

# Ambivalence about disability: Why people with mild learning difficulties who are looking for employment may not identify as disabled

Ruth Tarlo, Rachel Fyson & Simon Roberts

To cite this article: Ruth Tarlo, Rachel Fyson & Simon Roberts (2022): Ambivalence about disability: Why people with mild learning difficulties who are looking for employment may not identify as disabled, *Disability & Society*, DOI: [10.1080/09687599.2022.2073199](https://doi.org/10.1080/09687599.2022.2073199)

To link to this article: <https://doi.org/10.1080/09687599.2022.2073199>



© 2022 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 25 May 2022.



Submit your article to this journal [↗](#)



View related articles [↗](#)



View Crossmark data [↗](#)

## Ambivalence about disability: Why people with mild learning difficulties who are looking for employment may not identify as disabled

Ruth Tarlo<sup>a</sup> , Rachel Fyson<sup>a</sup>  and Simon Roberts<sup>a</sup> 

<sup>a</sup>School of Sociology & Social Policy, University of Nottingham, Nottingham, UK

### ABSTRACT

UK government policies over several decades have sought to actively encourage disabled people to take up paid employment, most recently by focusing on the 'gap' between employment rates of disabled and non-disabled people. These policies implicitly assume a clear distinction between people who are and are not disabled, linked to medically-oriented, hierarchical notions of deservingness. They also assume that people who need support will self-identify. This article explores factors that undermine those assumptions or expose their contradictory effects. It presents findings from qualitative research with people with mild learning difficulties, discussing their perceptions of disability and how they negotiated an ever-shifting balance of consequences of identifying as disabled or disclosing needs, linked to risks and experiences of prejudice, discrimination and exclusion.

### ARTICLE HISTORY

Received 26 June 2021  
Accepted 28 April 2022

### KEYWORDS

learning difficulties;  
disability; identity; paid  
work; social security;  
disability benefits

### Points of interest

- Government policy to support disabled people into paid work suggests that it is obvious who is and who is not disabled.
- This research looks at what disability means for people with mild learning difficulties who are looking for paid work.
- People with mild learning difficulties sometimes view themselves as disabled but sometimes refuse that label, even when they accept that they need support.
- The research participants gave a wide range of reasons for accepting or rejecting the label of disability.
- They showed how they balanced hopes for support against fears of rejection or abuse, based on their personal experiences.

**CONTACT** Ruth Tarlo  [ruth.tarlo@icloud.com](mailto:ruth.tarlo@icloud.com)

© 2022 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group  
This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

## Introduction

UK governments have long sought to actively encourage disabled people to take up paid employment and have introduced a range of both supportive and coercive measures to promote this (Powell 2020; Gulland 2019; Grover and Piggott 2015). The effectiveness of these measures is addressed in current government policy with reference to the 'disability employment gap' (DEG). This is a measure of the difference between the employment rate of disabled people and non-disabled people. The DEG is measured using the Government Statistical Service Harmonised Standard measure of disability, consistent with the 2010 Equality Act, and defined as: people who have a physical or mental health condition or illness lasting or expected to last 12 months or more that reduces their ability to carry-out day-to-day activities. Under that measure, there were 7.9 million working-age people with a disability in the 3<sup>rd</sup> quarter of 2019, which is 19% of the working age population (Powell 2020). At that time, the rate of unemployment in the UK was 3.7% and the unemployment rate of people with a disability was 6.7% (Powell 2020).

There is an implicit assumption within these policies that not only can a clear distinction be made between people who are and are not disabled, but that people who are disabled will necessarily self-identify as such in order to access employment-related benefits and on-the-job support. However, labels relating to identity, disability and impairment have not only economic and political, but also social and cultural consequences for the individual and for social groups. Labels may confer eligibility for rights, services and resources, but may also exclude or marginalise. Labels may signify belonging and pride or rejection and stigmatisation. Moreover, it is acknowledged that the label of 'disability' is often socially laden with negative connotations, reflecting "dominant discourses of tragedy and inferiority" (Swain, French, and Cameron 2003:15). It is therefore likely that some people may reject that label even in situations where it may confer rights.

There is little doubt that people with learning disabilities and difficulties need support to gain and retain paid employment. Official statistics are lacking on employment rates for "the whole population of working age adults with learning disabilities" (Hatton 2018). However, large-scale surveys suggest that only 15-20% of this group are in some form of paid employment (Hatton 2018) and that people with learning difficulties are likely to experience "non-standard employment conditions and job insecurity" (Emerson et al. 2018:201); they are also more likely than their peers to transition from non-standard employment to economic inactivity (ibid:202). If Government support is to be meaningful, the issue of whether and how people with mild learning difficulties identify as disabled is important. The acceptance or rejection of the label of 'disability' may have a material impact on the employment support available to people with mild learning

difficulties, but these are not the only considerations. For example, when linked to employment, the label disability can facilitate 'reasonable adjustments' under the Equality Act 2010 but may also be associated with bullying and harassment from co-workers (Fevre et al. 2012).

In that context, this article explores connections between the ways in which people with mild learning difficulties consider themselves to be disabled and their experiences at work or while looking for work. It draws on research carried out with a group of people who self-identified as having mild learning difficulties, were not receiving adult social care and were looking for work. The study explored how participants talked about disability, revealing a wide range of views. This article discusses how individual experiences of being in paid employment and of engaging with processes of looking for work might explain that diversity of views about self-identifying as disabled. By connecting such experiences to identity, the discussion exposes wider negative implications of binary and essentialist thinking about who is or is not disabled.

It is acknowledged that a raft of cultural, social, economic and political factors, from media depictions to education and healthcare provision to democratic representation, produce and reinforce the "abuse, rejection and marginalisation of disabled people" (Goodley 2017:97). Within that broader framework, this article focuses on the relationship between employment, employability and related circumstances such as claiming out of work benefits, and the self-identification of people with mild learning difficulties as disabled.

### **Complexities in the definition and use of the term 'learning difficulties'**

The term 'learning difficulties' is used here to encompass a spectrum of conditions relating to global cognitive impairments which start before adulthood and have a lasting effect. In educational settings they may be variously labelled as, amongst other things, 'non-specific learning difficulties', 'processing delays', 'communication difficulties', 'memory problems' or 'special needs'. The word 'difficulties' has been used in preference to 'disabilities' to open up discussion about the relationship between learning difficulties and disability itself. However, 'learning disabilities' is the more commonly-used term in UK public policy and third sector organisations in relation to health and social care.

The term 'learning disabilities' was defined in the 2001 White Paper, *Valuing People*, as including "the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;

- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development” (DoH (Department of Health), 2001:14).

The term ‘learning difficulties’ may also sometimes be found within UK government documents, in place of ‘learning disabilities’, but is more commonly used in third sector and educational settings (Cluley, Fyson, and Pilnick 2020). Claims that it is the preferred term of “the majority of people who live with these labels” (Willettts 2011:99) are harder to verify, but are consistent with usage by some self-advocacy organisations (Goodley 2001; People First (undated)).

Traditionally, the medical identification of learning difficulties has been associated with measures of IQ (Fulton and Richardson 2014; Porter and Lacey 2005). Flaws in the concept and testing of IQ have been widely documented (Webb 2014) including errors in the design and administration of testing and a lack of evidence linking IQ scores to “autonomous functioning” (Webb 2014:12). Nevertheless, these IQ-related qualifiers remain in widespread use as signifiers of the degree of impairment experienced (mild, moderate, profound) and the level of support a person may be entitled to. It is important to acknowledge the weakness of the testing and diagnostic basis of statistics relating to the categorisation of people by intellectual competence (Jenkins 2014) and to note how IQ-related cut-off points for categorising people have been altered historically to reduce eligibility for services (Simons 2000). In contrast, the political work of disability activists, including people with learning difficulties, has shown how ‘competence’ can be identified as a social rather than individual phenomenon (Bates, Goodley, and Runswick-Cole 2017).

Almost all research studies involving adults with learning difficulties (Emerson and Hatton 2014) are based on administrative data for people who are known to be using specialised services. However, a much larger section of the population may have been identified as having special educational needs at the end of compulsory schooling. In transitioning to adulthood, people with less severe conditions are unlikely to use specialist social care services, becoming part of a “hidden majority” (Emerson and Glover 2012:141) of people with mild learning difficulties who either choose not to use social care services or, more likely, do not meet the strict eligibility criteria (Emerson and Hatton 2014; Emerson and Glover 2012). In this sense, people with mild learning disabilities may lose the administrative label of ‘disability’ as they enter adulthood.

The history of terms such as ‘learning difficulty’ and ‘learning disability’ illustrates how this categorisation is socially constructed (Simons 2000). However, the concept of learning difficulties can be useful, despite being highly complex, and does have meaning relating both to the consequences of intellectual impairments themselves and to the responses of others. It

may be illuminated further by considering how disability is understood more broadly, and how cognitive impairments might be similar to and different from other types of impairment. However, any attempt at precise definition of 'mild learning difficulty' would be misleading, since this and related terms and labels result from "a social, cultural and political moment" (Goodley 2017) and usage changes over time.

## Research design and methodology

Sixteen participants with mild learning difficulties were recruited, both through direct recruitment (posters in public libraries) and via interactions with gatekeeper organisations such as employability support organisations and social support groups. The research accepted people as having mild learning difficulties if they self-identified as such. Participants were only included if they were not eligible for adult social care services. A summary of the demographic characteristics of each participant is shown in Table 1.

Data collection consisted of individual, audio-recorded, semi-structured interviews with each participant, as well as observations of key activities (e.g. attending Jobcentre Plus appointments), in a process which positioned participants as authorities on their own experiences (Clarke et al. 2005; Booth and Booth 1996). Fifteen of the 16 participants were interviewed more than once, and 14 were interviewed three times. All interviews and observations

**Table 1.** Research participants.

Name	Age	Sex	Ethnicity	Disability or health-related benefits? (see note)	Ever in paid work?	In paid work during the fieldwork period?
Anthony <sup>^</sup>	26-30	M	White British	PIP	Yes	No
Emily*	18-25	F	White British	none	Yes	No
Jack*	26-30	M	White British	DLA	No	No
Jeff	56-60	M	White British	none	Yes	Yes, contract starting
Kevon	18-24	M	White-Black Caribbean British	none	No	No
Lillian	36-40	F	White British	ESA	Yes	Yes, contract ending
Louise <sup>^</sup>	26-30	F	White British	PIP	Yes	No
Nick	26-30	M	White British	WTC	Yes	Yes
Peter	26-30	M	White British	none	No	No
Phil	36-40	M	White British	ESA	No	No
Ravina	41-45	F	Sikh British Asian	none	Yes	Yes, looking for alternative
Robbie	18-24	M	White British	ESA, DLA	Yes	No
Ryan	26-30	M	White British	none	Yes	No
Sam	18-24	M	White British	none	Yes	No
Sergei	18-24	M	White British	DLA	No	No
Tyler	18-24	M	White British	none	Yes	No

Note: Personal Independence Payment (PIP) and Disability Living Allowance (DLA) are non-means tested benefits not affected by employment status; Employment & Support Allowance (ESA) is a means tested benefit for people who are assessed as having limited capability for work. The number of hours worked threshold for Working Tax Credit (WTC) is lower for people assessed as disabled.

<sup>^</sup>Anthony and Louise were a couple; they lived together but were interviewed separately.

<sup>^^</sup>Emily and Jack were a couple who both still lived with their respective parents; they were each interviewed separately.

were carried out in person by the lead author, as part of her PhD (Tarlo 2020). Data coding and analysis was carried out by the researcher under the supervision of two experienced academics who are co-authors of this paper.

Interviews were transcribed in full and data was then coded and analysed using thematic analysis (Braun and Clarke 2006) to explore the research question: how do people with mild learning difficulties relate to concepts of disability and how does that affect their sense of rights and entitlements? This provided a way of exploring the tensions and contradictions in the ways that participants spoke about disability, drawing on all of the interview data and not necessarily confined to the discussions of employment and unemployment.

The research received ethical approval from the University of Nottingham School of Sociology and Social Policy Ethics Committee. Participants' names were anonymised in transcripts and in the analysis, with participants offered the option of choosing their own pseudonym in recognition that "acts of naming are political and personal" (Allen and Wiles 2016:163).

## Findings

The participants used the term disabled and disabilities in a variety of ways, in reference to both themselves and to other people. Their perspectives on disability were explored not only through direct but abstract questioning (e.g. "what does it mean to be disabled?") but also through analysing the way they talked about themselves and others who they referred to as disabled. Only five of the 16 participants identified themselves as disabled without any caveats. Ten of the participants were ambivalent about identifying themselves as disabled and one participant rejected the identification out of hand.

Three overarching themes were identified and analysed from the data: (1) Am I disabled? (2) The impacts of my mild learning difficulties; and (3) What difference does it make? Within the first theme there were two sub-themes: what does disabled mean; I'm somewhere in-between. Four sub-themes were identified within the second theme: stress and anxiety; literacy, focus and memory; social interaction; slowness. The third theme covered three sub-themes: telling employers; comparing myself to siblings and peers; rights.

Each of the overarching themes will be discussed in turn, to explore the way participants talked about their own conditions, about disability, and about whether or not they self-identified as disabled.

### *Am I disabled?*

All participants had a strong sense of what they frequently referred to as "struggles" with a range of embodied conditions which affected not only

their interactions with others but also dealing with their daily lives: eating patterns, sleep patterns, managing their own physical and mental health, but this did not necessarily translate into an association with the term 'disabled'. The five who strongly identified as disabled expressed this as a sense of being different from other people:

Disabled ... means having a mental or physical... impairment... something that separates you from other people [Sam]

These five were also more likely (as will be discussed later) to refer to disability as a legal status, to refer to concepts of rights and discrimination or administrative labelling and the receipt of disability benefits.

However, most of the participants, like much of the population at large, considered being 'disabled' to be "a physical thing" [Ravina], especially relating to mobility, and therefore not something with which they identified:

I automatically think "wheelchair", because that's just the symbol it gives, but I'm not in a metal contraption [Jack]

I'm not exactly disabled...I can walk around everywhere [Ryan]

Moreover, although all participants associated themselves with the label 'mild learning difficulty', many expressed a sense that the label 'disability' was associated with a greater intensity or severity of impairments, using phrases such as "how severe it is" [Lillian] or "a lot worse than myself" [Jack]:

real autism... unable to look after themselves... not people like me [Tyler]

These responses could be interpreted as attempts to distance from a stigmatised label, but this is not the only possible interpretation. Monteleone and Forrester-Jones (2017:313) suggest "poor comprehension of disability terminology" and "self-degradation stemming from negative judgements of others" combine to block "healthy" identification with disability. However, it is also possible that participants did not perceive the "taken-for-grantedness of the stigma attached to 'being intellectually disabled'" (Rapley 2004:111). The tone of the responses and the language used by many of the participants was more suggestive of an empathetic response towards people that they perceived as 'really disabled' and a sense that they did not deserve either the label or the level of support that they would expect disabled people to receive.

Doubts about deservingness were compounded by experiences of welfare benefit re-assessments which resulted in the loss of disability-related benefits. This reluctance to identify themselves as 'really disabled' is also consistent with media and political narratives of 'fake' disability (see for example, Ryan 2019; Elgot and Osborne 2017) and these were occasionally reflected in comments which contradicted participants' own experiences of difficulty in claiming disability benefits:



It's really not hard to say to someone: "oh I got a disability", act like an absolute lunatic and then get money for it [Tyler]

In Tyler's case, his guardian had been in receipt of DLA while he was a child, but the benefit had been stopped after an assessment when he turned 18. Several other participants had either had disability-related benefits stopped, following re-assessment, or were concerned that this might happen in the near future.

All but one of those who said 'yes' to being disabled were in receipt of non-means tested disability benefits (DLA or PIP) or had recently been in receipt of them and were in the process of re-applying. All had received support from employability support services who specialise in supporting people with disabilities. Their acceptance of the disability label was either explicitly stated:

Researcher: And would you consider yourself to be disabled?

Well I get, if I get DLA then, yeah [Phil]

or implied:

I am legally considered disabled [Sergei]

However, it was not always the case that those who had been awarded disability benefits self-identified as disabled. Both Anthony and Louise were in receipt of PIP and ESA but appeared to view these as more closely associated with Louise's ill-health than with both participants' mild learning difficulties; Jack and Lillian were also receiving ESA and Lillian had been awarded a disabled person's bus pass; Nick had been in receipt of Working Tax Credit, qualifying for the disabled worker element. But all expressed some ambivalence about identifying as disabled:

You have severe learning disabilities [Louise to Anthony]

Whatever you want to call it.... I wouldn't class myself as disabled [Anthony]

If I need to use it, I'll use it, but if I don't, I'll discard it [Jack, in response to being asked if he would say he was disabled]

I suppose disabled is quite a, I don't know. I have a disability, but to be disabled, I'm not sure, I'm, I'm, I'm unsure where I fit [Lillian]

For these participants the idea of being labelled as disabled conflicted with their strong sense of the term as referring either to physical and sensory impairments or to people with more severe cognitive impairments. They were not at all ambivalent about the barriers that they faced in their search for paid work or about the impact of their mild learning difficulties on daily life, but these factors did not result in self-identification as disabled.

Only one participant, Jeff, never used either 'disabled' or 'disability' with reference to himself. This may be connected to Jeff's age, as the oldest person in the sample, as well as his long work history and experience of living independently. As another participant commented, referring to an older family friend with learning difficulties, he was:

just labelled as a being a bit thick...he's not thick by any stretch of the imagination, but that was what people often got billed as in days gone by [Peter]

Although Jeff had attended a special school as a child and had only lived independently from his parents since his mother moved to a care home, he was not aware of having ever been in receipt of disability benefits and had a long history of paid work, albeit very part-time and low paid. He associated disability with a sense of "if a person can't do it", and his rejection of the association for himself, suggested a strong connection between his identity and his experience in the labour market, particularly in maintaining long-term paid work contracts. Despite recognising that he "can't read properly" and that he struggled to "understand things", Jeff did not think of himself as disabled because he was able to do what he wanted to do, which was primarily to find and keep paid work.

### ***My mild learning difficulties***

Although the majority of participants expressed at least some ambivalence about the label 'disability', they all accepted the label 'mild learning difficulties'. In this context, they were prompted to discuss these difficulties. Typically, exploration of this topic would begin with an open question such as "tell me about your learning difficulties", with follow-up questions to probe the response where it was very broad, for example "I have trouble with a lot of things" [Jack].

Most participants talked in negative terms when asked how they felt about having mild learning difficulties. Some made deeply negative remarks such as:

It sucks, I hate it, cos I wish I was like, you know, normal, instead of being counted as a weirdo. [Jack]

my autism's a curse [Nick]

Negative comments were largely about how participants felt towards themselves, rather than about how their conditions might impact on other people. These were epitomised by words and phrases such as "something wrong", "limitations", "liability", "setback" and "what I may have lost".

This kind of talk was not universal, however. Six of the participants consistently used more neutral language when talking about having mild learning difficulties, some referring to being different, but others denying

difference. For example, Anthony indicated an acceptance and even some sense of pride about his mild learning difficulties:

I'm fine with it...it's who I am, it's me ... I can't change who I am [Anthony]

Kevon also commented "it just makes me who I am", but later added:

It don't make me different to, being to do what I need to do [Kevon]

Other participants indicated a more guarded assessment, as shown here by use of the word 'shouldn't':

it doesn't really bother me ... as long as you can get on with your daily life, ... what you need to do, it shouldn't really... affect people [Phil]

These comments could be interpreted as downplaying the significance of mild learning difficulties in the participants' lives, indicating resistance to a disabled identity and a refusal to be "categorised on the basis of bodily difference" (Watson 2002:525). The comments might also reflect the greater significance of other aspects of their social identity, such as age or social class, which were not directly discussed. These participants were regularly participating in social groups of people (with and without mild learning difficulties) looking for paid work, such as job clubs and youth groups, where they might meet people without mild learning difficulties who were experiencing similar barriers to finding work.

These sometimes-negative attitudes towards having a mild learning difficulty could be linked to the perceived impact it had on participants' daily lives and – in the context of this research – their search for work. Participants highlighted stress and anxiety; concentration, memory and understanding; social interaction; and slowness as experiences and/or personal attributes which they associated with their mild learning difficulty. It is not the intention here to suggest that participants are defined by or reduced to impairments or functional limitations. However, by focusing on the way participants talked about each of these areas, there is an intention to respect and attend to the significant and serious impact that having mild learning difficulties can have on individuals' everyday lives, as well as on their notions of disability, and to recognise that this impact is not well known.

Most participants (13 out of 16) referred to experiencing some form of stress or anxiety as part of their mild learning difficulties. This included high levels of anxiety experienced in childhood as well as into adulthood, often worsened by dealing with uncertainty, "changes in schedules" [Peter], or newness, and manifesting as fear or in some, "panic attacks" [Lillian]. Stress and anxiety were also exacerbated by a sense of frustration or dejection about their own limitations:

if I can't do what anything I want to do [Emily]

the amount of pressure that was building up...I would freak out [Lillian]

not knowing where I'm supposed to be going or...what I'm supposed to be doing, that freaks me out summat fierce, like damn near a phobia [Robbie]

Robbie's use of the phrase "supposed to" draws attention to a sense that there are things he should be doing, that he may have not registered or forgotten. He talked about how it fails to "click in my head" that certain things are important. Other participants frequently described anxiety in relation to this sense of missing out on something, or fearing that they had missed something, whether it was a work task, a Jobcentre Plus appointment, or catching a bus, or related to a social interaction such as missing the meaning of an instruction or a joke.

Robbie described how his anxiety manifested itself in a "flare up" of psoriasis that would regularly disrupt his sleep. Participants also used phrases such as "nervous breakdown", "mental breakdown", "meltdown" and "brain freeze". These are metaphors of crisis and destruction, emphasising the negative impact of anxiety.

Those who talked about anxiety indicated that they felt they over-reacted to worrisome situations:

when I get panicky, I get really, really panicky [Jack]

I care so much, I don't do anything [Sergei]

These responses signalled awareness that the levels of stress and anxiety that they experienced were unusually high. Participants spoke of it not being "normal" to experience such levels of stress and anxiety. There was also a sense that they compared themselves unfavourably with other people, in how they were able to deal with the stress and anxiety:

...my inability...not being able to handle stress [Lillian].

Five participants also directly referred to episodes of depression, which fits with research suggesting a higher risk of mental health problems among "adults with mild intellectual disabilities" (Emerson and Hatton 2014:59). Nick talked openly about this, using words and phrases such as, "suffer from depression", "mood swings", "obsessions", "suicidal". Other participants also indicated periods where their mental health had deteriorated significantly, most often linking it to a lack of progress in finding paid work, but also to family troubles such as illness and bereavement.

Many of the experiences the participants talked about had exacerbated feelings of stress and anxiety. These included bullying at school and college, assessments for disability-related welfare benefits, and repeated and long-term lack of success in applying for paid work. However, there were also strong indications that their higher than average stress and anxiety levels were

deeply-rooted, arising in childhood as well as manifesting during adulthood, rather than being purely a product of adult life experience. This is consistent with population-based studies (Emerson and Hatton 2014).

It is important to acknowledge the depth of this anxiety, in order to understand that participants did not only experience it in the labour market, whether as actual or potential employees. Anxiety was not only the effect of interpersonal interactions, working conditions or benefit conditionality, but was a pre-existing factor influencing those interactions and experiences. For example, Sergei's experience of a work placement in which he felt well supported, where he enjoyed the work and found the co-workers friendly and welcoming, nevertheless ended in what he described as "emotional breakdown".

Stress and anxiety manifested in many ways and were often associated with other difficulties. When asked about their mild learning difficulties 11 participants noted difficulties with reading, writing and spelling, although comments about literacy were often qualified:

...struggle reading difficult words [Jack]

I can't read properly [Jeff]

I can't read things really high up [Phil]

The addition of the words "difficult" and "properly" and "really high up", may have been intended to signal competence at a basic or functional level, reinforcing a sense of the stigma of being unable to read. It was apparent from the kinds of work that the participants were pursuing, the ways they were looking for work, or what they were doing outside of work, that all participants were able to read and write at some level. However, many had received additional support in school to help with reading and writing, which would have reinforced the sense of a connection between the label mild learning difficulties and their literacy skills.

The references to literacy skills could also be seen as an attempt by participants to distance themselves from stigmatised ideas about learning difficulties and disabilities, and the label of disability, making a connection to a much broader section of the population since difficulties with reading and spelling 'difficult' words may be something shared with (non-disabled) family and friends (Rapley, Kiernan, and Antaki 1998). This may be reinforced by family and support workers aware of the stigma associated with mild learning difficulties. The risk is that it not only underplays the extent to which participants struggled with literacy but may also imply that mild learning difficulties can be remediated straightforwardly by educational programmes.

When talking about experiences of work or looking for work, many participants also referred to being forgetful, finding it difficult to concentrate and having problems understanding instructions:

I have a job to understand things... I keep, you know, forgetting things [Jeff]

...say "do three things", I remember number one [Lillian]

Sometimes it makes focusing and concentrating incredibly difficult [Sam]

And some participants made connections between concentration, memory and anxiety:

When there's too many tasks involved, it's just too much [Ravina]

...when I get stressed I get muddled, and when I get muddled I get stressed [Robbie]

Participants' talk also indicated an awareness of the stigma associated with these difficulties, relating to a sense that they signalled lower intelligence. The concept of 'intelligence' as a characteristic that can be clearly tested is readily open to critique (Goodley 2017; Jenkins 2014; Simons 2000) but nevertheless remains highly influential (Goodley 2017), and the idea of below-average intelligence remains strongly stigmatised:

I won't say anything, cos I think, oh god, they'll think you're thick [Louise]

I don't always take instructions very well...I pretended I knew what he was talking about, but I never [Ravina]

I don't want people to take the mick out of me and say "oh he's got learning difficulties, oh he can't do this, he can't do that" [Ryan]

Participants were not only aware of the stigma associated with misunderstandings and forgetfulness, but also indicated some appreciation of their significance to employers. However, participants generally did not dwell on these aspects of employability when discussing what they might need to do to gain or retain work in the future, referring more to matters relating to teamwork and getting along with other people. This suggested a mismatch between participants' priorities and concerns and those of employers given, that communication skills, memory skills, skills in interpreting instructions and responding to ambiguity, are increasingly seen as essential by employers, even for relatively 'unskilled' work such as cleaning.

For more than half of the participants (9 out of 16), their stressors also included social interaction, such as the way that they talked and their difficulties with conversational cues. Of these, five participants said that they talked 'too much', and that this resulted in negative reactions from others:

I never shut up half the time. People tell me all the time, "shut up, Jack, you're talking too much" [Jack]

I did waffle on quite long, did kind of get on everybody's nerves [Robbie]

Others referred to repeating themselves, again emphasising the impact on others:

I'm conscious of irritating people, over the repetitive asking [Lillian]

These comments show that although participants were aware of the conversational 'rules' they were often unable to prevent themselves from breaking them. In similar vein, some participants referred to difficulties with humour, jokes and banter, both in terms of understanding and of being understood. The examples they gave related to work environments where they were expected to work as part of a team and where they were dependent on the goodwill and support of co-workers, supervisors and managers. Getting it 'wrong' in these environments frequently resulted in exposure to complaint and bullying. As Sam put it:

Every time I don't engage in social interaction I feel left out, but every time I do, it's the wrong thing to do

As already noted, most participants highlighted issues relating to teamwork and getting on with co-workers and supervisors as priority areas for employers. However, those with the most work experience had gravitated away from work involving high levels of social interaction towards work that they could do in relative isolation, mostly cleaning. Such work tends to be low paid, offering few hours and unsocial hours, and on precarious contracts.

The fourth and final aspect of mild learning difficulties which participants discussed was 'slowness'. Half of participants (8/16) directly referred to concerns about being slow, or slower than others:

I'll still do it, but it might take me a bit longer [Kevon, talking about work on a bad day]

We just going to be slower...we can do it, at us own pace [Louise]

Bar work's too fast for me [Ravina]

The significance of this emphasis of slowness goes beyond the idea of completing tasks over a longer time period. Speed is increasingly significant within the labour market, related to a long-term rise in work intensity and computerisation (Green et al. 2018). Many participants indicated that being 'too slow' was a major obstacle to gaining or retaining paid employment. Nevertheless, those who mentioned their slower speed of working suggested that this should be incorporated into working life, despite their experiences of negative reactions from employers, supervisors and co-workers. The result, in some instances, was continuing rejection by employers, or even individual offers to work extra time for no pay to 'make up' for slowness. The identification of slowness as part of their disability did not result in any benefits to individuals: participants were unable to negotiate any 'reasonable adjustments' to their workloads except at their own cost.

### ***What difference does it make?***

Participants were asked various questions to explore how their mild learning difficulties might relate to their experiences of employment and unemployment, and what effect identifying or not identifying as disabled might have on these experiences. These included questions about whether or not (and why) they would tell employers and potential employers about their mild learning difficulties. Participants were also asked how they felt their experiences differed from those of siblings and peers who did not have mild learning difficulties.

Half of participants saw disclosure as preferable or even necessary and said they would tell employers about having mild learning difficulties. There were three broad reasons given for this: a desire for openness, a hope for support and a wish to manage expectations. Three participants related disclosure to a need for openness:

I can't lie about it [Ryan]

This related to their earlier affirmative comments about mild learning difficulties being part of who they were:

That's just me, I'm an honest person [Anthony].

For these participants, disclosure was signalled as part of their identity and essential to their relationships with others, regardless of whether or not their mild learning difficulties were 'obvious'. In contrast, other participants said that they would probably only disclose if there was a prospect of gaining support either at work or from employability service providers:

...my disability adviser was my regular job coach [Sergei]

Disclosure to Jobcentre Plus work coaches had the potential to result in a direct referral to a specialist service offering supportive advice and a greater probability of finding paid work experience, although some felt it made no difference:

I think they were just following the rules... it's all about ticking boxes [Nick]

Employability services were generally expected to take a sympathetic view of the barriers that participants were facing, and to offer support and encouragement. However, this was not always the case:

I would try and explain to her I had learning disabilities and need help but "no, he's a big boy he can do it himself" ...she just didn't care whether you had a disability or not [Jack]

In contrast, participants appeared to have much lower expectations about the effect of disclosure to employers and co-workers:



I thought they'd be, go a little bit easy on me [Anthony]

...because I... told them, and then they tell me what to do... they show me what to do [Emily]

Moreover, participants who said they would disclose their mild learning difficulties to employers and co-workers mostly related disclosure to managing the expectations of others, rather than in expectation of practical support:

It's acceptance... that they have the ability to work round my disability [Lillian]

I always say I've got it... so they don't think I'm being weird [Ravina]

More covering my own backside than anything else, cos if there's a problem because of it and I haven't told them... [Robbie]

Without an expectation or demand for support, this kind of disclosure appears to signal that the person with mild learning difficulties is anticipating that they will not meet the expectations of managers and co-workers. Disclosure becomes a way of forewarning of this shortfall. By disclosing, they were effectively signalling 'do not expect too much of me', or even 'I am a liability'. It is therefore unsurprising that many participants decided against this kind of disclosure.

Of the eight participants who said they would not voluntarily disclose, only one directly identified as disabled. This was also the only participant who actively sought to distance himself from association with other people with mild learning difficulties, linking this to negative experiences of specialist schools:

I try to distance myself from people with learning disabilities...cos I have one and I don't hold myself in high regard [Sergei]

However, although Sergei's views were expressed in the strongest language, seven other participants also indicated a preference for hiding or minimising their mild learning difficulties, saying either that they would not disclose, that they were unlikely to, or would only do so if directly asked:

I tried to hide it...because I didn't want them to know cos I didn't want them to make fun of me [Louise]

If I didn't [tell them] then they might, I might have a good chance of being taken on [Phil]

If I put that down, they tend, they would probably tend to think of it as a negative [Tyler]

Participants also linked non-disclosure to concerns about not being believed or exposing themselves to accusations of being fake. This concern about being considered fake was also reflected in experiences of mild

learning difficulties being denied or doubted. In the most extreme case, one participant had repeatedly been told that she was not disabled, leaving her feeling afraid to work with others:

...people don't believe me when I tell them about my disability...it serves no purpose, so I don't tell people [Lillian]

...it was the fear that they weren't going to believe me...the fear of discrimination [Lillian]

Despite – or perhaps because of – their reluctance to disclose an identity of disability, almost all participants thought that it was harder for them to find paid work than for their non-disabled or non-mild learning difficulties peer group or siblings.

Although participants clearly associated their mild learning difficulties with less favourable outcomes than their peers and siblings, they tended to focus more on their individual conditions and what they saw as individual limitations and failings, rather than collective experiences or social arrangements. This negative, individualistic focus also largely underpinned the way participants spoke about their expectations that they might get extra help and support. Only two of the participants offered an alternative focus, suggesting positive contributions people with mild learning difficulties might offer employers:

... it's been quite a gift... because I can understand what it's like to have it [Ravina, talking about working with people with learning disabilities in residential care]

Ravina's use of the word "gift" was also echoed by Nick, who talked about autism as a "curse" but then also said it was a "blessing", explaining that it meant he was more "focused" and "driven" than someone without an autistic spectrum condition. However, in general there was little indication that the participants enjoyed a positive appreciation of disability as "brilliant imperfection" (Clare 2017:57).

The majority of participants were at best ambivalent about claiming that they were disabled and most of the talk about disability had an individualistic focus. Where participants made reference to rights they referred to social and economic rights in principle, such as the right to decent conditions of work, more than to individual rights in practice, such as the right to compensation for discrimination. It is also pertinent to consider what was not said about rights.

Participants were specifically asked about policy proposals, reported in the national media (Bloom 2017; Morris 2014), that disabled people might justifiably be paid less than the National Minimum Wage. Participants largely used the language of deservingness as a defence against such an idea, but also drew on a discourse of rights and discrimination. In doing so, participants highlighted a sense of mild learning difficulties as a condition or set of conditions outside their personal control:

...we're struggling more than everybody else, so we deserve, like, more rights [Emily]

I was born with that disability, I didn't choose to have it, so it's discrimination isn't it? [Lillian]

...why should I be paid less for something I cannot control? [Robbie]

Although participants used the language of rights to reject the hypothetical idea of being paid less than the National Minimum Wage, this contrasted with an almost complete absence of talk about their rights in relation to their actual experiences of barriers to paid employment, loss of welfare benefits or job loss. Only one participant had negotiated a change in her working conditions with direct reference to her mild learning difficulties, but this had involved adaptations by her, rather than by the employer, effectively 'allowing' her to spend more time on her work than she was contracted to do (or paid for). Yet in view of her past experience of being denied even this form of adjustment, she noted:

...my bosses are far more understanding than they ever were at the last couple of jobs I've had [Lillian]

None of the participants had formally negotiated reasonable adjustments in a workplace, made applications to the Access to Work fund or sought advice about their employment rights. Only one participant mentioned joining a trade union, and that same participant was the only one to directly refer to legal protections, which he had been informed about by a disability specialist employment support service:

with the like Discrimination Acts... the 2010, they can't discriminate against me, they can't say you've got autism, go away, don't wanna hear about it... that's really boosted my confidence [Robbie]

## Discussion

The association of disability with physical and sensory impairments is deeply-rooted culturally, most commonly illustrated by the wheelchair or guide-dog symbols used to identify facilities and services for disabled people. This essentialist and debility-oriented view of 'disabled' is closely linked to the medical model of disability (Barnes 2012; Scully 2002). UK government policy claims (for example in DWP and DoH 2017:33) a commitment to a social model view of disability (Oliver 2009). However, this does not translate into the way that employment, employability support, or out-of-work benefit provision is presented and perceived. Participants' talk about disability as physical or sensory impairment was consistent with their experience of being denied access to services and disability benefits.

Although only one participant overtly drew a distinction between having a disability and being disabled, other participants indicated something similar in their ambivalent comments, and this was also reflected in the way participants talked about disclosing their mild learning difficulties to others, including to employers. This could be interpreted as uncertainty about the significance of their impairments or uncertainty about wishing to embrace a stigmatised identity. Such uncertainty fits with the social context of devaluing, neglecting and stigmatising disability in general and cognitive disability in particular (Goodley 2017; Kafer 2013; Jenkins 1998).

Negative social attitudes towards disability reinforce the exclusion of disabled people from economic and social resources. However, it also reinforces and is reinforced by the rationing of resources to those who are deemed 'disabled enough' (Roulstone and Prideaux 2012). In that sense, participants' ambivalence also suggested an acceptance that the label 'disabled' should exclude them because they did not deserve to be included within a term that was associated with entitlements to services and benefits. This acceptance was reinforced by their actual exclusion from these entitlements and the withdrawal of entitlements following welfare state assessments.

By identifying the impact of mild learning difficulties as an individual functional limitation, participants' views were aligned with the direction of Government employment policies which regard disability as an individual deficiency to be addressed, for example, by offering training courses and confidence-building exercises. In this context, most participants were clear that disclosure could make them less likely to be hired, because employers would see mild learning difficulties as a negative factor; or make them less likely to thrive in the workplace, because co-workers would be unwelcoming. They recognised the barriers to employment that they faced in relation to their mild learning difficulties and were open to the idea of additional support. However, their rejection of the idea of disclosure appeared to indicate a sense that employers' and co-workers' prejudice about what it means to have mild learning difficulties was the biggest barrier of all, outweighing any potential benefits from disclosure.

The link between the way disabled and unemployed people talk about themselves and the dominant media "scapegoating of the disabled" (Ryan 2019:3) and discourses of "scroungerphobia" (Patrick 2017:145) has been widely documented. When employers and co-workers hear claims for reasonable adjustments and additional support from people with mild learning difficulties the consequences may be disadvantageous whether accepted or rejected. Accepted claims that result in financial or other forms of redistributive consequences may "stigmatize the disadvantaged" (Fraser 1995:86) in contrast to cultural depictions of disabled people as extraordinary or heroic (Grue 2015) and the valorisation of the "autonomous reflexive individual self"

(Davies 1998:124). Conversely, rejected claims may reinforce “social generalization about the epistemic trustworthiness” of the speaker (Fricker 2009:32), drawing on stereotypes about “disability and ability, incapability and capability, impairment and normality, learning disabilities and learning abilities” (Goodley 2017:126) that underpin the construction of disability as deficiency.

## Conclusion

People with mild learning difficulties are constantly faced with the risk that disclosure, whether intentional or unintentional, is met with prejudice, discrimination and exclusion. The way the participants in this study talked about disability and disclosure of their learning difficulties illustrates an ever-shifting balance of consequences.

Official recognition of learning disability through access to social care services, or as a possible response to self-identification, is likely to exclude the majority of people with mild learning difficulties. Their experiences expose how government policy is based on an inadequate conceptualisation of disability.

## Acknowledgements

The authors would like to acknowledge the support of the Economic and Social Research Council and University of Nottingham Doctoral Research Centre.

## Disclosure statement

No potential conflict of interest was reported by the authors.

## Funding

This work was supported by the Economic and Social Research Council [ES/J500100/1].

## ORCID

Ruth Tarlo  <http://orcid.org/0000-0002-8000-6458>

## References

- Allen, Ruth E. S., and Janine L. Wiles. 2016. “A Rose by Any Other Name: Participants Choosing Research Pseudonyms.” *Qualitative Research in Psychology* 13 (2): 149–165. doi:10.1080/14780887.2015.1133746.
- Barnes, Colin. 2012. “Understanding the Social Model of Disability.” In *Routledge Handbook of Disability Studies*, edited by Nick Watson, Alan Roulstone, and Carol Thomas, 12–29. London: Routledge.

- Bates, Keith, Dan Goodley, and Katherine Runswick-Cole. 2017. "Precarious Lives and Resistant Possibilities: The Labour of People with Learning Disabilities in Times of Austerity." *Disability & Society* 32 (2): 160–175. doi:10.1080/09687599.2017.1281105.
- Bloom, Dan. 2017. "Top Labour MP Blasted by His Own Party's Welfare Chief over Claim Firms Could Pay Disabled People under Minimum Wage." *Mirror Newspaper*, September 26. <https://www.mirror.co.uk/news/politics/top-labour-mp-shot-down-11239835>.
- Booth, Tim, and Wendy Booth. 1996. "Sounds of Silence: Narrative Research with Inarticulate Subjects." *Disability & Society* 11 (1): 55–70. doi:10.1080/09687599650023326.
- Braun, Virginia, and Victoria Clarke. 2006. "Using Thematic Analysis in Psychology." *Qualitative Research in Psychology* 3 (2): 77–101. doi:10.1191/1478088706qp0630a.
- Clare, Eli. 2017. *Brilliant Imperfection: Grappling with Cure*. Durham: Duke University Press.
- Clarke, Charlotte L., Monique Lhussier, Christopher Minto, Catherine E. Gibb, and Tony Perini. 2005. "Paradoxes, Locations and the Need for Social Coherence: A Qualitative Study of Living with a Learning Difficulty." *Disability & Society* 20 (4): 405–419. doi:10.1080/09687590500086534.
- Culey, Victoria, Rachel Fyson, and Alison Pilnick. 2020. "Theorising Disability: A Practical and Representative Ontology of Learning Disability." *Disability & Society* 35 (2): 235–257. doi:10.1080/09687599.2019.1632692.
- Davies, C. A. 1998. "Constructing Other Selves: (in)Competence and the Category of Learning Difficulties." In *Questions of Competence: Culture, Classification and Intellectual Disability*, edited by Richard Jenkins, 102–124. Cambridge, UK; New York: Cambridge University Press.
- DoH (Department of Health). 2001. *Valuing People: A New Strategy for Learning Disability for the 21st Century*. Norwich: TSO.
- DWP and DoH. 2017. *Improving Lives: The Work, Health and Disability White Paper*. London: The Stationery Office.
- Elgot, J., and H. Osborne. 2017. "Welfare Funds Must Serve 'really Disabled' People, Says MP." *Guardian*, February 26. <https://www.theguardian.com/politics/2017/feb/26/welfare-funds-must-serve-really-disabled>.
- Emerson, Eric, and Gyles Glover. 2012. "The 'Transition Cliff' in the Administrative Prevalence of Learning Disabilities in England." *Tizard Learning Disability Review* 17 (3): 139–143. doi:10.1108/13595471211240988.
- Emerson, Eric, and Chris Hatton. 2014. *Health Inequalities and People with Intellectual Disabilities*. Cambridge: Cambridge University Press.
- Emerson, Eric, Chris Hatton, Janet Robertson, and Susannah Baines. 2018. "The Association between Non-Standard Employment, Job Insecurity and Health among British Adults with and without Intellectual Impairments: Cohort Study." *SSM - Population Health* 4 (April): 197–205. doi:10.1016/j.ssmph.2018.02.003.
- Fevre, Ralph, Duncan Lewis, Amanda Robinson, and Trevor Jones. 2012. *Trouble at Work*. London: Bloomsbury.
- Fraser, Nancy. 1995. "From Redistribution to Recognition? Dilemmas of Justice in a 'Postsocialist' Age." *New Left Review* 212: 68–93.
- Fricke, Miranda. 2009. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.
- Fulton, Rorie, and Kate Richardson. 2014. *Supporting Individuals with Learning Disabilities: Understanding the Context, a Care Quality Guide for Health and Social Care Staff and Carers*. Hove: Pavilion Publishing.
- Goodley, Dan. 2001. "Learning Difficulties; the Social Model of Disability and Impairment: Challenging Epistemologies." *Disability & Society* 16 (2): 207–231. doi:10.1080/09687590120035816.

- Goodley, Dan. 2017. *Disability Studies: An Interdisciplinary Introduction*. 2nd ed. London: Sage Ltd.
- Green, Francis, Alan Felstead, Duncan Gallie, and Golo Henseke. 2018. *Work Intensity in Britain - First Findings from the Skills and Employment Survey 2017*. London: Centre for Learning and Life Chances in Knowledge Economies and Societies, UCL Institute of Education. [https://www.cardiff.ac.uk/\\_\\_data/assets/pdf\\_file/0009/1309455/4\\_Intensity\\_Minireport\\_Final.pdf](https://www.cardiff.ac.uk/__data/assets/pdf_file/0009/1309455/4_Intensity_Minireport_Final.pdf).
- Grover, Chris, and Linda Piggott. 2015. "Disabled People, Work and Welfare." In *Disabled People, Work and Welfare: Is Employment Really the Answer?*, edited by Chris Grover and Linda Piggott, 1–21. Bristol: Policy press.
- Grue, Jan. 2015. *Disability and Discourse Analysis. Interdisciplinary Disability Studies*. Farnham, Surrey; Burlington, VT: Ashgate.
- Gulland, Jackie. 2019. *Gender, Work and Social Control: A Century of Disability Benefits*. <https://public.ebookcentral.proquest.com/choice/publicfullrecord.aspx?p=5829900>.
- Hatton, Chris. 2018. "Paid Employment Amongst Adults with Learning Disabilities Receiving Social Care in England: Trends over Time and Geographical Variation." *Tizard Learning Disability Review* 23 (2): 117–122. doi:10.1108/TLDR-01-2018-0003.
- Jenkins, R. 1998. "Culture, Classification and (in)Competence." In *Questions of Competence: Culture, Classification and Intellectual Disability*, edited by Richard Jenkins, 1–24. Cambridge, UK; New York: Cambridge University Press.
- Jenkins, Richard. 2014. *Social Identity*. 4th ed. Key Ideas. New York: Routledge, Taylor & Francis Group.
- Kafer, Alison. 2013. *Feminist, Queer, Crip*. Bloomington, IN: Indiana University Press.
- Monteleone, Rebecca, and Rachel Forrester-Jones. 2017. "'Disability Means, um, Dysfunctioning People': A Qualitative Analysis of the Meaning and Experience of Disability among Adults with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities: JARID* 30 (2): 301–315. doi:10.1111/jar.12240.
- Morris, Nigel. 2014. "Lord Freud: Tory Welfare Minister Apologises after Saying Disabled People Are 'not Worth' the Minimum Wage." Independent, October 15. <http://www.independent.co.uk/news/uk/politics/lord-freud-tory-welfare-minister-accused-of-claiming-disabled-people-are-not-worth-the-minimum-wage-9796062.html>.
- Oliver, Michael. 2009. *Understanding Disability: From Theory to Practice*. 2nd ed. Basingstoke, Hampshire [England]; New York: Palgrave Macmillan.
- Patrick, Ruth. 2017. *For Whose Benefit? The Everyday Realities of Welfare Reform*. Bristol: Policy Press.
- People First. undated. "Our Values." <http://peoplefirsttd.com/about-us/our-values/>.
- Porter, Jill, and Penny Lacey. 2005. *Researching Learning Difficulties: A Guide for Practitioners*. London: SAGE.
- Powell, Andrew. 2020. *People with Disabilities in Employment*. House of Commons Library Briefing Paper 7540.
- Rapley, Mark. 2004. *The Social Construction of Intellectual Disability*. Cambridge: Cambridge University Press.
- Rapley, Mark, Patrick Kiernan, and Charles Antaki. 1998. "Invisible to Themselves or Negotiating Identity? The Interactional Management of 'Being Intellectually Disabled.'" *Disability & Society* 13 (5): 807–827. doi:10.1080/09687599826524.
- Roulstone, Alan, and Simon Prideaux. 2012. *Understanding Disability Policy*. Bristol: Policy Press.
- Ryan, Frances. 2019. *Crippled: Austerity and the Demonization of Disabled People*. London: Verso.

- Scully, J. L. 2002. "A Postmodern Disorder: Moral Encounters with Molecular Models of Disability." In *Disability/Postmodernity: Embodying Disability Theory*, edited by Mairian Corker and Tom Shakespeare, 48–61. London; New York: Continuum.
- Simons, Ken. 2000. *Life on the Edge: The Experiences of People with a Learning Disability Who Do Not Use Specialist Services*. Brighton: Pavilion Pub. in association with Joseph Rowntree Foundation and Norah Fry Research Centre.
- Swain, John, Sally French, and Colin Cameron. 2003. *Controversial Issues in a Disabling Society. Disability, Human Rights, and Society*. Buckingham: Open University Press.
- Tarlo, Ruth. 2020. *Social Justice and the Experiences of People with Mild Learning Difficulties Who Are Looking for Paid Work*. Nottingham: University of Nottingham.
- Watson, Nick. 2002. "Well, I Know This is Going to Sound Very Strange to You, but I Don't See Myself as a Disabled Person: Identity and Disability." *Disability & Society* 17 (5): 509–527. doi:10.1080/09687590220148496.
- Webb, Jenny. 2014. *A Guide to Psychological Understanding of People with Learning Disabilities: Eight Domains and Three Stories*. London; New York: Routledge, Taylor & Francis Group.
- Willetts, Chris. 2011. "People with Learning Difficulties - Issues of Vulnerability." In *Vulnerable Adults and Community Care*, edited by Keith Brown, 97–112. Exeter: Learning Matters.