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Knowledge of learning disability: Twenty years on

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Abstract

Aims: An understanding of learning disability is important for ensuring people are identified and receive the support they need. This study aimed to explore the knowledge of the criteria for learning disability in community staff.

Methods: A total of 264 social care staff were asked to provide their understanding of the term 'learning disability' and their responses were coded against the three diagnostic criteria.

Results: The most commonly identified criterion related to intellectual functioning, with childhood onset being mentioned least often. Just under 5% of participants identified all three criteria for learning disability and over 50% identified none or only one of the criteria.

Conclusions: While the results were an improvement on the results found over 20 years ago, they indicate an ongoing need for improving understanding. Implications for the role of learning disability nurses in addressing this need are discussed.

Keywords: knowledge, learning disability criteria, social care staff, training

Background

The term learning disability (also referred to as intellectual disability) is used today to refer to people who need additional support because of significant difficulties with their intellectual and daily functioning that have existed from childhood (American Psychiatric Association 2013). As learning disability is a social construct, the primary reasons for categorising people as having a learning disability have varied according to the wider context of society at the time.

Significant historical drivers for categorisation have included economic reasons when, following industrialisation, it was a way of identifying individuals who were unable to support themselves financially and who would, therefore, need poor relief. During the 19th Century, learning disability was primarily viewed within a medical context and standardised assessment methods were developed to identify those who fell within this category (Murray and McKenzie 2020). This medicalisation of learning disability continued for many years. It was not until the 1960s, when the rise of the civil rights movement, the development of the philosophy of normalisation (Wolfensberger 1972), and public outrage at the institutional abuse of people with a learning disability triggered the process of deinstitutionalisation in the United Kingdom (UK). National policies which aimed to promote the inclusion of people with learning disability in the wider community were published throughout this period (e.g., Department of Health 2001; Scottish Executive 2000). Associated with this, was the recognition of a need for a well-trained workforce who could support people with a learning disability in homes in their own communities.

Research during this period, however, highlighted a low level of knowledge about learning disability among both health and social care staff. This raised concerns about the potential negative impact that this might have on the support that people with a learning

disability might receive (McKenzie et al 1999). Over 20 years later, the need for a knowledgeable workforce to support people with a learning disability remains an important issue.

There are a number of reasons for this. The first is the ongoing need to develop good quality community services for people with a learning disability. In 2014, following further incidents of institutional abuse of people with a learning disability, the urgent need to end inappropriate institutional care was again highlighted and became a government priority (NHS England 2014). The success of this 'Transforming Care' strategy relied on having a skilled community-based workforce in place to support people with a learning disability. A second reason is the recognition that early identification of learning disability can result in early interventions that can help benefit the child and wider family unit (Guralnick 2017), such as improving adaptive and academic skills (e.g. Sheppard and Unsworth 2011, Spooner et al 2019). A third important reason is that people with a learning disability continue to experience significant health inequalities (Emerson et al 2016). This includes being at an increased risk of dying from an avoidable medical cause of death, compared to the general population (The LeDeR Team 2021).

Limited knowledge about learning disability can, however, lead to delayed or missed identification (Emerson and Glover 2012, McKenzie et al 2019). This, in turn, can prevent access to interventions that are designed to improve the quality of life, skills and health of people with a learning disability. In relation to the latter, people with a learning disability may lose out on health care initiatives (e.g., NHS England 2018), such as annual health checks, because the person is not placed on the GP Learning Disability Register. Research suggests that both medical students (Harwood and Hassiotis 2014) and qualified health professionals continue to have deficits in their knowledge of learning disability (Whittle et al 2018) and that this can reduce access to good quality health provision.

Research also suggests that low levels of staff knowledge can act as a barrier to identifying people with a learning disability in services where they are particularly vulnerable and in need of support, such as criminal justice (see Townsend et al 2020) and homeless services (see Brown and McCann 2021). By contrast, the timely identification of those who have a learning disability can bring a number of benefits including increased understanding of the person, and the provision of support and interventions that meet the person's needs (see McKenzie et al 2021). In addition, having greater knowledge about learning disability is associated with more positive attitudes towards those with the condition (e.g., Alnahdi et al 2020).

People with a learning disability are a heterogeneous group, with a wide range of different needs. Understanding the criteria for learning disability is, however, important as an indicator of the broad areas where people are likely to need support (Williams et al 2009). These three criteria are: significant impairments in intellectual functioning (for example, reasoning, planning, abstract thinking); significant impairments in adaptive functioning (for example, communication, social interaction, and skills required for independent living); and childhood onset (American Psychiatric Association 2013).

In 2019, Skills for Care and Skills for People published the Core Capabilities Framework for Supporting People with a Learning Disability. This outlined the key areas of knowledge that staff in different roles required in relation to people with a learning disability. As part of this, all staff were expected to 'know what is meant by the term learning disability' (p22). Related to this, was the development of the Oliver McGowan Training, aimed at providing health and social care staff working with people with a learning disability and/or autism with knowledge and skills appropriate to their role (Department of Health and Social Care 2019).

Aim

In this context, the aim of the present study is to explore whether there have been changes in the knowledge of social care staff about the criteria for learning disability, over 20 years since this was first explored.

Method

Design

The study used an observational design. This type of design simply measured the responses of staff without using any type of intervention to try to change these responses.

Ethical considerations

Ethical approval for the research was granted by the ethics committee of the first author's university. All participants provided consent and responses were anonymous. Participants were asked to provide a code to identify their data should they subsequently wish to withdraw from the study.

Participants

Participants were 264 staff who worked in social care organisations. Of these, 65 (24.7%) were male and 198 (75.3%) were female. Their ages ranged from 19 to 64 years (*mean age* = 40.7, *standard deviation* = 11). The majority (*number* = 259, 98.5%) described themselves as being white British or white other. Just over half (*number* = 137, 51.9%) worked as direct support workers, 85 (32.2%) held a managerial role, 28 (10.6%) were team leaders and 3 (1.3%) described their role as 'other.' The participants had worked with people with a learning disability between 6 months and 35 years. The mean length of time was 11.8 years (*standard deviation* = 8.3).

Procedure

Participants were recruited from social care services in the North-East of England. Potential participants were sent a link to an online platform that provided information about the study and a section where those who wanted to take part could indicate their consent and provide a code. They were then asked to provide some demographic information, including age, gender and length of time working in learning disability services. Following this they were asked to ‘provide a brief description of your understanding of the term learning disability.’ These responses were typed into a free text box by participants and subsequently coded, based on comparison with the three criteria for learning disability. Participants were allocated a point for each of the criterion that was correctly identified. The possible range was 0-3, with higher scores indicating greater knowledge of learning disability. All responses were coded by two raters and any disagreements were resolved through discussion. Table 1 provides an example of participants’ responses for each criterion.

Results

Table 1 shows the number and percentage of participants who identified each of the three criteria for learning disability, with sample responses.

Table 1: The number and percentage of participants who identified each of the three criteria for learning disability.

Criteria	Number (percentage)	Example Responses
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Intellectual Functioning	197 (74.6)	<ul style="list-style-type: none"> • A reduced capacity to learn new things and to retain information and can take longer to learn how to do things. • Reduced cognitive ability to understand situations, tasks and information.
Adaptive Functioning	134 (50.8)	<ul style="list-style-type: none"> • Difficulty with everyday tasks/activities • It is a person who finds it harder to have life skills and needs support from others to do things and learn how to do these things.
Childhood Onset	31 (11.7)	<ul style="list-style-type: none"> • Brain development has been affected either before they were born, during childhood or early childhood. • Childhood onset

A Cochran's Q test showed that there was a significant difference in the frequency with which each of the three criteria were identified. The results of the test showed the value of the test was $Q = 189.8$ and that the probability that the result was due to chance was less than 1 in a thousand ($p < .001$). A series of McNemar tests (using a Bonferroni correction for multiple comparisons) showed that participants were significantly more likely to refer to the criteria of intellectual impairment than either impairment in adaptive functioning or childhood onset. Participants were also significantly more likely to refer to the criteria relating to adaptive functioning than childhood onset. In all cases, the probability that the result was due to chance was less than 1 in a thousand ($p < .001$).

Table 2 shows the number and percentage of participants identifying none, one, two or three of the criteria for learning disability.

Table 2: The number and percentage of participants identifying no, one, two or three of the criteria for learning disability.

Number of criteria identified	Number	Percentage
None	29	11.0
One	121	45.8
Two	101	38.3
Three	13	4.9

Total knowledge scores

A significant difference in knowledge scores was found. The results show the value of the test was $t = 2.04$ and that the likelihood of the result being due to chance was less than 5 in hundred ($p = .022$). Those in managerial roles had greater knowledge (*mean score* = 1.51, *standard deviation* = .77), compared to those in other roles (*mean score* = 1.31, *standard deviation* = .73).

There was also a significant correlation between the length of time that the person had worked in learning disability services and total knowledge scores. Those with more experience had higher scores. The value of the test was $r = .191$. The probability of the result being due to chance was two in a thousand ($p = .002$),

Discussion

Limitations

The study did have limitations. First, the participants were all from the North-East of England, which may limit the generalisability of the results. It may be that staff from different geographical areas would have different levels of knowledge. Second, participants responded to the questions by giving written responses. A different method, such as interview, may have encouraged participants to give longer, more detailed responses. These limitations must be kept in mind, when considering the results of the research.

The ongoing move from institutional to community-based support and associated need for a skilled social care workforce who are knowledgeable about learning disability is as important today as it was 20 years ago. Having a basic knowledge of the criteria for learning disability is key to understanding the broad areas where people are likely to need support (Williams et al 2009) and helps to identify those who might have a learning disability in the first place (Emerson and Glover 2012, McKenzie et al 2021).

The study found that the most commonly identified criterion for learning disability related to difficulties with intellectual functioning. Some reference to this was made by almost 75% of participants. The level of understanding, however, varied, with very few noting that people with a learning disability had *significant* difficulties with intellectual functioning and most just referring broadly to difficulties with learning. This suggests that there may be confusion between learning disability and specific learning difficulties, such as dyslexia. Indeed, Harwood, and Hassiotis (2014) found that undergraduate medical students confused the two conditions. This confusion is perhaps understandable, given the changes in terminology over time, that some people with a learning disability prefer to be referred to as having a 'learning difficulty,' and that different terms for learning disability are used interchangeably in different contexts (see Cluley 2017).

The second most frequently identified criterion was that of adaptive functioning. This was identified by just over half of the participants. The final criterion, childhood onset, was rarely mentioned by participants. This may reflect that staff in the present study mainly worked within adult services and so may have been less aware of this criterion. The Core Capabilities Framework for Supporting People with a Learning Disability (Skills for Care and Skills for People 2019), however, has as a key competence that staff understand that learning disability is a life-long condition.

The overall pattern of results was very similar to that found by McKenzie and colleagues in 1999. In both cases, the criterion of intellectual functioning was significantly more likely to be identified, followed by adaptive functioning. The percentage of staff identifying both the intellectual and adaptive functioning criteria was, however, higher in the present study (as compared with the 1999 results for residential social care staff). Nearly 75% of staff in the present study compared with 66% of residential staff in the previous study identified the criterion of intellectual functioning. The figures for adaptive functioning were 50.8% and 30% respectively. There was little difference in relation to the childhood onset criterion, with approximately 12% of participants identifying this in both studies.

In terms of overall knowledge, only 13 (4.9%) participants identified all three criteria for learning disability. Over 50% identified none of the criteria or only one. While this is an improvement compared with the results of the 1999 study (with the corresponding figures being 2% and 84%), it suggests an ongoing need for social care staff to have an improved understanding of what a learning disability is.

Both the role of staff and length of time spent working with people with a learning disability impacted on knowledge. Those in managerial roles and those who had more experience of supporting this group of people had greater knowledge of the criteria for

learning disability. This is consistent with the previous results of McKenzie et al (1999), who also found a positive relationship between experience and knowledge.

The results have implications for practice. Previous research suggests that staff training about learning disability can make a positive difference to knowledge and attitudes (Harwood and Hassiotis 2014, Jones et al 2014, Rae et al 2011). The ongoing development and wider roll-out of the Oliver McGowan Training to health and social care staff may help to address the gaps that still exist for some staff in their knowledge about what a learning disability is. Professionals such as learning disability nurses, are well placed to support this wider training effort, as they often liaise with both social care and other health service staff.

Learning disability nurses can continue to use informal opportunities to educate their colleagues about what a learning disability is and inform others about the implications of the criteria for the types of broad support that people with a learning disability may need. This may be in relation to their intellectual understanding of the world and their day-to-day skills (Williams et al. 2009) and the health issues that are commonly associated with learning disability (Emerson et al 2016).

They can also raise awareness of formal training opportunities, such as the Oliver McGowan Training, in the local area and of the requirements of the Core Capabilities Framework for Supporting People with a Learning Disability. Learning disability nurses can also help support managers in social care services to develop ways to more widely disseminate basic information about learning disability to their social care workforce.

Learning disability nurses can signpost others to reliable sources of information about learning disability and ways of identifying those who are likely to have a learning disability, such as the use of evidence-based screening tools (see, for example, <https://learningdisabilitymatters.co.uk/tools/>). Research suggests that among other benefits,

the use of such tools can help increase awareness about learning disability (McKenzie et al 2020).

Conclusion

The study found a similar pattern of results to that found over 20 years ago. There was also evidence of some improvement in knowledge levels of social care staff over time. The results, do, however, indicate that gaps in staff knowledge remain. Learning disability nurses have a role in supporting both formal and informal efforts to improve the basic knowledge of social care staff about learning disability.

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Implications for Practice

Learning disability nurses, as specialists in the field, can:

- Use opportunities to educate their colleagues in social care and other services about what a learning disability is and the implications of this for the support needs of this group of people
- Support those in managerial roles in social care services to disseminate this knowledge more widely with their social care workforce.
- Support, disseminate information about and raise awareness of formal training initiatives and the Core Capabilities Framework for Supporting People with a Learning Disability
- Signpost others to evidence-based ways of identifying those who are likely to have a learning disability, such as the use of screening tools.