for the systematic use of screening tools for learning disability in primary care. Most of the participants had some awareness that such tools existed both in general: 'I'm aware of various tools that are available' (P4) or on their own systems: 'So, I use...in our practice we have ... a set of templates...and in there there's an inclusion tool, I think it comes from Leeds' (P2). Only two participants appeared to use them consistently while most did not: 'I've just never been introduced to it before, so I'd have to have a proper sit down and look at it...I just feel sorry that I haven't had anything much to do with them' (P1) and: 'I've never used a tool with anybody' (P5).

Many participants used other methods to identify people who potentially had a learning disability. This included using codes from their own systems: 'I think we rely on the code. We don't have another screening tool, no' (P6), relying on other services to alert them to the person's status: 'I think it's more likely that we get advised on it from school. It seems to be identified in schools rather than in primary health' (P5), or relying on their own judgement: 'So, you know I have yet to come across a circumstance in my own clinical

practice, a circumstance where I wasn't more or less certain someone had a learning disability or not' (P5).

In a number of cases, the existing systems to identify people with a learning disability were very informal: 'perhaps where people would highlight to us perhaps, you know, "do you think this person has a learning disability?"' (P2) and relied on local knowledge: 'Sometimes folks are just known to receptionists, so there is a bit of local knowledge. So, there isn't an automatic way of knowing, no.' (P6). In other cases, practices relied on the information that already existed in the case notes being accurate: 'It's a part of the patient plan so as soon as you open up the plan it pops up' (P1) or on time-consuming processes involving searching through the notes:

I'll look through the notes and if there's been a letter from the community learning disability team saying they've got a learning disability end of story—they have...you know if they've gone to a special school and have things like education health and care plans then, you know, make your decision based on that (P4).

A number of limitations with these informal systems were highlighted by the participants. These included people being missed by primary care because they were not identified by other services: 'but it's not really being flagged up so it's not coded' (P3) and people were potentially being inappropriately included on the GP register: 'There's more of an issue actually with people being inappropriately

coded as learning disability... I think people are maybe being over included potentially.' (P5).

### 3.1.2 | Subtheme 2: 'this is a work in progress'

This subtheme explored some of the reasons why screening tools for learning disability were not routinely used in primary care. A key issue was the need for such screening tools to be more high profile and used in a proactive, systematic, and routine way:

I think they need to be more visible, they need to be more obvious, more part of everyday life with regards to patients who you think might have a learning disability. I've only really come across them myself in the last year or two and I'm supposedly the lead in my area. I think because people need to think more proactively about their registers, and whether they are right, and whether there are people in their practices that are learning disabled that they haven't identified; and that is a work in progress. (P2)

Some practitioners also highlighted the importance of any screening tool having a robust evidence base:

Obviously if they've been researched to make sure that the ones you're using are validated when they are being used...are researched to make sure they are a validated tool—if they're not validated, obviously it could pose an issue giving the wrong diagnosis (P1).

The lack of an evidence base for, and imprecision of, the 'inclusion tool' checklist recommended by the NHS were seen as drawbacks: 'I think the drawbacks [of using the NHS recommended tool] were that they were quite soft signs and it wasn't saying it's entirely accurate' (P3). This checklist was contrasted with another evidence-based screening tool: 'but this tool [LDSQ] says it's highly accurate, and it tells you where it's less accurate... this puts it more as a, it's more sort of a formula I guess, so I think that erm I would definitely like to use this going forward' (P3).

There was also consideration of the workload implications of using a learning disability screening tool: '...it does take up your time and that's maybe why people don't use it so often' (P1). The need for an efficient, systematic approach to screening was highlighted in this context: 'So anything that happens automatically in the background is massively preferred rather than casting a net out, that takes a lot of time and effort that perhaps will pick up a single little fish' (P6). In general, however, it was felt that any short-term increase in workload due to the proactive use of a screening tool would be more than offset by the potential health benefits for people with a learning disability: 'I think I'd probably be happy to increase my workload for something that's beneficial for people' (P3). The potential benefit of reducing mortality was seen as a powerful motivator for screening:

I think it does increase workload, but equally if you don't identify someone with a learning disability they die potentially of avoidable and preventable causes... so my workload, you know, front-loading my workload with 5-minutes of an inclusion tool compared to them dying 20 years younger, you know for me that's no competition. (P2)

## 3.2 | Theme 2: 'I think they're great [screening tools] that they exist'

The second subtheme explored GP views about the benefits and wider issues around using a screening tool in primary care settings.

### 3.2.1 | Subtheme 1: 'it looked quite helpful when I had a quick look at it today'

Despite the limited awareness and inconsistent use of learning disability screening tools, their use was generally viewed positively: 'I think they're great that they exist' (P4) and thought likely to be of benefit if they were used: 'The one that we use, the system that's on...it looked quite helpful when I had a quick look at it today' (P1).

The participants identified a number of potential benefits, at every stage of the healthcare process, of using an accurate, structured and evidence-based screening tool. First, it could help practitioners overcome their reluctance to broach the topic of learning disability with patients in the first place: 'there are some people when you talk to them you possibly would suspect [that they have a learning disability] but I have never, I would never, it's not something I would ever bring up with somebody' (P5). It was seen as a way of reducing stigma and embarrassment in this type of situation:

I had to ring people up, cold call them, cos the system had identified them as possibly having a learning disability...if you are doing a more standardized questionnaire I feel like it's a bit less offensive, because you know if you're reading a question that's phrased in a certain way rather than just bumbling through it, if you know what I mean (P3)

A good screening tool was seen as facilitating and structuring the identification process, which in turn would help with the delivery of appropriate interventions:

They guide your thought process and guide your diagnosis into, you know, asking the right questions and drawing down on certain criteria... I think being able to guide you to make that correct decision, and to

take the patients on a really good flow of their condition and diagnosis and to make sure you get the right treatment and diagnosis as well (P1).

This structured approach was particularly important when the person's presentation was less obvious, or when the cause of the person's difficulty was less clear:

I think it particularly helps you when someone has a mild learning disability...one of the things that's a problem I think is that someone can present as having a learning disability, but just actually have had just really poor education, erm had lots of time out of school, have ADHD, have had really lots of health problems through school and not attended a lot and/or have autism, and I think it just helps focus your mind on what sort of assessment you might need going forward for that person (P2)

Screening tools were also seen as helping nonspecialist staff to feel more confident in their opinion:

...especially the GPs in my practice with regards to a learning disability...they say 'what, are we allowed to do that, do they need to have a specialist assessment by a specialist person first, do they need to have been seen by paediatrics or are we allowed to do that?' so giving us the confidence as GPs to assess them as either yes or no (P3)

Screening tools were seen as being of particular benefit to those with less experience of people with learning disabilities: 'It's getting you to ask certain questions and it's giving you more knowledge ...especially for someone who has never done it before' (P1). They provided a starting point for people who were unfamiliar with the common difficulties experienced by, and support needs of, many people with learning disabilities: 'if you've not worked in this area or if you are new like I was when I started, I wasn't really sure how you work out who these people are, you get a feel for them from talking to them, but what question do you ask you know' (P3).

Having been identified as likely to have a learning disability, the person could then be entered on the GP learning disability register to receive additional support with primary health care: 'It'll definitely increase the register' (P3) and 'Everybody who has a learning disability should be coded in the records, so if the inclusion tool helps us increase the registers then, yes definitely' (P2). It was also seen as being helpful in informing practitioners about whether to refer on to specialist services for further assessment and support: 'I don't think I would feel confident or competent to make a diagnosis myself. But it could help us screen out whether or not you would need a referral' (P5)

### 3.2.2 | Subtheme 2: 'ooh I don't like to deal...' issues to consider in the use of screening tools

Some participants also highlighted potential issues, that were related to the wider context within which a screening tool might be used, rather than with screening per se. One such issue was the medicalisation of what is a social condition:

One of the other things that I'm really against is the medicalization of learning disability...and I point out to people that learning disability is not a disease and obviously it can't be treated with medication or therapy, and as such the referral for diagnostic purposes I think is inappropriate anyway...but I do accept that specialist services do have an ability to assess and determine whether somebody has a learning disability or not, but for people, generalists, nurses, GPs I think screening tools are really excellent (P4)

A second issue was a potential reluctance on the part of secondary services to accept referrals for people with a learning disability, due to their own lack of confidence and/or knowledge:

Sometimes when you refer to secondary care and you flag-up that the patient has a learning disability they go 'ooh, ooh I don't like to deal...' not everybody, but there's sometimes an attitude that they find it difficult to deal with learning disability, and that's not a problem in terms of that's their problem and they need to learn how to deal with learning disability, but sometimes you'll get a reply back saying that it would be difficult to have this patient in the clinic because we would need to get extra time and extra staff and extra this and extra that why don't you just do this instead. So, they miss the chance to see a specialist. So, there may be some slight negatives to being labelled with a disability. (P3)

There was also some debate about who would be best placed to use a learning disability screening tool, whether by which clinician was seeing the person at that time: 'Yeah which ever practitioner was seeing the person' (P1) or in the context of an established relationship with a known practitioner:

Sometimes I find I think 'oh do you know I think they might have a learning problem a learning disability', and it's often those people that you've known for a while, and then suddenly someone else says something to you and you just think 'you know I don't think they are as able as you thought', or something happens like maybe the end of a relationship or someone dies in the family and you



realise that actually there's been a lot of support going into that family, or that person and you didn't realise how much that other person was doing for them, and actually it's kind of a gradual thing. I don't necessarily think on your first meeting with someone that you would necessarily know. So, I don't think it's something that you can just do (P2).

There was also consideration of when, and with whom the screening tool should be used. In general, while it was thought that theoretically it could be used with everyone, in practice it was considered to be better to use it when concerns were present: 'so I suppose yes in theory you could go through this with everybody... when concerned...you know I don't think you can use it on everybody...as they feel it's appropriate (P2) or highlighted by others: 'I think, yes, if a parent brought a child in and had worries about it, it would help us identify it' (P5). There was, however, an acknowledgement of the 'hidden' nature of learning disability: 'you know there have been patients that I genuinely have not known that they have had a learning disability' (P2) and that people may, therefore, not come forward for screening: 'to be perfectly honest as a GP I can't think of a time when anyone's come to me and said "I think I've got a learning disability" it's not something, a condition, that people present with' (P5).

It was suggested that the screening tool could be used to help differentiate in situations where there were commonly co-occurring conditions, such as autism and learning disability: 'We have a lot of patients coming in at the moment and saying I think I've got autism...and I wonder if sometimes some of those people may have more of a learning disability so I suppose you could use it in that situation' (P5) and where there was uncertainty about the person's condition: 'would tend to use the tool if there was ever any doubt' (P4).

## 4 | DISCUSSION

The aim of the study was to explore the awareness and perspectives of primary care staff in relation to the use of screening tools for learning disability. The study found that most practitioners had some knowledge of such tools, but tended not to use them in a systematic or consistent way. The importance of any screening tool having an evidence base was highlighted and there was some concern that the NHS-recommended checklist-based Inclusion tool (NHS England and NHS Improvement, 2019) was imprecise. As the outcome of a screening tool can have a significant impact on the lives of individuals and their families (McKenzie, Murray, Thompson et al., 2020), it is important that they meet the same standards in terms of having robust psychometric properties as any other form of clinical assessment tool (Glascoe, 2007).

To identify people with a learning disability, most practitioners relied on informal approaches or methods that were time-consuming, relied on external services or lacked an evidence base. There was

some recognition that such approaches could lead to people being overlooked or misidentified. In the context of the continued and significant health inequalities that are experienced by people with a learning disability (The LeDeR Team, 2021), it is concerning that there is not an efficient, systematic, evidence based process to identify them being used in primary care.

Despite the intermittent use of screening tools, and some concerns over medicalisation of learning disabilities, there was general consensus that these were beneficial, in particular where staff may lack experience and confidence working with people with a learning disability or where the person's presentation was subtle, or complex. The views identified in the current study are supported by research which suggests that the majority of people with a mild learning disability are likely to have their condition overlooked, or recorded status lost as they transition from child to adult services (Emerson & Glover, 2012). A similar result was found with children, with McKenzie et al. (2019a) reporting that even those who are attending specialist paediatric services may have their learning disability missed.

Importantly, the participants felt that a robust screening tool would help to structure the identification process and ultimately help improve health outcomes for people with a learning disability. This is consistent with previous research with the LDSQ and CAIDS-Q screening tools, which found that their use informed the support needs of both adults and children and led to additional support for them (McKenzie, Murray, Murray et al., 2020). The findings are in accordance with 1 of 10 recommendations co-developed with people with learning disabilities, in which screening tools were viewed as useful to help identify people with learning disabilities and understand their needs (Wigham et al., in review).

The second theme also explored some of the wider contextual issues which were identified by participants, including the ways in which learning disability screening tools should be used in practice. This is important because, without understanding the wider context within which clinical practice takes place, it is difficult to identify the principles that underpin practice change and the actions that might promote it (Davidoff, 2019). Previous research in services for homeless people suggests that it is important to use such tools in the context of a trusted relationship and in a way that does not make the person feel stigmatised (McKenzie et al., 2019b). As Reeve (2021) highlights, having reliable data on which to base the formulation of a patient's difficulties is crucial to facilitating patient trust. She notes that: 'trustworthy consulting is a data-informed negotiation between experts' (p.360).

The relationship between primary and secondary care services in respect of people with a learning disability was also highlighted in this theme. Some secondary care services were seen as being reluctant to accept referrals for people with a learning disability. While it was recognised that this was an issue that went beyond that of screening, it did highlight the importance of ensuring that identifying that a person has a learning disability is beneficial (e.g. facilitates access to reasonable adjustment), rather than detrimental to them.

## 4.1 | Practical implications

The results have important implications for practice, particularly in light of the NHS England (2018) specification to clearly identify those who require reasonable adjustments to their health care, and the continued increased risk for people with learning disabilities of dying due to an avoidable medical cause (The LeDeR Team, 2021). The participants generally seemed open to making changes in their practice, particularly if it was of benefit to the health of people with learning disabilities, even if this increased their workload. The current methods used by the participants to identify people with learning disabilities were, however, informal, time-consuming, and lacked an evidence base. This suggests the need to support primary care practitioners in the systematic use of evidence-based screening tools, that are brief, accurate, easy to use, and which require minimal interpretation on their part. Such tools do already exist, are used extensively in other clinical settings and have been used to support practice and help the development of service pathways (see McKenzie, Murray, Murray et al., 2020); however, they are not yet used routinely in primary care. Introducing and evaluating the impact of the use of evidence-based learning disability screening tools in primary care may help facilitate a wider-scale change in practice to using more effective and efficient methods of identifying those with learning disabilities and additional healthcare needs.

## 4.2 | Limitations

The study had some limitations that need to be considered. As with all qualitative research, the results can not be assumed to be representative of all general practices. The study took place in the North-East of England and it may be that the experiences and views of staff in different areas of the country would differ from those of our participants. The study also took place at a time when primary care services were still under considerable pressure from the impact of Covid-19 and it may be that their perceptions and experiences would be different under different circumstances. Related to this, the sample size was relatively small and it may be that only those with a particular interest in the healthcare of people with learning disabilities chose to participate because of the pressures that services were under.

## 4.3 | Conclusion

The study found that participants, while aware of screening tools for learning disability and positive about their use, did not generally use them on a regular basis or in a systematic way. Their current practices were somewhat informal, time-consuming and lacking an evidence-base. The study highlighted the need for changes in practice to support primary care staff to access and systematically use evidence-based efficient and effective screening tools for learning disability.

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## CONFLICT OF INTEREST

The first author is a co-developer of two of the screening tools that were referred to in the paper (LDSQ and CAIDS-Q) and receives a small payment for their use.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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