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Impact of screening for ID

## **The impact of an adult intellectual disability screening questionnaire on service providers and users**

Professor Karen McKenzie, Dr George Murray, Dr Aja Murray, Ms Rachel Martin

**Background:** One contributor to the health inequalities that people with an intellectual disability (ID) face is failure to identify their ID. The Learning Disability Screening Questionnaire (LDSQ) can identify adults who are likely to have ID, but little is known about its impact.

**Method:** A modified Delphi approach (literature search, interviews with staff and service users [n = 28] and completion of an online survey by professionals [n = 29] was used to develop a framework to evaluate the impact of using the LDSQ.

**Results:** Items endorsed by 60% or more of respondents (9/18) were included in the final framework. These all related to benefits of the LDSQ, including identifying people not previously known to have ID; helping prioritise diagnostic assessment; informing support needs and helping increase wellbeing and life chances.

**Discussion:** The LDSQ may offer one way of helping address the health inequalities that people with ID face.

**Key words:** Learning Disability Screening Questionnaire; impact; evaluation; inequality

## Impact of screening for ID

People with an intellectual disability in the United Kingdom (UK) continue to experience a number of significant health inequalities, despite a number of initiatives, policy documents and recommendations aimed at improving their health. (e.g., NHS England, 2018; Truesdale & Brown, 2017). These inequalities include lower life expectancy, poorer health and an increased risk of specific serious health threats, such as particular types of cancer, than their typically developing peers (Emerson, Baines, Allerton, & Welch, 2012). People with an intellectual disability are also three times more likely to die from an avoidable cause (Heslop, Blair, Fleming, Hoghton, Marriott, & Russ, 2013). These health inequalities are persistent, with 2016 analyses indicating an average difference in life expectancy for females and males with an intellectual disability of 18 and 14 years respectively, compared with the general population (NHS Digital, 2017).

One key barrier to quality health care is delayed or missed identification of the person's intellectual disability. Recording of this may not occur until late childhood, into adulthood or at all (Hamilton, 2006), particularly if the person's intellectual disability is mild (Emerson, Hatton, Baines, & Robertson, 2016). Even if diagnosed in childhood, many people with an intellectual disability will not be identified as such in adulthood by health and social care services, with Emerson and Glover (2012) reporting a sharp fall in estimated administrative prevalence of intellectual disability at the point of moving from child to adult services, from approximately 4-5% to 0.6-0.7%.

As knowledge of intellectual disability is low in many staff groups, including health staff (Emerson et al., 2012), they are unlikely to pick up indicators of intellectual disability and refer the person on for further assessment. This means that reasonable adjustments which are needed to help people with an intellectual disability access appropriate and targeted healthcare will not be offered to 'the hidden majority' of this group (Emerson et al., 2016) and their health is likely to suffer as a result. One such adjustment is the right of people aged

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14 years or above on GP intellectual disability registers in the UK to receive an annual health check and associated health action plan.

Any initiative to improve the health of people with an intellectual disability is, however, unlikely to succeed if the biggest proportion of the group being targeted is not recognised as having an intellectual disability. This highlights the need for a systematic, structured, evidence-based way of quickly and easily identifying who is likely to have an intellectual disability. This need has recently been acknowledged in recommendation seven of the Government response to the Learning Disabilities Mortality Review (p6) which specifies that: 'Providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision.' (NHS England, 2018).

Early identification of intellectual disability has a number of direct and indirect benefits (see McKenzie et al., 2018 for an overview). These include identifying and promoting increased understanding of the support needs of people with an intellectual disability and their families/carers (McKenzie et al., 2018a) and facilitating access to resources, such as early intervention that can result in improvements of the adaptive and intellectual functioning of the individual (Guralnick, 2017). Identifying that a person has an intellectual disability also helps to maximise their health and life chances by preventing health conditions becoming chronic and more expensive to treat (see Guralnick, 2005).

Evidence indicates that annual health checks offered to those on GP intellectual disability registers in the UK result in the detection and targeted treatment of previously undiagnosed conditions, many of which are serious or life-threatening (Robertson, Roberts, Emerson, Turner, & Greig, 2011). Early research has also indicated that prompt identification of intellectual disability has economic benefits. Based on financial considerations alone, the

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costs associated with overidentification of those with a disability are much less than the lifetime cost of under-identification and the subsequent impact of this (Barnett & Escobar, 1990).

There has been a recognition that screening questionnaires, while not designed to replace full assessment, can offer one way of quickly and easily identifying those people who have an increased likelihood of having an intellectual disability. As such, these people can be prioritised for further assessment and appropriate adjustments in their support and healthcare. The Learning Disability Screening Questionnaire (LDSQ) and the child and adolescent version, the CAIDS-Q have established psychometric properties and have been shown to be accurate at discriminating between individuals with and without an intellectual disability in a number of different service settings. The LDSQ has sensitivity and specificity ranging between 91.5-82.3% and 91.7-84.4% respectively, while the corresponding figures for the CAIDS-Q are between 100-82.2% and 94.4-82.2%, depending on setting and age of person being screened (McKenzie et al., 2018; McKenzie & Paxton, 2006; McKenzie, Michie, Murray, & Hales, 2012; McKenzie, Paxton, Murray, & Milanesi, 2012; McKenzie, Murray, & Murray, 2013; McKenzie, Sharples, & Murray, 2015). They have also been shown to be able to successfully identify individuals who were not previously known to have an intellectual disability (McKenzie et al, 2018, 2018a). The LDSQ and CAIDS-Q are increasingly being used in a range of health, forensic and other settings in the UK and abroad, where it is acknowledged that people with an intellectual disability may be particularly vulnerable or likely to have their health and other support needs overlooked (CIRCA 2017; McKinnon Thorp, & Grubin, 2015; Murphy, Gardner, & Freeman, 2015).

Despite this, little is known about the impact of the use of the screening questionnaires on the quality of service provision to people with an intellectual disability. As with other aspects of successful intervention for people with an intellectual disability, this

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highlights the need for an evidence-based evaluation framework that reflects the priorities and practices of different service settings and which is consistent with policy targets (Guralnick, 2017). Building on the work conducted in child services (McKenzie et al., 2018a) the present study had the following aims:

- To develop a consensus-based framework for identifying the impact of using the LDSQ on services and the individuals with an intellectual disability that they support.
- To utilise the consensus framework to assess the impact in practice of using the LDSQ.

## **Method**

### **Ethics**

The study received ethical approval from the ethics committee of the first author's university and from a local NHS Research and Audit Department. All participants provided informed consent.

### **Design**

An adapted Delphi technique with purposive sampling was used for the study (Palinkas, Horwitz, & Green, 2015). This approach traditionally involves the same expert stakeholders contributing at number of stages in order to reach consensus on a topic of interest, usually through their anonymous responses to questions which are relevant to the topic being explored. The process is iterative, with items that reach a pre-determined level of consensus being retained for the next round of questioning, until a final set of questions is arrived at (McMillan, King, & Tully, 2016). This approach is particularly appropriate where there may be a need to overcome barriers to participation, such as the power differential between service providers and the people they support. It also has the strengths of providing a structured method of exploration where stakeholder opinions are likely to be subjective,

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diverse and little researched (McIntyre, Novak, & Cusick, 2010; McMillan et al., 2016). The Delphi method also allows for some adaptation and flexibility in the way that the consensus framework is developed, with a number of researchers now incorporating initial literature searches and qualitative approaches, such as interviews (Brady, 2015; Field et al., 2015; Howell et al, 2017).

## **Procedure**

A multi-stage approach was used (see Table 1 for an overview), with three stages contributing to the development of the consensus framework and a fourth stage which involved using the framework as a tool to evaluate the impact of using the LDSQ in services. A consensus framework developed in child services was used as a starting point to develop potentially relevant areas of impact for adult services (McKenzie et al., 2018a). A literature search subsequently identified additional areas where people with an intellectual disability were unlikely to be identified and particularly vulnerable: in homeless and criminal justice services and when pregnant, the latter also being a stage at which intergenerational health equalities can be perpetuated (McKenzie, Michie et al., 2012; NHS England, 2018; Oakes & Davies, 2008; Stewart, MacIntyre, & McGregor, 2016). To explore these areas further semi-structured interviews were conducted with staff working in, and with individuals using, homeless services and with professionals with experience of using the LDSQ in criminal justice, midwifery and other services. As recommended (Brady, 2015), all responses were anonymised and thematic analysis was used for the analysis and interpretation of the results.

The third stage involved creating an online survey which included statements about key areas of potential and actual impact (positive and negative) of using the LDSQ, which were identified in the preceding stages. Respondents (all of whom had experience of the LDSQ) were asked to indicate the extent to which they agreed with each of the statements by

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choosing a response from the following: ‘agree’, ‘neither agree or disagree’, ‘disagree’ or ‘not applicable’. Those items that had a valid percentage of 60% or above of ‘agree’ ratings (i.e. when ‘not applicable’ ratings were excluded), were retained in the final framework. In the fourth stage, the responses from stage three were analysed in order to evaluate the impact of using the LDS, with examples provided by respondents (see Table 2). Finally, respondents were asked to provide overall ratings of the extent to which they perceived the use of the LDSQ had benefited the individual and the service, with 0 indicating no benefit and 100 indicating maximum benefit.

## **Participants**

In the current research there were 28 participants in stage two, and 29 participants in stages three and four, five of whom had also contributed to stage two (see Table 1 for details).

## **Results**

Eighteen items (covering 15 potential positive impacts and 3 potential negative impacts of screening) were included in the stage three survey. Of these, nine were endorsed by 60% or more participants. Table two illustrates the retained items, level of percentage agreement and associated comments, where available. The items that were not retained (with percentage of those endorsing and those who were neutral about each item, respectively in brackets) were: ‘Helps inform the support that is needed for the family/carer’ (32%, 41%); ‘Helps reduce the waiting list/time for the service’ (28%, 56%); ‘Reduces time taken for assessment’ (50%, 36%); ‘Reduces assessment costs’ (36%, 41%); ‘Increases service user satisfaction’ (23%, 73%); ‘Contributes to increasing the wellbeing and life chances of the person with an intellectual disability’ (52%, 35%). None of the items relating to disadvantages of using the LDSQ were retained. These were ‘using the LDSQ

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inappropriately as a way of restricting access to services' (18%, 14%), 'Using the LDSQ inappropriately in place of diagnostic assessment' (24%, 5%) and 'Causes service users to feel stigmatised' (19%, 19%). In terms of overall rating of benefit to the person with an intellectual disability of using the LDSQ, the mean score was 70 (SD = 28.8), while for overall benefit to the service the mean score was 72.1 (SD = 20.61).

### **Discussion**

The study aimed to develop an evidence-based consensus framework that could be used as a basis for measuring the impact of screening for intellectual disability and provide an indicator of service quality. A second aim was to use the resultant framework to evaluate the impact of using the LDSQ across 29 different services that had experience of its use in practice. Of the 18 original items, half were endorsed by over 60% of respondents in stage three and included in the final framework. All of these items were also retained in the version developed to evaluate the impact of using the child and adolescent version of the screening questionnaire, the CAIDS-Q (McKenzie et al, 2018a), although the item 'helps the service prioritise diagnostic assessment' was worded as 'helped the child receive diagnostic assessment more quickly' in the child version. In the present study, one respondent indicated that helping the service to prioritise diagnostic assessment also resulted in reduced waiting time for diagnosis. As waiting times are used internationally as indicators of service quality and performance (Bowers, 2011), helping to prioritise and reduce the wait for diagnostic assessment may be an important benefit of the LDSQ.

As with the child and adolescent framework, the most commonly endorsed benefits of the LDSQ were identifying people who were not known to have an intellectual disability and identifying potentially vulnerable people. Research suggests that over 50% of adults do not have their intellectual disability recognised by services, particularly those with a mild intellectual impairment (Emerson et al., 2016). The main purpose of the LDSQ is to help

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identify those who are likely to have an intellectual disability, particularly in settings where they may have increased vulnerability and where staff may not have expertise in recognising their intellectual disability and associated needs (McKenzie, Michie et al., 2012; Oakes & Davies, 2008; Stewart et al., 2016). The LDSQ, while a screening, rather than a diagnostic tool, has been found to have good levels of sensitivity and specificity, identifying those with and without an intellectual disability with high levels of accuracy (e.g. McKenzie, Michie et al., 2012, 2014; 2015, 2018; McKenzie & Paxton, 2006). The results of the present study suggest that the LDSQ is largely successful in achieving this in a wide range of practice settings across the UK.

The LDSQ was also seen as having the benefit of being accessible for use by a wide range of people. The LDSQ was specifically designed to be used this way, without the need for a specific professional qualification, background or training. One of the suggested reasons for delayed identification of many people with an intellectual disability is that diagnosis requires assessment by specialist staff (McCarthy et al., 2015), specifically by an appropriately qualified applied psychologist (British Psychological Society, 2001). In addition, the diagnostic process can be time-consuming (Winters, Collett, & Myers, 2005). One of the ways in which the LDSQ appears to facilitate diagnosis is by helping a range of staff to identify those who are most likely to have an intellectual disability. These people can then be prioritised for full diagnostic assessment.

The use of the LDSQ was also seen as raising awareness of intellectual disability in general. This is important as research has indicated that knowledge of intellectual disability is low in many staff groups who are likely to come in regular contact with people with an intellectual disability, including primary care (McKenzie, Murray, Matheson, McCaskie, 2000) and education staff (Rae, McKenzie, & Murray, 2011). There is, however, little point in identifying people who are likely to have an intellectual disability in the absence of a

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system to also recognise and meet their support needs. The study indicates that the use of the LDSQ is seen as both informing the support needs of people with an intellectual disability and subsequently contributing to improving their wellbeing and life chances. This finding is supported by other research that indicates that the integration of the screening questionnaires into assessment and care pathways can result in additional assessment and support being provided to people with an intellectual disability (Griffiths, 2018; Murphy et al., 2015).

As with any screening measure, the benefits of using the LDSQ must be weighed up against the disadvantages (Andermann, Blancquaert, Beauchamp, & Déry, 2008). Three areas of potential negative impact were included as questionnaire items; the inappropriate use of the LDSQ in place of diagnostic assessment; or to restrict access to services; and that it would be perceived as stigmatising by those being screened. All three items received low levels of endorsement and were not included in the final framework. This is not to suggest that these negative impacts will never occur, however they were not commonly experienced by respondents.

The Delphi method has a number of advantages that made it suitable as a methodology for the study. It has no set recommended sample size, with researchers suggesting numbers between 10 and 50 (Aronson, Janke, & Traynor, 2012). The present study had a sample size of 29 and involved a wide range of stakeholders, however, there were also some limitations. First, it cannot be assumed that the respondents reflect the views of all stakeholders. The views of users of homeless services were reflected in the development of the framework, however, people with an intellectual disability who use other types of services may have different perspectives about important benefits and drawbacks of using the LDSQ. Second, the LDSQ was developed and validated in the UK and the study had the strength of including staff from a range of professional backgrounds and service settings across the UK. The questionnaire is, however, also used out with the UK and obtaining a

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more international perspective on its impact in other countries is a further important area of future research. Finally, an obvious area where health inequalities for people with an intellectual disability can begin to be addressed is in primary care, but none of the respondents worked in this setting. At present, evidence-based screening questionnaires for intellectual disability are not used in a systematic way in primary care services to help identify those who are likely to require additional support. This may change in light of recent government recommendations that health care providers should clearly identify those who require reasonable adjustments (NHS England, 2018).

In conclusion, the results of the present study, and previous research (McKenzie et al., 2018) suggest that it is possible to develop a framework that includes the main areas of impact in both adult and child services of using screening questionnaires for intellectual disability. The LDSQ may offer one way of facilitating the identification of people with an intellectual disability and therefore, helping to address the health inequalities they face.

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**Table I:** An overview of each phase of the study including participants information, inclusion criteria, recruitment, data collection and analysis

Stage	Participants	Demographic Information (where available/applicable)	Purpose	Inclusion Criteria	Recruitment and data collection method
1. Adaptation of existing consensus framework (developed from work in child services) based on a literature search of relevant literature in adult services	N/A	N/A	To identify additional topic areas to include in the survey.	N/A	N/A
2. Semi-structured interviews with staff and service users	Interviews (n = 28) were completed with: <i>Staff</i> (n = 20) comprising staff working in homeless services (n = 16), three clinical psychologists and one health team manager with experience of the use of the LDSQ in criminal justice,	<i>Staff</i> M = 3, F = 17; age 23 – 67 years, mean = 36.3, SD = 12.3.  <i>Service users:</i> M = 7, F = 1; age 28 - 52 years, mean = 42.7, SD = 11.	To explore the areas of impact identified in stage one in more detail, and identify any potential gaps, particularly with respect to midwifery, homeless and criminal justice services.	<i>Staff:</i> working in, or in conjunction with, homeless, midwifery or criminal justice services which offered support to people with an intellectual disability.  All had 6 months or more of experience of	Homeless service: A senior manager at the participating homeless service was contacted initially by email and provided with details about the study. These were cascaded to staff and service users. Those who provided written consent participated in a semi-structured interview in a private room in the service setting.

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community and midwifery services.

*Service users* (n = 8)

working in a relevant service.

*Service users*  
Individuals who accessed support from the participating homeless service; who had the capacity to provide informed consent to participate; and who were not under the influence of drugs or alcohol at the time of the interview.

Staff from other services were identified as meeting the inclusion criteria and as having experience of using the LDSQ from previous contact with the first author. Interviews with this group were conducted by telephone.

All participants were provided with information about the study, given the opportunity to ask questions and a suitable time to conduct the interview was arranged.

Interviews were semi-structured and addressed areas of impact identified in stage one. Participants were invited to identify additional areas of impact. Data were analysed using thematic analysis.

3. Creation of impact framework

This was completed by staff (n = 29) comprising 13 psychologists, of whom 10 were

female = 22  
age range = 26-67  
(mean = 42.7, SD = 10.1)

To establish if a consensus could be reached by service staff about the most important areas of impact of

*Service staff*  
Had experience of the LDSQ being used in their service or

*Other service staff*  
Staff meeting the inclusion criteria were identified from previous contact with the

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clinical psychologists; 7 intellectual disability nurses; 2 midwives; 2 social workers; 1 mental health nurse, 1 researcher, 1 independent practitioner, a support worker in a homeless service and forensic medical practitioner

screening for intellectual disability.

an associated service.

first author in relation to using the LDSQ.

Participants were emailed a link to the online survey and asked to complete it. Data were analysed using descriptive statistics. Items that had over 60% agreement were retained for stage four.

V. Using the questionnaire to identify impact

As above

As above

Based on the included questions, the specific impact of using the LDSQ reported by participating staff was summarised.

As above

Data from the phase three survey were analysed in respect of the retained questions.

Impact of screening for ID

**Table 2:** Participant responses in terms of areas of impact of the screening process

Area of impact	Percentage agreement	Sample comments
Helps to identify people who were previously not known to have an intellectual disability	95.8	<ul style="list-style-type: none"> <li>Helped flag up that GPs needed a way of identifying people who were likely to have LD</li> </ul>
Helps the service to prioritise diagnostic assessment	85.7	<ul style="list-style-type: none"> <li>[Helpful] in identifying whether someone has a LD and is eligible for Learning Disability services</li> <li>Supports clinical judgement</li> <li>Eligibility in conjunction with clinical interview and judgement</li> <li>It is helpful in identifying when further assessment is likely needed and when it's not</li> <li>Reduced waiting time for assessment</li> <li>Quick to administer</li> </ul>
Helps inform the support that is needed for the individual	63.6	<ul style="list-style-type: none"> <li>Identified a patient required additional support and support was put in place</li> <li>To enable them to access the right support from the most skilled professionals.</li> <li>Determining eligibility for services and signposting.</li> </ul>
Can be used by a range of people	95.6	<ul style="list-style-type: none"> <li>[Helpful] within Criminal Justice Agencies</li> </ul>
Contributes to increasing the wellbeing and life chances of the person with an intellectual disability	65.2	
Increases awareness of intellectual disability	77.3	<ul style="list-style-type: none"> <li>Has helped raise the midwives awareness and understanding of LD. It has also increased midwives confidence in referring woman onto the LD service.</li> </ul>
Helps identify potentially vulnerable people	91.3	<ul style="list-style-type: none"> <li>The screening tool identifies patients who are unable to undergo police interview independently as well as gaining valid consent</li> <li>To help partner agencies identify potentially vulnerable adults</li> <li>The value depends on what happens next - any screening tool needs to be part of a systematic approach that includes action based on the results. I have seen examples of this being done well, e.g. as part of a strategy</li> <li>Used by a specialist midwifery service who work with vulnerable woman.</li> </ul>
Gives an indication of a person's level of functioning	66.7	

Impact of screening for ID

Useful for research purposes

66.7

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