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From "Learning disability to intellectual disability"—Perceptions of the increasing use of the term "intellectual disability" in learning disability policy, research and practice

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Accessible summary:

- "Learning disability" replaced the outdated term, "mentally handicapped" in the UK over 20 years ago. Recently, some services and professionals have been using the term "intellectual disability" instead. In America, "intellectual disability" has been chosen to replace the old term, "mental retardation." There has been lots of explanation why this has happened.
- In the UK, there has not been much explanation. It is important to know what terms mean and why they are being used because their use affects the lives of people with learning disabilities.
- This article looks at what different people in the UK think about term "intellectual disability."

Abstract

Background: The term "intellectual disability" is increasingly used to refer to people with learning disabilities in British learning disability policy, practice and research. This change is undoubtedly a reflection of the changing international context. The inclusion of the term "intellectual disability" has been particularly pronounced in countries such as the USA. By contrast, this change has been relatively silent in England.

Methods: In light of this, the paper explores the discussions of 12 focus groups conducted with professional and lay groups working in or influencing learning disability research and practice in England. Each focus group was asked the following two questions: Have you heard of the term "intellectual disability" and how do you feel about the term "intellectual disability?."

Discussion and Conclusion: Thematic analysis of the discussions identified four dominant themes: dislike and disbelief; ambiguity; tautology; and fear. It is concluded that more explanation is required in order for researchers and practitioners in England to understand this semantic change.

KEYWORDS
intellectual disability, learning disability

1 | INTRODUCTION

"Learning disability" has long been described as the UK's preferred term (Walmsley & Johnson, 2003) to refer to people who have "significantly reduced ability to understand new or complex information, to learn new skills" and a "reduced ability to cope independently which starts before adulthood with lasting effects on development" (Department of Health, 2001 p. 14). While other terms exist, and

might be preferred by certain groups, as with "learning difficulty" among some self-advocates (Goodley, 2011), "learning disability" has been in common and accepted use among people with and without learning disabilities alike for over 20 years (Gates & Mafuba, 2016). Recently, however, the term "intellectual disability" is increasingly used in replacement of or synonymously with "learning disability" and is now increasingly visible in UK professional discourse (British Institute of Learning Disabilities, 2017). Despite the growing presence of the term "intellectual disability," there is little visible explanation as to why this is; "Intellectual disability" is, more often than not, used without question or explanation.

On the surface, a change in terminology might not seem problematic; many terms have multiple words that can be used to describe them. "Learning disability," however, is not a term that can be replaced without thinking. The terminology used is value-laden, politically imbued and socially constructive. As Wendell (1996) p.32 tells us "how a society defines disability and whom it recognises as disabled are of enormous psychological, social, economic and political importance, both to people who identify themselves as disabled and to those who do not but are nevertheless given the label." Further to this, labelling theory (Becker, 1963) tells us that the social construction of labels has more than just practical implications. A label can dictate the life paths of those so labelled, particularly if labels are also associated with stigma as is the case with terms such as "learning disability" and "intellectual disability" (Green, Davis, Karshmer, Marsh, & Straight, 2005). The term used by professionals, lay people and people with learning disabilities alike is of direct consequence to the lives of people with learning disabilities and their inclusion.

This paper seeks to present how both professional and lay groups who are part of learning disability practice in England are experiencing this silent shift in their vocabularies with the hope of starting a discussion that highlights the importance of terminology. To do this, the paper draws on focus group discussions with 12 different professional and lay groups working in and/or with the potential to influence learning disability practice in England.

The discussion presented in this paper addresses focus group participants' responses to two set questions:

1. Have you heard of the term "intellectual disability?"
2. How do you feel about the term "intellectual disability?"

Four dominant themes identified across the focus group responses are presented and discussed in relation to their experience and perception of the addition of the term intellectual disability into their lay and professional vocabularies. It is concluded that more explanation is needed as to why "intellectual disability" is thought to be synonymous with "learning disability" in order for practitioners to understand this change.

2 | BACKGROUND

The World Health Organisation provides an international definition of "intellectual disability." Here, "intellectual disability" is defined as "a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development" (WHO 2017) Similar to the Valuing People (Department of Health, 2001) definition, provided in the introduction, that was adopted with the specific aim of including social and environmental factors that had not featured in previous terminology, the WHO definition goes on further to state: "disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society" (WHO 2017). Currently, a number of countries use "intellectual disability" as their preferred label of choice, including Ireland (Inclusion Ireland 2013), Canada (Canadian Association for Community Living, 2017), the USA (Schalock, 2007), Australia and New Zealand (Higgins, 2014).

In the USA, there has been much discussion on the term "intellectual disability" and its outright replacement of the term "mental retardation" (Schalock, 2007, 2010). The American Association on Intellectual and Developmental Disabilities (AAIDD), formally the American Association on Mental Retardation (AAMR), positions "intellectual disability" as a progressive term that allows the inclusion of social barriers while also acknowledging individual bodies (Schalock, 2007). Following and in conjunction with the AAIDD's adoption of the term "intellectual disability," internationally used diagnostic manuals are also working towards changing their terminology from the radically outdated, "mental retardation," to the term "intellectual and developmental disability." The Diagnostic and Statistical Manual of Mental Disorders (DSM) V (American Psychriatric Association, 2013), for example, is now using the term "intellectual disability (intellectual disorder)" and the World Health Organisation ICD-11 to be published in 2018 is thought to be adopting the term "intellectual developmental disorder." (Higgins, 2014).

Evidence of the recent trend to use the term "intellectual disability" can be seen across a range of settings in the UK. In academia, examples of the use of "intellectual disability" can be found in: journal titles, research papers, grant applications and conference presentations. In their paper, Haydon-Laurelut (2014) for instance, use the term "intellectual disability" to refer to people seen by the NHS Community Learning Disability Teams from which they were interviewing staff members. Examples of "intellectual disability" replacing "learning disability" are also increasingly found within learning disability practice. A number of NHS learning disability services have changed their names to reflect this shift. For example, Nottinghamshire NHS Trust, who to their credit have provided a visible explanation why on an internal wall in their building, have renamed their "Learning Disability Services," "Intellectual and Developmental Disability Services." Further to this, Mansell's (2010) report for Mencap, *Raising our Sights*, adopts the term "profound intellectual and multiple disabilities" instead of the previous and more commonly used term, "profound and multiple learning disabilities." British Medical Association (2014) report addressing physical health among people with mental ill health and learning disabilities,

Recognising the importance of physical health in mental health and intellectual disability, also uses the term "intellectual disability" synonymously with "learning disability."

The increasing terminological shift from "learning disability" to "intellectual disability" in the UK is no doubt a reflection of the changing international context. What is interesting about the move towards "intellectual disability" in the UK is its relative silence in comparison with other nations, such as the USA (Schalock, 2010) and Australia (Higgins, 2014). Of course, this is not the first time that "learning disability" has experienced a name change in the UK; terminology has been subject to frequent change. The turnover of such labels in the UK has accelerated over time, reflecting the increasing pace of social change (Rix, 2006). Over the years terms have included the following: "natural fool," "idiot," "person of weak intellect," "mental imbecile," "mentally infirm," "simpleton," "feebleminded," "moral imbecile," "mental defective," "mentally deficient," "subnormal," "mental retardation" and "mentally handicapped." Originally, such terms were used for a variety of reasons, such as: medical classification, welfare distribution and law enforcement, as well by lay people to refer to real people living with a learning disability (Gates & Mafuba, 2016). The intention to replace the term "mentally handicapped" with "learning disability" was made explicit in *Valuing People* (Department of Health, 2001). This followed its prior introduction by progressive practitioners, academics and service users alike some 10 years beforehand (Gates & Mafuba, 2016). As already stated, the change in terminology was made for similarly progressive reasons as the AAIDD's replacement of "mental retardation." "Mentally handicapped" was not considered to reflect the social construction of the lived experience of learning disability. By contrast, there is yet to be such an explicit explanation of the increasing use of the term "intellectual disability" in England.

The addition of another term does not necessarily mean that "learning disability" will become a redundant term. Although not widely accepted, a number of the terms listed above continue to be used today, particularly in lay language as pejorative terms. "Learning disability" has and likely will continue to have many synonyms that can be useful or not depending on social context. When speaking with self-advocates in England, for example, the term "learning difficulty" may be preferred (Goodley, 2011). In contrast, when speaking to mainstream teachers in England, the term "learning difficulty" could mean something different entirely, such as what is known as a "specific learning difficulty," like dyslexia or dyspraxia.

3 | METHOD

Twelve focus groups were conducted with: social care providers, local authority councillors, clinical psychologists, personal assistants, parent carers, mainstream teachers, student teachers, special school teachers, healthcare professionals, student journalists, student social workers and social scientists. Parent carers were included as lay professionals by virtue of their long-standing caring responsibilities. These groups were chosen for the reason that they will more likely use the term "learning disability" within their vocabularies, and

because their roles have the potential to influence the lives of people with learning disabilities. The sample was an opportunity sample. Those included represent the professional and lay groups that could be accessed within the constraints the project. All of the focus group participants lived and worked in England, specifically within the East Midlands region and had prior experience of working with people with learning disabilities. The focus groups involved between three and eight participants, with an average of four participants per focus group. All focus groups were attended by different participants. The focus groups were audio-recorded and transcribed verbatim. Ethical approval for the wider project was granted by The University of Nottingham. Within the focus groups, two set questions addressed intellectual disability; these were:

1. Have you heard of the term "intellectual disability?"
2. do you feel about the term "intellectual disability?"

The focus groups were part of a wider study titled, "What does learning disability mean in the real world?" This study used a combination of focus groups with people without learning disabilities and photovoice (Cluley 2017) with people with learning disabilities, to re-evaluate concepts of learning disability. While the views and perceptions of people with learning disabilities were included in the wider study, these groups were not asked about the term "intellectual disability" specifically. It is recognised that that the views of people with learning disabilities are of absolute importance to this addition to vocabulary, and therefore, it is highly recommended that further research explore the views of people with learning disabilities.

4 | ANALYSIS

Thematic analysis was used to analyse the focus group discussions. Thematic analysis is an iterative process that identifies patterns of meaning across the data. The themes that emerge are closely related to the data, allowing an in-depth focus on the data corpus (Guest, 2012). There is no one fixed or prescriptive method for carrying out a thematic analysis, rather the process is flexible and can differ depending on the aims of the research and the epistemological standpoint of the researcher (Guest, 2012). It is important, however, to identify how themes came to "emerge" from the data to ensure transparency and rigour. Here, Braun and Clarke's (2006) flexible six-step guide was adopted to thematically analyse the focus group responses. This involved the following: familiarisation with the data, coding; the identification of themes within, between and across codes; review of the themes; formalisation of the themes; and write-up. In accordance with Braun and Clarke's (2006) six steps, the participants' talk was initially organised into 11 codes. The four dominant themes that emerged from and are linked to these codes have been labelled as follows: disbelief and dislike; ambiguity; tautology; and fear. Each of the themes is illustrated and discussed in the sections that follow.

5 | FINDINGS

Before the four themes are presented, in accordance with step 1 of Braun and Clarke's (2006) guide, a general overview of the responses to the set questions is outlined.

5.1 | Have you heard of the term "intellectual disability?"

Only four of the focus groups had heard of the term "intellectual disability." These four groups were the social care providers, the clinical psychologists, the parent carers and the special school staff. Of these four groups, only one, the clinical psychologists, used the term regularly as part of their everyday practice. In contrast to this, all 12 focus groups had heard of and used the term "learning disability" as part of their everyday vocabulary.

5.2 | How do you feel about the term "intellectual disability?"

The responses to this question were relatively homogenous. "Intellectual disability" was not considered to be a favourable term by any of the focus groups. Across the focus groups, the participants associated "intellectual disability" not with a progression but with a regression to a time when now pejorative terms were accepted as the norm. Participants that used the term reported that they only did so out of necessity.

5.3 | Theme 1: Disbelief and dislike

Disbelief that "intellectual disability" is a term in current use and dislike for the term was common among all of the focus groups regardless of whether or not they were familiar with the term. The two emotions are discussed together under one theme because the participants often used one to talk about the other, following their disbelief with dislike and vice versa.

When asked "have you heard of the term 'intellectual disability'?," the respondents who had not, often responded as although it might be a trick question, as although they couldn't believe "intellectual disability" could be an acceptable term in current use. The mainstream teachers' and the student journalists' initial reaction was to laugh, as demonstrated in Table 1.

TABLE 1 Extracts from the mainstream teacher and student journalist focus groups

Facilitator:	Can I just ask, have you heard of the term intellectual disability?
Mainstream Teacher1:	What!!? (Laughing)
Facilitator:	Intellectual disability
Mainstream Teacher 1:	Ha ha (laughs loudly and pulls a shocked facial expression) No!
Mainstream Teacher 3:	No! I don't use that term
Mainstream Teacher 2:	That's not one I've ever heard anyone use before
Mainstream Teacher 1:	It sounds a bit negative
Mainstream Teacher 2:	Yeah
Facilitator:	Have you heard of the term intellectual disability?
Student Journalist1:	No!! Ha ha (giggles uncomfortably)
Student journalist 2:	No? (says this in a questioning tone)

In each of these extracts, the participants use laughter to demonstrate their dislike for the term "intellectual disability" and their disbelief that such a term might exist. Laughter is often used in talk to achieve a specific rhetorical end point without having to actually say a lot (Osvaldssn, 2004). Here, it can be seen that neither of the focus groups say much about the term "intellectual disability" but instead use laughter to convey their thoughts. The participants' instant reaction to laugh indicates their shock that such a term might exist and adds a depth to their discomfort evidenced in their talk. When later asked how they feel about the term "intellectual disability," the participants added words to confirm their initial laughter and openly discussed their dislike for the term. Where participants had heard of the term, this did not equate to them being accepting of it. Two examples of this can be seen in the initial responses of the special school teaching staff and the parent carers, presented in Table 2.

TABLE 2 Extracts from the special school teacher and parent carer focus groups

Facilitator:	Have you heard of the term intellectual disability?
Special School Teacher 3:	Oh for god's sake!
Special School Teacher 1:	I have heard it
Special School Teacher 6:	I think it sounds quite derogatory really we should have moved on from IQ
Special School Teacher 4:	Well it implies that its only academic ability and that's not the whole of it at all
Special School Teacher 1:	It's not something I would use, learning disability is better
Facilitator:	Have you heard of the term learning disability?
Parent carer 5:	Oh god, that!

In both of these extracts, the participants use an appeal to God to convey their frustration. Special School Staff Member 3 exclaims "Oh for God's sake!" and Parent Carer 5 similarly asserts "Oh God, that!" Both of these exclamations demonstrate a number of emotions bound up in the participants' experience of the term "intellectual disability." Both appeals demonstrate a clear dislike for the term. Within their display of dislike, the participants also indicate impatience, irritation and disbelief. For Parent Carer 5, "intellectual disability" is reduced to

a "that" and for the special school teachers, it is said to be "derogatory," "not something I would use" and is said to represent a return to IQ, something "we really should have moved on from." Such a reaction was common across the focus groups. Extracts from the focus groups with the Personal Assistants, the Student Social Workers and the Social Care Providers, seen in Table 3, further illustrate a general dislike for the term.

TABLE 3 Extracts from the personal assistants, student social workers and mainstream teachers focus groups

Personal Assistant 3:	No it's a bit, it's a bit, er no I think its best just to not use labels like that. It's not very, well it's not that friendly. It sounds a bit, yeah
Student Social Worker 1:	I don't know how I feel about it
Student Social Worker 2:	I would avoid it personally
Student Social Worker 1:	It, it feels a little bit like, hmm…
Student Social Worker 2:	No, I think it's making them sound unintellectual as if they have got nothing there
Social Care Provider 4:	I don't use it. I wouldn't use it. I've probably learnt that it's not for me
Social care provider 1:	I only use it if I have to. You know in meetings or something
Social Care Provider 4:	It is yeah, it's a mine field, knowing what to say. I try to steer away from it

In each of these extracts, the participants' demonstrate that based on their dislike for the term "intellectual disability," they try not to use the term, stating, "I think it's best just to not to use labels like that," "I would avoid using it personally," "I don't use it," "I wouldn't use it," "I have learnt that it's not for me," "I only use it if I have to" and, "I try to steer away from it."

In addition to dislike for the overall term "intellectual disability," the participants also demonstrated dislike for the constitutive terms within "intellectual disability." "Intellectual," as seen in the extract taken from the focus group with the special school teachers, presented above, was equated with IQ, individual capacity and, academic ability. Talk within the focus groups clearly illustrated that a reliance on IQ was seen to be a thing of the past and that more comprehensive ways of seeing disability that account for social context were now valued. The extract taken from the focus group with Clinical Psychologists, shown in Table 4 demonstrates this interaction.

TABLE 4 Extract from the clinical psychologist focus group

Clinical Psychologist 3:	But that's [intellectual disability] something specific to us as a profession. I agree with you on that, I see exactly why it changed for on a professional level, I completely get it. On a kind of common language level, but when I hear the word "intellectual" I think clever, and I think that's probably what people commonly think "he's an intellectual, she's an intellectual, they're NOT"

Clinical Psychologist 2:	Yeah it's confusing isn't it?
Clinical Psychologist 3:	And so I think its just something about intelligence as opposed to process, the ability to be able to do something and that's the bit I struggle with, because I think as soon as we talk about intellectual, we think about intelligence and that takes us right back to it being based in that very individualised thing of IQ and someone's intelligence rather than, do you know what I mean? Rather than what you [CP 2] were saying which I really liked, about, it is a global process. I'm a bit like "ooo ok…., this is an odd one."

Here, the word "intellectual" is associated with individual academic ability, the capacity to be "clever" and the quantification of this via IQ testing. Clinical psychologist 3 tells the group that although she understands why there has been a change within her professional vocabulary to include the term "intellectual disability," for her the word intellectual equates to being clever, stating "when I hear the word intellectual I think clever." Clinical psychologist 2 agrees, confirming that for her the use of the word "intellectual" makes things "confusing." Prior to this discussion, in response to a question included as part of the wider project, Clinical Psychologist 2 had described "learning disability" as a "global process" that is impacted upon and created by a variety of factors such as social barriers, individual biology and environmental and cultural factors. As illustrated in this presentation, for the Clinical Psychologists, the term "intellectual disability" does not conjure such an understanding, but rather focuses attention on individual capacity. Discussions like this one were common throughout the focus groups with participants linking the word "intellectual" to people like doctors, the Queen and those that can complete The Times crossword.

Dislike for the word "disability" is demonstrated in the two extracts below taken from the focus groups with the Social Scientists and the Clinical Psychologists, shown in Table 5.

TABLE 5 Extracts from the social scientist and clinical psychologist focus groups

Social Scientist 1:	Because I don't like any labels. I have huge problems with labels and I think the moment you label something you make a moral judgement so when we talk about disability, I don't like the word disability
Clinical Psychologist 3:	I'm not sure, I'm not quite sure about how I feel about the change in language, I don't know if I quite understand, I'm not, the bit I most dislike is disability! Ha ha. I just think that if we are going to change anything, why can't we get rid of that one!
Clinical Psychologist 2:	Yeah
Clinical Psychologist 3:	Ha ha ha, because that's the bit that really cheeses me off

When talking about why they dislike the term "disability," across the focus groups talk focused on the stigma they perceived to be attached to the term. "Disability" was seen as a negative word that could potentially be "frightening" [Health Professionals] for people because of its "permanent" connotation [all]. "Disability" was said to imply a "lack of hope" [Healthcare Professionals], "negativity," [Social Care Providers] "stigma" [Mainstream Teachers and Health Professionals] and "something that has broken." [Clinical Psychologists] These thoughts are expressed the in two extracts presented on Table 6, taken from the focus groups with the health professionals and the mainstream teachers.

TABLE 6 Extracts from the health professional and mainstream teacher focus groups

Health Professional 3:	Disability sounds so much more permanent than difficulty and maybe even more frightening for parents
Health Professional 2:	Yea disability definitely has that aspect to it. You know it's permanent; it could make people think that there is no hope
Mainstream Teacher 1:	I must admit, I would say it's disability. To say people with learning needs, it's not as bad
Mainstream Teacher 3:	Learning support?
Mainstream Teacher 1:	It's never going to sound great
Mainstream Teacher 3:	No
Mainstream Teacher 1:	But it's not going to sound as bad or as negative as disability
Mainstream Teacher 3:	I think it's an awful word to be using
Mainstream Teacher 2:	Yeah

While the term "disability" is bound up in its own theoretical discussions (Shakespeare, 2014), the general consensus across the focus groups was that "its an awful word to be using." A word loaded with stigma and negativity; connotations the participants worked hard to avoid in their own talk.

5.4 | Theme 2: Ambiguity

Tied up in the focus groups' general dislike for the term "intellectual disability," was a prevailing perception that "intellectual disability" could include anyone. Across the focus groups, "intellectual disability" was seen as a term that could include anyone, with participants including themselves as potentially having an "intellectual disability". This is demonstrated in the extracts taken from the focus groups with the Parent Carers, the Student Journalists and the Special School Teachers, presented in Table 7.

TABLE 7 Extracts from the parent carer, student journalist and special school teacher focus groups

Parent Carer 3:	Well I can't do The Times crossword so I would have an intellectual disability
Student Journalist 2:	I think I could probably call myself intellectually disabled! Ha ha ha
Special School Teacher 3:	I could [have an intellectual disability] because I'm not good at all intellectual things

Participants also reported that the word "intellectual" conjured images of an elite minority. Specifically, the word "intellectual" was thought to divide the population into a minority, those who are clever, and a majority, those who are not. This thought process is demonstrated in the extracts presented in Table 8, taken from the focus groups with the special school teachers and the parent carers.

TABLE 8 Extracts from the special school teacher and parent carer focus groups

Special School Teacher 3:	It's just getting silly. Again anyone could have an intellectual disability
Parent Carer 3:	Are we talking about doctors here? You could say that only those up "there" wouldn't have the intellectual disability, anyone below a certain, below the Queen sort of thing would have an intellectual disability

"Intellectual disability," therefore, was viewed as so ambiguous a term that its parameters could extend to include people without learning disabilities by virtue of them not being considered intellectuals.

5.5 | Theme 3: Tautology

Across the focus groups, the participants expressed the view that "intellectual disability" represented another term to add to their vocabularies. As when Health Professional 2 said, "It's still the same thing although really isn't it? It's just a different way of expressing it" and Social Care provider 1 said, "Yeah but that's [intellectual disability] just the same isn't it."

When discussing the addition of another term, the participants revealed a malaise for new terminology. Many of the participants had experienced numerous name changes within their professional careers and did not welcome another addition. Such malaise and apathy are expressed in the extracts shown in Table 9.

TABLE 9 Extracts from the special school teacher and parent carer focus groups

Special Teacher 3:	It's just another term isn't it? It's not like we need any more of them
Special Teacher 5:	I wish people could just accept people with learning disabilities as people, like we do. There is no difference. We are all human and we all do things differently, why we keep labelling them I don't know
Parent Carer 1:	I don't see the difference between intellectual disability and mental handicap in some ways. The problem with all these terms is that they start off being ok but then they become derogatory anyway
And later in the discussion	
Parent Carer 6:	I mean it would be nice to have a term that didn't keep changing wouldn't it?
Parent Carer 1:	Yes

When talking about the range of terms available to them, the participants also talked about how they have come use different terms in different settings to obtain the results that they desire. Tautological malaise was also reflected here, in that "intellectual disability" was considered to be just another term to add to their repertoires to be used as and when they considered best. This was particularly pronounced within the discussions in the focus groups with Parent Carers and Clinical Psychologists, as demonstrated in Table 10.

TABLE 10 Extracts from the parent carer and clinical psychologist focus groups

Parent carer 1:	But what I have found, I learn, I rote learn the correct language for the correct thing. Because if you use the wrong language you don't get what you want AND professionals label you as inappropriate. So if you, we all know this, if you went in to a meeting and you called your child mentally handicapped, you will get a label slapped on your forehead, metaphorically speaking, which will say erm, "poor parent", "prejudice", blar blar blar, because you are not saying "their" current thing. So I treat it as a bit of a comical game, in my mind, in order to handle this ridiculous situation that I have to live within and I have a whole list of labels......I learn the terms and I use them and then every so often in meetings, if I am being really naughty, which I will be as a parent, I will deliberately say, "now which term am I using in this meeting?" And I run through the list
Clinical Psychologist 3:	To be honest I will use the one that makes the conversations I have to have with people easier. So I will use learning disability if I was having a conversation with someone who wasn't in the business I would probably talk learning disability. If I was having a conversation with someone who was, I would do it in the same way I use diagnostic categories if I have to

In both of these extracts, the term "intellectual disability" is seen to belong to professionals. The Parent Carers use it to impress professionals to get what they need for their children and the Clinical Psychologists use it among themselves but not with those who aren't "in the business." Both the Clinical Psychologists and the Parent Carers have accepted the term as another to add to their "list of labels," to be used to "make things easier."

5.6 | Theme 4: Uncertainty and fear

As well as being tired of a changing vocabulary of terms to refer to the same thing, participants talked of the uncertainty this had created. Special School Teacher 7 summed this up when she said, "Well it's like with black or gay or whatever, the terms are always changing and sometimes you don't know what is best." The participants used various metaphors to express their uncertainty, they talked about feeling like "walking on egg shells," [Social Scientists] navigating a "minefield," [Social Care Providers] disappearing down "the rabbit hole" [Local Authority Councillors] and, "drowning in a sea of terminology" [Student Teachers].

When talking about their uncertainty due to the range of terms available to them to refer to the same thing, the participants revealed a fear of getting it wrong and a fear of causing offence. The participants were concerned that in not knowing which is the most current and preferred term to use they might choose the "wrong" term, which could both cause offence to the person they are referring to and also reveal their uncertainty. Such worries are demonstrated in Table 11.

TABLE 11 Extract from the Local Authority Councillor focus group

Local Authority Councillor 1:	By far the biggest anxiety that I have when we go anywhere, I was off today up in _____, at a re-provision of our day services for people with mental ill health, and the hardest thing is not big crowds or speaking in front of people it's not, you know "how will the staff respond?", nothing like that, not talking to service users, none of that. It's getting, using the right terminology because I don't think I am in a position to set, I couldn't sit down and write here's what, here is how you should describe x, y and z because you know that language evolves over time. I am never quite sure if I am up to date and I know that's a fear that others have. So you worry that sometimes we can entrench it too by, because as I say on the way up to _____, I thought "oh there is loads of ways I can describe this – mental health conditions, mental health issues" and you know you never want to offend anyone, and you do want to get it right but it's never, it's not always clear what right is, so you know, you can end up being, in trying to do right, you do wrong

Here, Local Authority Councillor 1 expresses his fear of not being "up to date" and of "trying to do right" but "do[ing] wrong." When talking about their fear of causing offence, it was generally agreed by all of the focus groups that the safest option is not to use any specific terminology at all. Participants across the focus groups agreed that safer options when referring to people with learning disabilities included general labels such as: "service users" [Student Social Workers], "visitors" [Social Care Providers], "clients" [Student Social Workers], "patients" [Health Professionals] and "students" [Social Scientists]. The participants also considered specific diagnoses, such as "Down syndrome," to be safer options. The extract presented in Table 12 surmises the general feeling across all of the focus groups as to the why such options feel safer.

TABLE 12 Extract from the student social worker focus group

Student Social Worker 1:	Yea because a medical condition is not likely to be seen as a label, it is like you say it's a diagnosis, it's a condition
Student Social Worker 2:	It can be proven
Student Social Worker 1:	It's not got a social context about it

The participants, moreover, felt on safer ground when using either "objective" diagnoses or general categories. The term "intellectual disability" was thought to contain too much potential for offence by virtue of its semantic connotations and position within a changing vocabulary.

6 | DISCUSSION

Two commonalities link the four themes presented. First, the participants' discussions reveal an explicit and shared scepticism towards the introduction of "intellectual disability." All of the participants were familiar with the term "learning disability"; although they did raise concerns regarding this term (analysed as part of the wider project), they all expressed a preference for "learning disability" over "intellectual disability." Indeed, all participants presented the addition of the term "intellectual disability" as an irritating hindrance to their professional practice. Overall, "intellectual disability" was not viewed favourably by any of the focus groups. Considered too ambiguous to be a descriptive label, intellectual disability was viewed as just another term to be used as and when needed to achieve a desired outcome at best; at worst, it was viewed as a laughable step back in time. In addition to this, the semantic construction of the term was intensely disputed. As presented, the word "intellectual" was not considered to reflect the population group being labelled. "Intellectual" was perceived to be too vague, thus creating a term that could include anyone who isn't exceptionally clever. "Disability" was considered by some of the participants to be socially limiting.

Second, the participants' discussions reveal a contrasting understanding of the term "intellectual disability" to its progressive construction outlined by the AAIDD. While "intellectual disability" has been described in the USA, convincingly or not, as an intentional move away from negative constructions of disability as a biological problem, towards the inclusion of social barriers as causes of disability (Schalock, 2007), such discussions have not been made explicit in the UK. Rather, "intellectual disability" has slipped into vocabularies relatively silently. This relative silence perhaps explains the participants' lack of understanding expressed in the theme, dislike and disbelief. In addition to their general lack of knowledge of the international context, the participants were particularly concerned that use of the term "intellectual disability" could be stigmatising for those so labelled. The term "disability" was considered to be loaded with stigma, as seen in the extracts presented in Table 6. Bound up in the participants' immediate response to the term "intellectual disability" is their awareness that there are "acceptable" and "unacceptable" ways of seeing learning disability. This awareness reflects theoretical debates within disability studies (Shakespeare, 2014). The term "intellectual disability," moreover, was not considered to reflect the lived experience of people with learning disabilities as is suggested by the AAIDD (Schalock, 2007) and the WHO (2017) definition.

7 | CONCLUSION

The research findings presented here demonstrate a tension between the international context, whereby, mainstreaming of the term "intellectual disability" is framed (convincingly or not) as a positive change; and the negative perception of "intellectual disability" found among those spoken to as part of this project. If "intellectual disability" is going to be used in replacement of "learning disability" in UK policy documents, research findings and practice manuals, as appears to be the case, practitioners require an explanation in order for them to understand this change. Knowledge of the wider context will allow practitioners to come to an informed opinion, whether positive or negative. The research findings outlined here indicate that without knowledge of the wider context, the term "intellectual disability" is not likely to be viewed as a positive change and practitioners will be left wondering what the purpose of an additional term might be. As seen in the analysis of the research findings, there is a risk that "intellectual disability" will be seen and used as and when is considered useful rather than being used, or not, as an informed choice. It is important to remember that terminology affects and shapes the lives of people with learning disabilities. The term "learning disability" was specifically chosen for its inclusion of social context and the impact this would have upon the lives of people with learning disabilities. Knowing what a term means and understanding its background and social context is extremely important. It is time to discuss the increasing presence and relatively unquestioned use of the term "intellectual disability" in ways that are accessible to practitioners and lay people alike. This is of particular importance in the current policy and practice environment where austerity predominates, services are experiencing increasing pressure to create efficiency savings and hate crimes towards people with learning disabilities are increasing.

In addition to the research findings presented here, it is imperative that the thoughts and opinions of people with learning disabilities are sought. The presence of an additional term to refer to people with learning disabilities is of direct consequence to their lives and therefore requires their input. It is strongly recommended that further research is conducted to explore the perceptions of people with learning disabilities. It is also recommended that the findings of this research once conducted are disseminated so as to be accessible to other people with learning disabilities and practitioners alike.

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