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Talking about learning disability: Discursive acts in managing an ideological dilemma

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ABSTRACT

Learning disability is a term that can mean different things to different people. It is also a term that has undergone much revision and critique, being linked to stigma and prejudice. Consequently, talking about learning disability can be a delicate matter. This paper analyses the discursive work done by focus group participants (professionals and lay people in supportive roles) to manage their talk about learning disability. We show how participants drew on six interpretive repertoires, organised as three binary pairs, to negotiate an ideological dilemma associated with stigma and the body. We argue that the participants drew on these repertoires to maintain a particular subject position, the 'good person' subject position, and performed what we call 'passing off' behaviour to manage their talk. We conclude that some aspects of learning disability remain 'unspeakable', and that this has consequences for the policies and practices which determine the support available to people with learning disabilities.

1. Introduction

This paper uses Potter and Wetherell's (1987) approach to discourse analysis to explore talk in 12 focus groups concerning participants' understandings and discursive constructions of learning disability. Learning disability is a term used in the UK 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' (DoH 2001 p.14). While the term is commonly used in UK policy documents, it exists in a semantic tangle of alternative terms, such as 'intellectual disability' or 'learning difficulty'. This tangle is complicated by the fact that everyday uses of all these terms can vary from the definition above (Cluley, 2018). An association of the term learning disability with stigma and shame (Thomas, 2020) has further problematized its use, as have common laymisunderstandings of normalisation theory which interpret the message as being that everyone is 'normal' and should be treated 'normally' (Wolfensberger, 1972). Consequently, talking about learning disability can be a difficult task within any social, political, or practical setting.

These semantic difficulties are grounded in the connection of the term to lived realities. 'Learning disability' is not only a descriptive evaluation but is also 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'. What learning disability means to different people and how it is used in their talk is of consequence to people with learning disability. As a label, learning disability may have positive benefits such as access to support, including social care services and welfare benefits, but it can also act to exclude, 'other' and limit social acceptance.

In the UK, where the study discussed here was conducted, the term learning disability has been in common and accepted use for over 20 years (Gates & Mafuba, 2016). It is a heterogeneous label that covers a continuum of ability including what are referred to as mild, moderate, severe and profound and multiple learning disabilities (Hardie & Tilly, 2012). It is worth noting that the UK is the only country to use the term 'learning disability' in this way (Emerson & Heslop, 2010). Other English-speaking nations such as the USA, Canada, Ireland and Australia use the term 'intellectual disability' to refer to the same phenomenon (Gates & Mafuba, 2016), and this latter term is also now used in global diagnostic manuals such as The Diagnostic and Statistical Manual of Mental Disorders (DSM) and the WHO International Classification of Diseases (ICD). Consequently, 'intellectual disability' is increasingly used within medical settings in the UK (Cluley, 2018).

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Outside of this medical context, learning disability continues to be used interchangeably with other terms, such as mental handicap, mental incapacity, cognitive impairment, learning difficulty, developmental delay, and in some instances is confused with mental ill health. A further complication is that the term 'learning difficulty' is identified as people with learning disabilities' own term of choice (Goodley, 2011). 'Learning difficulty', however, also has other, different connotations within the UK education system where it is used to describe conditions such as dyslexia and dyscalculia, which are not related to cognitive ability. As will be shown, this confusion was evident in the present study.

The fluctuating use of learning disability and its replacement terms cannot be separated from its complex semantic and social history. While academic and policy literature, from ancient Greece to present day, illustrates the presence of people with learning disabilities as a constant, terminology has been subject to frequent replacement (Scheerenberger, 1983, Rix, 2006). What is consistent, however, is the rapid translation of medical terminology into lay terms of abuse. Contemporary lay language reveals the pejorative use of a wide spectrum of medically redundant terms, such as idiot, moron, spastic, retard, and imbecile. Learning disability, therefore, is a term that has a long history of stigma attached to it. Given the universality of the stigma, it is important to note that while the argument made here addresses the use of the term learning disability in the UK it is expected that the findings are likely to be relevant to the use of alternative terms in other national contexts.

2. Discursive methods in learning disability research

There already exists a small body of research applying discursive methods within the field of disability studies and learning disability research. Much of this has focused on using conversation analysis to explore the interaction between people with learning disabilities and health and social care professionals. For example, Antaki et al. (2008 and 2009) use conversation analysis to identify practices to facilitate choice making in conversations between people with learning disabilities and care home support staff. Similarly, Finlay et al. (2008) use conversation analysis to explore how care home staff interpret non-verbal communication signals of residents. Two further papers (bib Antaki 2013 Antaki et al., 2009; Finlay & Antaki, 2011) explore interactions in conversations between care staff and people with learning disabilities in order to promote social care practices that are more responsive to needs.

Elsewhere, discursive approaches have been used to explore how people with learning disabilities make sense of their disability and talk about their identity. For example, Scior (2003) uses discourse analysis to identify how women with learning disabilities construct their identities in relation to gender and disability, while Rapley, Kiernan, and Antaki (1998) use discursive psychology to explore how people with mild and moderate learning disabilities make sense of the label 'intellectual disability'.

There has been less use of discursive methods to examine the use of 'learning disability' (or related terms) in conversations with peers. Danforth and Navarro (1998) use discourse analysis to explore how everyday talk can construct what they refer to as mental retardation as a specific identity. They conclude that speakers used mental retardation as part of their everyday vernacular without the intention of insulting individuals who have been categorised as mentally retarded, as in phrases such as: 'you are being retarded'. More recently, Patterson and Fyson (2016) used a discursive psychology approach similar to that used in this study to explore care workers perceptions of a televised exposé of the abuse of people with learning disabilities living in a UK care home. Using this approach Patterson and Fyson (2016) found that care workers positioned their response emotionally, particularly drawing on adjectives to denote shock in order to position themselves outside of behaviour they did not want to be associated with. No previous study has explored discursive constructions of learning disability from both lay and professional perspectives.

3. Methods

The data presented here were collected as part of a wider study, *What does learning disability mean in the real world? Re-evaluating perspectives on learning disability*, which explored how different stakeholders talk about and make sense of the term learning disability. The project involved both focus groups of people without learning disabilities and photovoice with people with learning disabilities (Cluley, 2017 and Cluley et al., 2021); the analysis presented here draws solely on focus group talk.

In total 12 focus groups were carried out, each with a cohort of participants from the same stakeholder group. In order to give a broad picture of how learning disability is understood in 'the real world', participants represented a range of lay and professional stakeholders within the field of learning disability in England. The sample comprised people with (i) direct personal or professional engagement with people learning disabilities and (ii) people who have the potential to influence public and professional opinion and/or policy (see Table 1 for more details).

Ethical approval from ___ was obtained for this project. All focus group participants provided informed consent and were advised they could withdraw consent at any time. All focus groups were audio recorded and transcribed in full prior to analysis.

4. Analysis

Potter and Wetherell's (1987) approach to discourse analysis was used to explore the focus group talk. Potter (1996) outlines two primary assumptions within discourse analysis: that discourse is a social practice; and that linguistic resources facilitate this social practice. Rather than simply reflecting reality, language, via the use of linguistic resources, is seen as having an active role in its construction. From this perspective, understandings of learning disability are manufactured and maintained by discourses that exist within society, that in turn affect the lived experience of people with learning disabilities. Potter and Wetherell's (1987) concept of interpretive repertoires was used to focus the analysis.

Interpretive repertoires are a linguistic resource used to construct meaning, defined as 'recurrently used systems of terms used for characterising and evaluating actions, events and other phenomena' that are 'constituted through a limited range of terms used in particular stylistic and grammatical constructions' and 'organised around specific metaphors and figures of speech' (Potter & Wetherell, 1987, p. 149). Others have likened interpretive repertoires to 'repositories of meaning: that is distinctive ways of talking about objects and events' (Edley, 2001 p.202).

As well as making sense of the everyday, interpretive repertoires also invoke identities and subject positions. As Tuominen et al. (2002 p.273) identify, 'different discourses enable different versions of selves and reality to be built'. Davies and Harré (1990) call this rhetorical identity work 'positioning'. Positioning can be both interactive, where one person positions another, and reflexive, where an individual positions themselves (Davies & Harré, 1990). As Edley and Wetherell (1999) found in their

Table 1
Focus groups ordered by profession.

	Profession	Number of participants
1	Social care professionals	5
2	Family carers	6
3	Healthcare professionals	4
4	Clinical Psychiatrists	4
5	Mainstream school teachers	3
6	Special School teachers	6
7	Student teachers	3
8	Student social workers	4
9	Student social workers	4
10	Local authority councillors	3
11	Social scientists	6
12	Student journalists	4

study of middle-class boys' accounts of their potential futures, the use of different interpretive repertoires allows participants to position themselves with contradictory identities. Identity, therefore, is constructed as an on-going process and language is a key site of identity construction (Edley & Wetherell, 1999). It follows that the linguistic resource of interpretive repertoires allows speakers to navigate the changing and contradictory landscape that is shared cultural and social knowledge.

In drawing on different repertoires at different times, according to context, speakers not only understand but also associate and disassociate themselves with particular identities (Davies & Harré, 1990). In doing this, speakers can also negotiate what Billig et al. (1998) call ideological dilemmas. Like interpretive repertoires, ideological dilemmas are reflective of shared social and cultural beliefs and the history that has produced them (Billig et al., 1998). Such shared beliefs contain contrary ways of understanding the world, since it is when two contradictory themes conflict that an ideological dilemma is created (Billig et al., 1998). Ideological dilemmas therefore create a situation in which 'people are pushed and pulled in opposing directions' (Billig et al., 1998, p. 163). It is this back-and-forth movement between contradictory repertoires that indicates the presence of an ideological dilemma (Edley, 2001).

Interpretative repertoires, used across the focus groups' talk, were identified by following the procedures outlined in Potter and Wetherell's (1987) flexible ten step guide to discourse analysis. These steps include 1. Research questions, 2. Sample selection, 3. Collection of documents, 4. Fieldwork, 5. Transcription, 6. Coding, 7. Analysis, 8. Validation, 9. Writing up, and 10. Application. Here we present our approach to coding (step six) and analysis (step seven). To begin, the first author organised the interview talk into broad codes using qualitative data analysis software (NVivo 12). Coding was an iterative process to identify specific topics discussed in similar and different ways. Analysis began with the first author re-reading codes and transcripts many times, searching for patterns across the talk, particularly instances where participants used similar patterns of words and phrases to make sense of what they were talking about, consistent with the characteristics of interpretive repertoires. Emergent patterns were discussed by all three authors. These patterns were related to the codes previously generated, resulting in the identification of three repertoire pairs that were used repeatedly. These were:

- I know what learning disability is/learning disability is a confusing term.
- I don't like labels/labels are useful.
- People with learning disabilities are different to me/people with learning disabilities are the same as me.

5. Findings

Talking about learning disability proved difficult for the participants across all focus groups, with sentences and descriptions commonly being abandoned, restarted or subsequently amended. Nevertheless, the three repertoire pairs, identified above, were found consistently throughout the participants' talk. As we discuss below, all three repertoire pairs were used to achieve the same two linked purposes – to construct a co-produced understanding of learning disability and to present a particular shared subject position – in order to overcome the ideological dilemmas associated with talking about a stigmatised group. We will go on to consider the discursive acts associated with these constructions, which we call 'passing off' and 'the good person subject position'. We will conclude by considering the implications of these discursive practices for the lives of people with learning disabilities and for policy and practice in the field.

5.1. I know what learning disability is/learning disability is a confusing term

The participants used the *I know what learning disability is* repertoire

both to demonstrate their knowledge and also to align themselves with what they perceived as the 'correct' way of seeing learning disability. Initially participants' definitions were rooted in the medical model of disability (whereby disability is seen as an individual, bodily deficit e. g. Swain et al. (2014)), and learning disability was located within individual bodies. Extracts taken from the focus groups with the Parent Carers and Student Journalists are presented below to illustrate this:

Parent Carer 3: Well it's [learning disability] about how your brain operates, how her brain operates, and how it has operated since birth.
Parent Carer 4: Can I just say something please? The thing with mentally handicapped, you knew that it was something to do with the brain.

Student Journalist 2: So I think obviously somewhere in the brain there is something that is kind of forgetting how to do everyday things and then that kind of really makes you think wow, something so simple as unzipping a bag is a struggle for someone every day.

In these presentations, learning disability 'is something to do with the brain' [Parent Carers] and it is located 'somewhere in the brain' [Student Journalists]. The participants refer to the learning disabled brain as an 'it'. It operates, it forgets how to do things, it works in problematic ways and it prevents people from doing things. In locating learning disability in individual brains/bodies, the participants position learning disability in terms of the medical model of disability whereby disability is an inherent condition of the body. However, the medical model of disability is now widely agreed to be a limited conceptualisation linked to paternalism and to discourses of personal tragedy (Swain et al., 2014). Therefore, in order to make the switch from 'medical model' discourse associated to a discourse associated with the social model of disability (whereby disability is considered a product of social and environmental barriers (Swain et al., 2014)), participants implicitly agreed upon a 'correct' way of seeing learning disability. To do this, the *learning disability is a confusing term* repertoire was frequently employed across all groups.

The Health Professionals' and the Student Teachers' talk, presented below, provides two examples of the use of the *Learning disability is a confusing term* repertoire when used as a consequence of their claim to know what learning disability is. Despite their rejection of the medical model of disability, the use of medicalised language and a reliance on its claimed objectivity, provides both groups with comfort and certainty; its absence has the opposite effect, making them feel uncomfortable and confused.

Health Professional 1: It's kind of broad

Health Professional 3: It's very broad erm in description and I feel uncomfortable using it on its own without an additional *diagnosis* or before a *diagnosis* has been given. It's where I get confused.

And later on.

Facilitator: So how do you feel about the term learning disability overall?

Health Professional 3: Well I think it can be confusing. I definitely don't feel comfortable using it unless it has been diagnosed already by someone else. But then erm like I said I don't know when a learning difficulty, because that's the term I would use if there isn't a diagnosis, then becomes a learning disability. So yea I'm a bit uncomfortable using it really, overall.

Here, it can be seen that the Health Professionals find certainty in medical diagnoses made by others. While the Health Professionals use the *I know what learning disability is* repertoire to identify that learning disability is 'very broad in description', they then switch to the *learning disability is a confusing term* repertoire, outlining their discomfort 'unless it has been diagnosed by someone else'. The Health Professionals do not

consider themselves to have this expertise, stating 'I don't know when a learning difficulty, because that is the term I would use if there isn't a diagnosis, becomes a learning disability'. Only when 'someone else' has made the diagnosis, do the Health Professionals feel safe to use the term learning disability.

This repertoire allows them to undo their certainty expressed in the *I know what learning disability is* repertoire. In this way, the *learning disability is a confusing term* repertoire acts as a disclaimer to the previous reliance on a medicalised perspective they do not wish to be straightforwardly associated with.

The tension this presents and the participants' oscillation between the two repertoires to manage this, is illustrative of an ideological dilemma (Billig et al., 1998) - to appear as though they know what they are talking about within the framework available to them, but also to align themselves with the 'acceptable' way of seeing learning disability that critiques the epistemological basis of their knowledge. Consequently, both repertoires function to allow the participants to manage and negotiate this dilemma.

5.2. *I don't like labels/labels are useful*

Similarly participants used the *labels are useful* repertoire with caution, almost always switching back to the *labels are damaging* repertoire as a caveat to their recognition of the practical use of the label learning disability. The term was generally constructed as a negative label with stigmatising and life changing consequences. Even when recognising the possible practical uses of labelling, for example in an educational context, the participants frequently made statements such as 'I would rather we didn't have to have a label really because they are human beings like all of us' [Special School Teaching Staff Member 3].

In contrast to this standpoint, all of the focus groups discussed the practical uses of labels and considered their use acceptable in certain contexts. Across the focus groups, the participants co-constructed learning disability as a practical category useful for both professionals when identifying people with particular needs and for the people so labelled in order to access services. Participants said things like 'you have to identify the groups you are working with' (Student Social Workers) and 'we need a uniform language' (Parent Carers). Here then, the participants moved rapidly back and forth between the repertoires, returning to the *labels are damaging* repertoire to disassociate themselves from the negative act of labelling despite its practical uses. This movement allows the participants to justify their use of labels. Hewitt and Stokes (1975) call this rhetorical work credentialing. Credentialing involves the provision of disclaimers to avoid 'an undesired typification' (Hewitt & Stokes, 1975, p. 4), and the need for this suggests the presence of tensions that will be addressed further in the discussion.

The participants expressed their unease with typification by drawing on the *labels are damaging* repertoire, using phrases such as 'people are people' [Social Scientists, Parent Carers, Special School Teachers], 'they are all human beings like the rest of us' [Special School Teachers], 'we all have stuff we can't do' [Social Care Providers] and 'we all have needs' [Student Social Workers with experience, Social Care Providers, Mainstream Teachers]. A further example of the repertoire is illustrated in the extract below, taken from the focus groups with Social Scientists.

Social Scientist 4: Maybe we acknowledge, maybe we are more comfortable, I certainly am, when someone else maybe with a learning disability, acknowledges themselves as different. I would never want to make that judgement or that decision but if someone else is comfortable then maybe that makes me feel more comfortable, like, yeah, it's just a rough area, you know certainly for me, I just wouldn't want to cross any lines or barriers or make anyone feel bad so you just kind of put yourself a bit back and just kind of don't make any judgement.

Social Scientist 1: Just wait for them to come up with it and kind of tell you.

Social Scientist 4: Yeah.

Social Scientist 1: Or I dunno, I kind of feel like before they make this acknowledgement 'ok I have a learning disability' or 'I don't' or 'I don't want you to recognise this' like, I feel like I am walking on egg shells, because I don't know, like I don't wanna, you know, show different treatment because for me people are people, regardless of you know whether they have a learning disability or not, whether they are like gay, from England, from Colombia you know I don't care about these things but you know it's kind of like, I dunno, before you know whether people are ok with, you know I think you need to get to know somebody first, you know I feel like I am walking on egg shells. I don't wanna come across as judgemental because I certainly wouldn't want anyone to do that to me.

Here, the Social Scientists are discussing how they feel about believing that some of their students have been labelled as having a learning disability.¹ They are speaking as both teaching professionals and as lay people; indeed, they switch between these identities in their talk to achieve certain aims. Social Scientist 4 talks for the group as a collective, by using the plural pronoun 'we' to refer to Social Scientists as a group, stating 'maybe we acknowledge, maybe we are more comfortable'. Social Scientist 1 reiterates this perspective by agreeing, stating 'wait for them to come up with it and kind of like tell you'. When using 'you', here, Social Scientist 1 is also referring to Social Scientists, as a whole. The Social Scientists are demonstrating their tacit knowledge that the label learning disability implies difference, which has an attached stigma. They imply through their talk that to associate the label learning disability with an individual student is to make a stigmatising moral judgement about that student. They further present this judgement and the stigma it holds as damaging to both the student and the professional. The student could be judged and the professional could 'come across as being judgemental' [Social Scientist 1].

The Social Scientists present learning disability as such a stigmatising label that they are only 'comfortable' using it once a student who has a learning disability identifies themselves. When Social Scientist 4 says, 'I would never want to make that judgement or decision' she not only recognises the dangers associated with labelling but is also constructing learning disability as a moral classification that she does not want to associate someone with unless the person themselves gives permission for this. Learning disability is constructed as something that has 'lines or barriers' that can be crossed, making the Social Scientists wary they could take a step in the wrong direction, causing them to feel 'uncomfortable', like they are 'walking on eggshells'. They do not want to upset their students and they do not want to appear to be associated with a judgemental subject position.

In order to disassociate themselves from the negative connotations that they implicitly associate with learning disability, the Social Scientists use the *labels are damaging* repertoire to assert their personal commitment to equality. When disassociating themselves from the stigma of learning disability, the Social Scientists switch to talking as lay people, asserting their own personal feelings about equality. First, Social Scientist 4 tells the group that she 'would not want to make anyone feel bad' by applying the label learning disability before a student claims this identity for themselves or before she gets to know them. Social Scientist 1 furthers this disassociation with the negative implications of labelling by telling the group that she does not want to treat anyone differently, that 'people are people' and that she doesn't 'care about' whether someone 'has a learning disability or not, whether they are like gay, from England, from Colombia'. She uses empathy to add further emphasis, saying that she 'wouldn't want anyone to do that [labelling] to me'.

The Social Scientists, therefore, use their professional and lay

¹ Notably, this demonstrates their misunderstanding of the term learning disability, which they are applying to university students with specific learning difficulties such as dyslexia.

identities to invoke different parts of the repertoire pair. They recognise that learning disability is part of their professional vocabulary and may have utility as a label in a professional context. At the same time, they are keen to disassociate themselves as individuals from the stigma that they attach to learning disability and the potential damage that they perceive labeling could cause.

As with the *I know what learning disability is/learning disability is a confusing term* repertoire pair, the participants experience a tension between their personal commitment to equality and their everyday language when using this repertoire pair. They want to show that they are cautious about the act of and consequences of labeling, but they are also individuals whose linguistic practices and professional knowledge uphold the system they disagree with. These contrasting aims that lead the participants into a similar ideological dilemma experienced in their use of the *I know what learning disability is/learning disability is a confusing term* repertoire pair. The participants ideally want to reject the act of labeling but cannot escape the need for categorisation and the dominant medical discourse this is premised upon. Both the *labels are damaging* and the *labels are useful* repertoires function to allow the participants to negotiate and manage this ideological dilemma in order to maintain their desired subject position.

5.3. *People with learning disabilities are different to me/people with learning disabilities are the same as me*

Across the focus groups, participants drew on the *people with learning disabilities are different to me* repertoire to discuss a range of external barriers responsible for creating difference in the lives of people with learning disabilities. These included: structural barriers such as the prevailing political economy; social barriers such as the presence/absence of family and support networks; and cultural barriers such as the widespread misunderstanding of the needs of people with learning disabilities. When talking about difference in this way the participants' talk is reflective of the argument made within the social model of disability, whereby disability is framed as a consequence of limiting barriers that are external to the individual (Swain et al., 2014).

The *people with learning disabilities are the same as me* repertoire often followed the participants' use of the *people with learning disabilities are different to me* repertoire, as in the example below.

Parent Carer 1: I think we come back to the same thing, that people are people

Parent Carer 7: well yes, I mean ____ [daughter] enjoys shopping, going to the football, she likes going to the cinema, she likes going out to the pub and going for meals and things like that, she enjoys social activities

Parent Carer 5: better life than me!

Collective: Laughter.

Here, the group is working to manage the acknowledgement of difference. This extract followed a long and candid discussion about the differences that people with learning disabilities experience, including living in a care home, living the life of a child, not being able to understand why things happen, needing regular support and attending day services. Parent Carer 7 had previously compared her life when she was 33 to her daughter's life as a current 33-year-old, stating, 'when I was 33 I had been to work, I was married I had 3 children, I had a house, all these things and they are all things that my daughter doesn't do. She lives at home. I mean my grandchildren now are three and five and really, in lots of ways you know her ability is only like theirs. She needs help to make decisions; she can't go out by herself'. Parent Carer 1 then moves to credentialise their talk about differences by reminding the group that although they can list differences, ultimately sameness prevails because, 'people are people'. Having been reminded of this, Parent Carer 7 begins to list all of the things that make her and her daughter the same. 'Social activities', including going 'shopping', 'to the football', 'to the cinema',

'to the pub' and 'out for meals' are all listed as things her daughter enjoys. Parent Carer 7 implies that these are all things that people without learning disabilities also enjoy when she says 'well yes, I mean ____ enjoys' and follows this up with the list of activities. In response to this Parent Carer 5 uses humour to demonstrate his agreement that people with learning disabilities are just like everyone else, going as far to suggest that people with learning disabilities are better off, by joking that Parent Carer 7's daughter has a 'better life than me!'

A similar exchange also occurred in the focus group with the Student Social Workers.

Facilitator: ok, so going back to what you were saying about a 'retracted' [sic] life for people with more profound learning disabilities

Student Social Worker 3: can it still be rich?

Student Social Worker 1: I struggle with that a lot. I don't know, with, with some people I have met with a learning disability I think 'your life is certainly rich, there is no shadow of a doubt' I worked with a girl that had got erm a part time job at the ice stadium and you know she had a good rich life but then having been to a centre for children with complex autism, and, and you know actually seeing pain on their faces, seeing struggle and I have to question, how, how, to what extent is that a rich life does the suffering, that the child is clearly experiencing, is it outweighed by ...

Student Social Worker 2: I think you can always make arrangements for their life so that at some points, it is as rich and it is the same sort of happiness, whether it's through sort of sensory means or you know day trips or something like that. You know at some point in their lives they could have that kind of like experience, even if it is not continuously rich throughout their whole life

Student Social Worker 1: well that's just life, life isn't rich all the time for any of us

Student Social Worker 2: no, no. I think they have sort of aspects of their life that are sort of as rich as other peoples, if not their whole life, at least sort of an aspect is you know?

In this presentation, Student Social Worker 1 offers a proposal that goes against the group's previous work of minimising difference, and Student Social Worker 2 reorients the discussion back to this theme. Where Student Social Worker 1 had previously adhered to the 'people with learning disability are just like me' repertoire, she subsequently admits to the group that she 'struggles' to apply this to people with complex learning disabilities and uses an example of when she has encountered this struggle. In detailing this example, Student Social Worker 2 interjects, stopping Student Social Worker 1 from going into further detail about the 'pain on their faces' and the 'struggle' and 'suffering' that she has witnessed. This is the only instance of the Student Social Workers talking in this way. That this instance is stopped so abruptly by Student Social Worker 2 is significant, as is the fact she reorients to the *people with learning disabilities are the same as me* repertoire. She uses the first person to tell the group that, 'I think you can always make arrangements for their lives', telling the group that such arrangements can bring 'the same sort of happiness' as experienced by people without learning disabilities. Following this interjection, Student Social Worker 1 reorients to the consensus of similarity, returning to the *people with learning disabilities are the same as me* repertoire by stating 'well that's just life, life isn't rich all the time for any of us'.

Across these examples, the participants are able to credentialise their talk of difference due to their presentation of learning disability in terms of normative ways of being. Across all of the focus groups' talk, people with severe or profound and multiple learning disabilities were largely not considered. In addition to this, when using the *people with learning disabilities are the same as me* repertoire, the similarities discussed were limited to likes and dislikes and social activities such as hobbies, enjoying going to the cinema, watching football and eating out. Issues such as relationships and sex, finances, having children, owning a house etc

while sometimes mentioned as differences, were later reframed as equalising and were ultimately ignored when presenting people with learning disabilities as the same as people without learning disabilities. In seeking to avoid the difficult task of avoiding talk about difference the participants once again encounter an ideological dilemma: their idealisation of the 'acceptable' way of seeing learning disability is challenged when the material reality of learning disability is present.

This section has shown how participants utilise the three linguistic repertoire pairs. It has also begun to outline how participants use these repertoires to associate with what they regard as an 'acceptable' way of seeing learning disability, associated with popular moral ideals of equality and fairness and the social model of disability. Despite using the term learning disability in their everyday language and practice, participants did not want to be seen to uphold any stigma associated with learning disability. They therefore work hard to craft their talk to achieve this. In doing so they encounter an ideological dilemma whereby their desired moral position is problematized by the reality of learning disability.

6. Discussion

Two discursive acts, found within the participants' use of the repertoire pairs, were relied on to manage the dilemmas arising from the challenges of talking about learning disability. We call these acts 'passing off' and 'the good person' subject position.

6.1. Passing off

The concept of 'passing off' draws on the work of Erving Goffman (1963) who explored how the stigmatised manage their label. He found that, in order to construct a front of normalcy, the stigmatised engage in 'passing' behaviour. We suggest that the participants' talk shows how those implicated in upholding stigma manage this role. Participants present their use of and recognition of the need for labels in terms of a regretful practicality that they feel the need to credentialise heavily. In other words, participants act to conceal the stigma they create by 'passing off' their behaviour as grounded in accepted moral ideals of equality and fairness. The participants' reliance on phrases such as 'people are people' and 'we all have needs' allows them to acknowledge people with learning disabilities as being people just like and equal to themselves despite the label that sets them apart as different. In this way, participants demonstrated a strong desire to be seen as, or to 'pass' for, people who reject stigma and who 'hate labels'. Their 'passing off' behaviour allows them to maintain their ideal in the face of the reality that labels are often necessary in practice and are typically based on perceived differences (Farrell, 2014). In this way, labels can be positioned as both necessary and meaningless. Cluley and Radnor (2021) makes sense of this tension by highlighting the need for public servants to use 'considered language' to navigate changing terms and social norms.

6.2. The good person subject position

At the same time, participants' talk was also organised so as to allow them to present as 'good people'; people who value equality and do not focus on difference (Cluley, 2018). People who, ultimately, see learning disability in the 'right' or 'acceptable' way. This acceptable way of seeing learning disability was co-produced across participants' interactions. The language used to do this mirrors the language of the social model of disability, whereby disability is seen as a consequence of social and environmental barriers. By contrast, participants' co-construction of the unacceptable way of seeing learning disability mirrors the medical model of disability, whereby disability is positioned as an individual, bodily deficit that can and should be managed clinically.

The participants made use of all three repertoire pairs to construct and reconstruct the 'good person' identity as necessary. Indeed, the participants performed both interactive and reflexive positioning work

(Davies & Harré, 1990) to align themselves with this subject position. They used caveats and disclaimers when addressing issues that might compromise this position (reflexive positioning) and if a group member risked compromising this shared identity they were quickly brought back into line by other group members (interactive positioning). The participants want to present as 'good people', but talk about the lives of people with learning disabilities necessitates talk about difference due to the support needs that people with learning disabilities have and that participants did not. However, talk about difference is something the participants were particularly keen to avoid. Acknowledging difference presents a fundamental challenge to the 'good person' identity.

We argue that the repertoire pairs and the ideological dilemma they are used to manage are products of learning disability's stigmatised social and cultural position. The discourse in this study suggests that there is a perceived 'right' and a 'wrong' way to see disability, grounded in the social model of disability. The social model repositions disability from an individualised medical/deficit approach to construct disability as a collective issue that is socially and environmentally produced (Swain et al., 2014). People with disabilities, including learning disability, are (in theory at least) less stigmatised than was historically the case and the social model position is now reflected rhetorically in academic and policy literature (Cluley et al., 2020). The medical model, closely linked with learning disability's more stigmatised past, is framed as an 'unacceptable' way of seeing learning disability. The participants draw on the repertoire pairs to demonstrate awareness of this social norm and to distance themselves from a medicalised way of seeing learning disability. In this way, the tensions between seeing learning disability as an individual deficit that creates individual differences and seeing learning disability as a social construction are played out as a theory/practice disjuncture that the participants attempt to negotiate by using passing off behaviour and positioning themselves as 'good people'.

However, this careful discursive positioning and used of 'considered language' (Cluley & Radnor, 2021) pays scant attention to the lived reality of learning disability, particularly for those with severe or profound and multiple learning disabilities. How people talk about people with learning disabilities is of consequence not only for the discursive construction of learning disability, but also for the ways in which these individuals will be treated within society. In discursively constructing people with learning disabilities as generally the same as those without learning disabilities, difference can be glossed over and the comfort of the 'good person' subject position is maintained.

7. Conclusion

Talking about difference, particularly cognitive difference, can be difficult and potentially exclusionary. This tension is seen throughout the focus group talk where the related desire of participants to present as 'good people' who do not see difference/impairment and to 'pass off' their use of labels dominated. This tension echoes similar tensions between the medical model and the social model of disability, where impairment is either accentuated (medical model) or neglected (social model). However, attempting to construct learning disability while discursively minimising difference or neglecting impairment has important social consequences. Such consequences can be seen in the widespread misinterpretation of normalisation theory. Normalisation theory was originally about making institutionalised services more closely reflective of the norms of the outside world (Wolfensberger, 1972; Nirje, 1980). The theory was later further developed as social role valorisation, following the move towards community services rather than institutionalisation: in this iteration, enhancement of the public image is seen as key to improving societal acceptance of people with learning disabilities (Wolfensberger, 1983). Over time, these theories have been absorbed into public consciousness as something quite different from the original. Normalisation in particular is often misinterpreted as being about ensuring people with learning disabilities are assimilated or accepted as 'normal'. While normalisation theory and social role

valorisation begin from positive attempts to address social disadvantage, the (mis)interpretation of both theories as being concerned with the 'normalisation' of individuals (rather than of institutions) is problematic: it leads first to minimising difference, then to a failure to acknowledge difference and finally to a denial of the real needs which may arise from such differences. This trend is illustrated in 'passing off' behaviour and the desire to be seen as 'good people' that we have highlighted in our participants talk.

To minimise or deny difference, as shown here and as has been discussed in policy analyses (Fyson & Kitson, 2007), runs the risk of undermining the rationale for specialist resources and services for people with learning disabilities. If the differences associated with learning disabilities cannot be discussed, and labels are problematic, this raises fundamental questions about how services can be effectively developed and targeted and how people with learning disabilities can be effectively supported. Discursive devices alone cannot address this. It is relevant to refer back to the family carers' talk here, where the term 'handicap' was perceived on the basis of their lived experience to be more effective than current terminology because it inferred a difference that was universally understood.

Moving forward, it is important for those working in health policy and practice to acknowledge the tensions we have highlighted here, including the over-riding discomfort that is associated with talk about difference, and to recognise that this can be detrimental and damaging to both the lived experience of people with learning disabilities and to the provision of services to support and facilitate their inclusion.

Talking about learning disability – ethical statement

Ethical approval from University of Nottingham was obtained for this project. All focus group participants provided informed consent and were advised they could withdraw consent at any time.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

References

- Antaki, C. (2013). Two conversational practices for encouraging adults with intellectual disabilities to reflect on their activities. *Journal of Intellectual Disability Research*, 57(6), 580–588.
- Antaki, C., Finlay, W., & Walton, C. (2009). Choices for people with intellectual disabilities: Official discourse and everyday practice. *Journal of Policy and Practice in Intellectual Disabilities*, 6(4), 260–266.
- Antaki, C., Finlay, W., Walton, C., & Pate, L. (2008). Offering choices to people with intellectual disabilities: An interactional study. *Journal of Intellectual Disability Research*, 52(12), 1165–1175.
- Billig, M., Condor, S., Edwards, D., Gane, M., Middleton, D., Radley, A., et al. (1998). *Ideological dilemmas: A social psychology of everyday thinking*. London: Sage.
- Cluley, V. (2017). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *British Journal of Learning Disabilities*, 45(1), 39–46.
- Cluley, V. (2018). From "Learning disability to intellectual disability"—perceptions of the increasing use of the term "intellectual disability" in learning disability policy, research and practice. *British Journal of Learning Disabilities*, 46(1), 24–32.
- Cluley, V., Fyson, R., & Pilnick, A. (2020). Theorising disability: A practical and representative ontology of learning disability. *Disability & Society*, 35(2), 235–257.
- Cluley, V., Pilnick, A., & Fyson, R. (2021). Improving the inclusivity and credibility of visual research: Interpretive engagement as a route to including the voices of people with learning disabilities in analysis. *Visual Studies*, 36(4–5), 524–536.
- Cluley, V., & Radnor, Z. (2021). *Considered language" in public service: Changing discourses and their implementation in practice* (pp. 259–276). The Palgrave Handbook of the Public Servant.
- Danforth, S., & Navarro, V. (1998). Speech acts: Sampling the social construction of mental retardation in everyday life. *Mental Retardation*, 36(1), 31–43.
- Davies, B., & Harré, R. (1990). Positioning: The discursive production of selves. *Journal for the Theory of Social Behaviour*, 20(1), 43–63.
- Department of Health. (2001). *Valuing people: A new Strategy for learning Disability for the 21st century*. London: HMSO.
- Edley, N. (2001). Analysing Masculinity: interpretive repertoires, ideological dilemmas and subject positions. *Discourse as data* (pp. 189–228). Milton Keynes: open University Press.
- Edley, N., & Wetherell, M. (1999). Imagined futures: Young men's talk about fatherhood and domestic life. *British Journal of Social Psychology*, 38, 181–194.
- Emerson, E., & Heslop, P. (2010). *Learning disabilities: A working definition*. (online) Department of Health. Available at <http://www.bris.ac.uk/media-library/sites/ci/pold/migrated/documents/learning-disability-criteria.pdf>. (Accessed 9 April 2021).
- Farrell, M. (2014). Labelling: New labels for old? *Investigating the language of special education* (pp. 58–74). London: Palgrave Macmillan.
- Finlay, W. M. L., & Antaki, C. (2011). How staff pursue questions to adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 56(4).
- Finlay, W. M., Antaki, C., Walton, C., & Stribling, P. (2008). The dilemma for staff in 'playing a game' with a person with profound intellectual disabilities: Empowerment, inclusion and competence in interactional practice. *Sociology of Health & Illness*, 30(4), 531–549.
- Fyson, R., & Kitson, D. (2007). Independence or Protection - does it have to be a choice?: Reflections on the abuse people with learning disabilities in Cornwall. *Critical Social Policy*, 27(3), 426–436.
- Gates, B., & Mafuba, K. (2016). Use of the term 'learning disabilities' in the United Kingdom: Issues for international researchers and practitioners. *Learning Disabilities: A Contemporary Journal*, 14(1), 9–23.
- Goffman, I. (1963). *Stigma; Notes on the management of spoiled identity*. New Jersey: Englewood Cliffs.
- Goodley, D. (2011). *Self-advocacy in the lives of people with learning disabilities*. Maidenhead: Open University Press.
- Hardie, E., & Tilly, L. (2012). *An introduction to supporting people with a learning disability*. London: Sage.
- Hewitt, J. P., & Stokes, R. (1975). Disclaimers. *American Sociological Review*, 40(1), 1–11.
- Nirje, B. (1980). The normalization principle. In R. Flynn, & K. E. Nitsch (Eds.), *Normalization, social integration and community services*. Baltimore: University Park Press.
- Patterson, A., & Fyson, R. (2016). I was just gobsmacked": Care workers' responses to BBC Panorama's 'Undercover Care: The Abuse Exposed'; invoking mental states as a means of distancing from abusive practices. *Discourse & Society*, 27(6), 607–623.
- Potter, J. (1996). *Representing reality: Discourse, rhetoric and social construction*. London: Sage.
- Potter, J., & Wetherell, M. (1987). *Discourse and social psychology: Beyond attitudes and behaviour*. London: Sage.
- Rapley, M., Kiernan, P., & Antaki, C. (1998). Invisible to themselves or negotiating identity? The interactional management of 'being intellectually disabled. *Disability & Society*, 13(5), 807–827.
- Rix, B. (2006). *All about us!*. London: MENCAP.
- Scheerenberger, R. C. (1983). *A history of mental retardation*. Baltimore: Paul H. Brookes Publishing.
- Scior, K. (2003). Using discourse analysis to study the experiences of people with learning disabilities. *Disability & Society*, 18(6), 779–795.
- Swain, J., French, S., Barnes, C., & Thomas, C. (Eds.). (2014). *Disabling barriers-enabling environments* (3rd ed.). London: Sage.
- Thomas, G. M. (2020). Dis-mantling stigma: Parenting disabled children in an age of 'Neoliberal-Ableism. *The Sociological Review*, 69(2), 451–467.
- Tuominen, K., Talja, S., & Savolainen, R. (2002). Discourse, cognition and reality: Towards a social constructionist metatheory for library and information science. In H. Bruce, et al. (Eds.), *Emerging Frameworks and methods: Proceedings of the fourth international conference on conceptions of library and information science*. Colorado: Greenwood Publishing Group.
- Wendell, S. (1996). *The rejected body*. New York: Routledge.
- Wolfensberger, W. (1972). *The principle of normalization in human services*. Toronto: National Institute on Mental Retardation.
- Wolfensberger, W. (1983). Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation*, 21(6), 234–239.