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## **Abstract**

People with learning disabilities face numerous barriers accessing health and social care. Previous studies have identified that poor communication can be a significant barrier but this has not been explored in depth. This article explores the perceptions and experiences of people with learning disabilities and their family carers regarding communication with health and social care professionals, in order to establish both the areas that they find problematic and also identify strategies that can lead to more effective communication. Five people with learning disabilities and their family carers participated in the study, sharing their experiences through the use of semi-structured and symbol exchange interviews, and pictures. Communication was an area of concern for all participants, affecting their access to health and social care. Participants reported instances of ineffective and disrespectful communication and identified a desire for professionals to use a variety of communication methods, such as gestures, touch, and images, rather than relying on verbal language alone and to treat people with learning disabilities with respect.

## **Keywords**

Access to care; communication; learning disabilities; intellectual disabilities; United Kingdom.

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## Introduction

Disabled people<sup>1</sup> report increased barriers to accessing healthcare, leading to suboptimal experiences of care, reduced uptake of preventive services, and reduced satisfaction with provided services (Rotarou & Sakellariou, 2017, 2019; Sakellariou & Rotarou, 2017a). People with learning disabilities in particular experience avoidable suffering due to compromised access to, often, inappropriate care (Michael & Richardson, 2008). Their needs often remain unmet (Baker et al., 2009), which might explain why they are disadvantaged across several health-related indicators, such as mortality and co-morbidities (Emerson et al., 2010; Ouellette-Kuntz, 2005). Austerity-driven reforms in healthcare have had a significant impact on healthcare access for disabled people (Sakellariou & Rotarou, 2017b), further exacerbating health inequalities. Such inequalities are linked to the structural disadvantages experienced by people with learning disabilities due to their social position and have wide-ranging effects in their lives, affecting most aspects of their social participation (Bollard et al., 2017).

Communication is an important dimension of healthcare access and is crucial for the provision of relevant services. The existing evidence suggests that there is a lack of effective communication in health and social care settings, disadvantaging people with learning disabilities and negatively impacting the quality of care they receive (Mencap, 2018). Our aim in this article is to explore the perceptions and experiences of people with learning disabilities and their family carers regarding communication with health and social care

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<sup>1</sup> We use the term ‘disabled people’ rather than people with disabilities to signal our use of the social model of disability, which sees disability as foremost a political and social issue rather than located in people’s bodies (Shakespeare, 2017).

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professionals (from now on, professionals), in order to establish both the areas that they find problematic and also identify strategies that can lead to more effective communication.

Although some literature on the topic does exist, communication is generally identified as one of many barriers to accessing care rather than studied in its own right. Additionally, the existing literature mostly seeks the views and experiences of people without learning disabilities, such as professionals and paid carers. The first part of the article presents a brief background to the study. Following this, we present the methods and the study findings. The latter part of the article discusses the findings in relation to the wider literature, with a specific emphasis on examining the impact language and communication have on reflecting and recreating the dominant ideas in society, drawing on the work of Voloshinov (1986) and Foucault (2003, 2012).

### **Communication as a dimension of access to health and social care for people with learning disabilities**

Communication is widely accepted as a key way in which society disables people with learning disabilities (Kasnitz & Block, 2012). Communication refers to the transmission of information and ideas (DeVito, 2014) and encompasses far more than verbal language, including a multitude of practices such as body language, vocalization and intonation, listening, natural gesture, eye contact, written language, assistive communication technology, picture exchange systems, facial expressions, and signing systems such as the British Sign Language, among others (Abudarham & Hurd, 2002).

In health and social care, communication is acknowledged as a core skill (O'Toole, 2012). For people with learning disabilities, communication has consistently been highlighted as a key barrier to access to care, with poor communication having been directly linked to serious injury or even death (Heslop et al., 2014; Mencap, 2007, 2012, 2018; Tingle, 2018).

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The use of 'poor communication' here draws attention to an often observed inability of professionals to engage with alternative communication methods, appropriate for people with learning disabilities. We use this term specifically to highlight communication failures related with professionals not acknowledging or failing to respect or use the preferred communication methods of service users with learning disabilities, rather than to infer that the communication methods used by people with learning disabilities are in any way inferior.

Professionals identify communication as one of their biggest challenges in working with people with learning disabilities and report that lack of effective communication can result to pain or symptoms remaining hidden or inadequately explored (Drozd & Clinch, 2016; Morton-Nance & Schafer, 2012). While training in appropriate ways of communicating with people with learning disabilities could lead to improvements in service provision, only 41% of nursing and 35% of medical courses currently include training on the Accessible Information Standard, designed to ensure people with learning disabilities can access health and social care (Mencap, 2018). Most healthcare professionals do not receive any training specifically on communicating with people with learning disabilities (Salvador-Carulla & Saxena, 2009).

Lack of, or poor communication due to healthcare professionals' lack of training or other reason is a strong theme in the existing literature, with people with learning disabilities reporting being unnecessarily kept in hospital (Castles et al., 2012) and not being informed about waiting times (Cumella & Martin, 2004), leaving people feeling "*fearful and sad, being ignored by staff, not understanding why tests were being performed or what treatment was being undertaken, and frustration and anger at what was being done to them*" (Cumella & Martin, 2004:34). When hospitalized, people with learning disabilities report that professionals either do not give any information about their health, or they give them too

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much information, which they cannot process (Gibbs et al, 2008; Webber et al., 2010). In other words, the right of people with learning disabilities to receive full and clear information about their care and to be meaningfully included in decisions about their care is not always realized.

Poor communication can have wide-ranging effects. People with learning disabilities report medical procedures or interventions being undertaken with little or no explanation, ranging in severity from changes in medication, to doctors performing minor surgery without informing patients of what is happening (Mencap, 2018). In one example, a patient was placed under a Do Not Attempt Resuscitation order without consulting them or their family (Mencap, 2018), drawing attention to the systemic failures that construct disabled people as unworthy patients, negatively affected by practices such as medical rationing, and deprioritized for life-saving medical procedures.

People with learning disabilities often feel that their symptoms are not investigated or treated due to communication failures; experiences reported in the literature range from not being offered pain relief medication in Accident and Emergency (Smith, 2016), to having reported musculoskeletal issues left unexamined (Tilly, 2013). While professionals report being concerned about their ability to interpret atypical responses to pain (Regnard et al., 2003), existing evidence suggests that most people with learning disabilities are able to communicate about their pain in an understandable way (McKenzie et al., 2012).

Professionals report a preference for people with learning disabilities to be accompanied by a carer during appointments (e.g. Redley et al., 2012). However, directing communication to carers is not always an effective strategy and may lead to people with learning disabilities feeling excluded from decisions about their own care (Cumella & Martin, 2004; Ziviani et al., 2004). Smith (2016:1) explained: "*When I was little the doctors always*

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*said hello to me first, now I'm a grown up not all of them do. They talk to my carer. I am a person and it's my body"*. Talking directly to people with learning disabilities and not their carer is the most appropriate communication strategy (Godsell & Scarborough, 2006).

However, speaking clearly at an appropriate level and incorporating humour without sounding patronizing appears to be something professionals may find challenging, with some professionals advocating the use of strategies normally reserved for children, such as promising an ice lolly after an examination of a patient's mouth (Wilkinson 2018). This is despite people with learning disabilities reporting a dislike for being spoken to in non-age appropriate language (Smith, 2016; Ziviani et al., 2004).

### **Methodology**

We used a qualitative design to engage in an in-depth exploration of the "*perceptions, meanings and interpretations*" (Holloway & Galvin, 2017:3) of people with learning disabilities and their family carers, and also examine the social context of the communication interaction (Voloshinov, 1986). We recruited participants in an urban area in England, U.K. via a purposive and convenience sampling technique, including people who were over 18 and had learning disabilities or were the family member of someone with learning disabilities. Participants were already known to the researcher (first author) as family friends and were approached with an introductory text message/phone call, followed by a formal invitation via email with a participant information sheet attached. Carrying out research with participants already known to the researcher is a strategy often used with hard-to-reach populations, and has been critiqued for producing a sample that is self-selecting and homogenous in terms of demographics (Ellard-Gray et al., 2015). The fact that the participants and researcher shared a pre-existing level of rapport and trust, however, enabled deep sharing that may not otherwise have been possible (Taylor, 2011).

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## **Data Collection**

As several of the research participants had learning disabilities, there was a somewhat tautological nature to the methodological design of this study; in order to interview these participants to ascertain their communication preferences, it was necessary to ascertain their communication preferences. People with learning disabilities, especially those who do not use speech, are underrepresented in research (Boxall & Ralph, 2011). Wanting to make the study accessible to people who could not use speech and ensure effective communication (Ware, 2004), we discussed with all participants and decided on the following three methods of data collection: semi-structured interviews, symbol exchange interviews, and pictures.

### ***Semi-structured interviews***

Semi-structured interviews were primarily used with the family carers of the participants with learning disabilities. The use of semi-structured interviews allowed for a degree of flexibility and also allowed participants to direct the conversation as well as suggest additional topics. This helped mitigate the inherent power dynamic that the researcher-participant relationship carries (Braun & Clarke, 2006). Two of the participants with learning disabilities participated in semi-structured interviews, with clarifications provided as needed. The questions were also presented in a written and pictorial format. As people with learning disabilities can have other conditions affecting concentration (Berney & Belshaw, 2011), a visual prompt was helpful in redirecting attention to the question when needed.

The participants with learning disabilities were present throughout the interviews with their family carers and vice-versa. It was felt by the carer participants that it was appropriate and beneficial for the participants with learning disabilities to be present while they were being spoken about; one set of parents commented that their son enjoyed watching social interaction even if he did not verbally engage. All interviews were audio-recorded.



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### ***Symbol exchange interviews***

A resource based on the Talking Mats format, often used in research with people with learning disabilities and rated favourably by them (Bunning et al., 2016; Bell & Cameron, 2003), was developed for two participants. A laminated sentence was placed on a coloured card and participants were asked to make a choice between two or more symbols to place on the mat to complete it; both participants verbally stated their choice when they placed the symbols. For one participant, these sentences were supplemented by pictures, while for the other words alone were used, according to their personal preferences.

The use of this resource raised concerns surrounding trustworthiness and bias, as the vocabulary available for participants was pre-selected by the researcher. Care was taken to mediate the unavoidable bias of pre-selecting vocabulary as much as possible, by discussing the vocabulary selection with one participant.

### ***Pictures***

One participant had a profound learning disability and communicated through behavior, facial expression, and noise with no written or verbal language. Photographs reflecting the questions asked of other participants were shown, and her responses were recorded verbally, alongside any interpretation from her carer. Researchers, for example Pickering et al. (2015), have used pictures in similar ways, treating the data gathered from nonverbal participants as part of a mosaic of data complemented by semi-structured interviews with parents and caregivers, and this is how we used this method in this study.

### **Data Analysis**

Audio recordings were transcribed verbatim and field notes typed up immediately after completing interviews. The data were then analysed thematically using line-by-line coding (Braun & Clarke, 2013) on NVivo. The codes were aggregated into larger themes,

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noting similarities as well as discord between participant views and experiences (Braun & Clarke, 2013). To ensure participants were satisfied with the representation of their views, the research findings and an Easy Read summary were circulated to all participants allowing them to challenge any perceived misrepresentation. Four participants responded and confirmed their agreement with the findings.

### **Ethical Considerations**

The study received ethical approval from [MASKED FOR BLIND REVIEW]. In order to ensure that participants could give informed consent, participant information sheets and consent forms were sent out in advance of the interviews, with a choice of a plain English text-only version and an Easy Read version. Participants were asked again at the beginning of the interviews whether they were still happy to take part.

During interviews, participants were asked to recall negative experiences of communication with healthcare professionals, experiences which are likely to have been upsetting. While care was taken to ensure questions were framed sensitively, the participant information sheet drew attention to this possibility and reaffirmed that participants could stop or withdraw from the research at any time. The researcher reminded participants with learning disabilities of their right to terminate the interview at any time and in order to facilitate choice presented participants with a red card reading 'stop' and a green card reading 'go', and informed that they could use these to stop and/or recommence the interview at any time. None of the participants withdrew consent.

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## Results

All participants with learning disabilities were in their 20s, while all family carers were in their 50s, apart from Jane who was in her 30s. The following paragraph provides an overview of the participants.

- **James and Beverly:** James was autistic<sup>2</sup> with a profound learning disability. Beverly was his mother. James mostly communicated through short words and phrases, and also used symbols, echolalia, and body language.
- **Miles, Jadzia and Julian:** Miles was autistic with a profound learning disability and epilepsy. Jadzia and Julian were his parents. Miles communicated through pointing or gesturing at people or objects, or through choosing between options that were written down. He occasionally used echolalia and short words or phrases.
- **Tasha and Kira:** Tasha had Angelman Syndrome. Kira was her mother. Tasha communicated through facial expressions and noises (e.g. to express satisfaction or displeasure), and occasionally through objects of reference, like sitting in front of the oven to indicate she was hungry.
- **Leonard and Deanna:** Leonard was autistic and had dyspraxia as well as a mild learning disability. Deanna was his mother. Leonard communicated mostly through verbal language, but often used written language if he was feeling anxious.
- **Michael and Jane:** Michael had Down’s Syndrome. Jane was his sister. Michael communicated through a number of means, including verbal language, symbols, Makaton, and written language such as Easy Read, as well as using social media to communicate with other people in the same house.

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<sup>2</sup> The term ‘autistic’ rather than ‘person with autism’ has been used in accordance with the expressed preferences of autistic adults as outlined in Kenny et al. (2015).

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Three key themes were identified: the first two themes focus on individual communication interactions between professionals and people with learning disabilities, and offer examples of positive and poor communication. The final theme is concerned with the social and political environment in which communication interactions take place, and how this is exemplified through communication interactions which are perceived by people with learning disabilities and their carers as disrespectful or insulting.

### **Give it a go**

This theme highlights desires expressed by all participants for professionals to experiment with forms of communication other than verbal language. Participants with learning disabilities preferred professionals to vary the tone and speed of their voice, and to use different facial expressions and body language, with a strong preference for professionals to smile and not stand too close.

When professionals could not communicate verbally with someone with learning disabilities, participants noted they immediately spoke to their carers rather than attempting another form of communication, as expressed by Julian and Jadzia:

Julian: I don't think anybody's ever actually probably tried other ways of communicating with Miles, apart from talking to him and if that doesn't work...

Jadzia: They give up.

All participants preferred using various resources to support verbal communication, including symbols, pictures, Easy Read, and written information. Tasha was at her most vocal and expressive when looking at a photograph of a professional using pictures with a client, as illustrated below.

Interviewer: What do you think of that one? Using pictures when they talk to you?

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Tasha: Mu-mu-mu-mum [smiling].

Kira: We like the pictures, don't we?

Tasha: Mu-mu-mu-mum [touching Kira's face and smiling].

Interviewer: Yeah, you're smiling a bit more at that, aren't you?

The use of touch was discussed and all participants felt that some touch would be appropriate. People with a more profound learning disability, such as James and Miles, preferred greater physical contact. As Jadzia noted in the extract below, Miles would normally touch both the 'yes' and 'no' option before making a selection; however, when the questions centred around the use of touch, Miles disregarded the 'no' option, and asked the researcher for a hug, clarifying his preference for physical communication.

Interviewer: Do you like them to hold your hand, yes or no?

Miles: Yes.

Interviewer: And do you like them to touch Miles' shoulder like this, yes or no?

Miles: Yes.

Jadzia: He's not even touching the no for that one.

Interviewer: Yeah. And do you like the health and social care staff to give Miles a hug?

Miles: Yes [gestures for a hug].

While there was limited agreement on the precise nature that verbal and non-verbal communication should take, the unifying thread to this theme was that professionals should be willing to try a variety of communication methods.

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### **Relax and have fun**

Participants emphasised a preference for communication to be relaxed and enjoyable. Carers felt it was more important that people with learning disabilities enjoyed the experience than that professionals accomplished the objective of their session. At Michael's most recent blood test, the nurse was not able to draw blood; however, Michael left the surgery having enjoyed the appointment, which Jane remarked was far more important.

Kira suggested that tasks such as personal care could be utilised as an opportunity for relaxed interaction, rather than a "*factory assembly line*" of tasks. She felt this would put people with learning disabilities and their carers far more at ease. All participants wanted extra time during appointments. Leonard found this allowed him to ask questions; as he explained, "*sometimes I take more time than people think about stuff*". Being rushed was a universally negative experience, with Michael remarking it made him "*not feel fantastic*". Deanna noted that professionals are often very time-limited and lamented the negative impact time pressure has on communication.

A consistent piece of advice offered by carers was to adopt a less professional approach. Beverly recounted James' most positive communication experience involving a surgeon who relaxed his professional persona, as outlined below:

James had an IV [intravenous] thingy in, he didn't really like it, so the surgeon just kind of pulled it out and said 'goodbye' and threw it away [laughs] and the nurses were tutting, because it meant there was like a needle on the floor somewhere, but he just instantly got it.

Some participants with learning disabilities expressed preferences that might be considered unprofessional. For example, Miles enthusiastically selected the 'yes' symbol for hugs and hand-holding from professionals, while Michael remarked that occupational

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therapists reminded him of his friends; friendship is a label that many professionals would tend to avoid when describing their relationships with service users.

Some carers sensed that professionals felt uncomfortable or awkward trying to communicate with them, and believed this stemmed from a lack of experience with people with learning disabilities. This had the potential to severely inhibit or even stop communication, as Deanna commented:

A lot of the other nurses didn't necessarily speak to Leonard or whatever, maybe because they were slightly unsure about how much he could take in, or, you know, they have their own judgements.

Deanna and Leonard recalled that the best communication from Leonard's most recent hospital admission was with catering staff, as they were less concerned with adhering to a set of professional guidelines. There was a clear sense from the participants that the more willing professionals were to relax their professional persona, the more positive the interaction would be. Relaxing in this way can be challenging for professionals, as it involves admitting their own knowledge deficit and vulnerability to making mistakes; however, all participants indicated that such a willingness to be vulnerable could have a significant positive impact on communication.

### **A little respect**

Both participants with learning disabilities and without described an acute lack of information, particularly when admitted to acute settings. Most participants recounted instances where professionals initiated assessment or intervention without attempting to communicate this, as illustrated by Leonard:

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I was asking them what I needed doing because they didn't entirely communicate with me, so they just took my temperature, so I said to them 'what are you doing now?'

Although carers and people with learning disabilities recounted these experiences in a lighthearted manner, they also expressed hurt and confusion over this poor communication.

Jadzia felt that this behavior amounted to a negation of Miles' personhood, as she explained:

Jadzia: It's the not treating him as somebody who needed communicating with, I think that was probably the worst.

Julian: Hmm.

Interviewer: Yeah, sort of almost treating him like a...

Jadzia: Like a piece of meat or something.

Although the absence of active communication was keenly felt by participants, listening was described as equally important. Several carers felt professionals did not listen to or believe them. Kira described an ongoing struggle to gain a formal epilepsy diagnosis for Tasha, as her seizures had not been observed by a doctor; the lack of a diagnosis meant there was no guarantee that Tasha's epilepsy management plan would be acted on by services. Kira felt the consultant had addressed her in sexist, patronizing language, that she was being accused of fabricating Tasha's seizures, and received a letter she felt implied she was "*the nutcase, or the stupid woman*".

Professionals often directed communication at the carer and not the persons with learning disabilities; this was received poorly by carers, but there was no agreement amongst participants with learning disabilities on this issue. Miles and James both preferred to be



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addressed before their carers, whereas Leonard was happy for professionals to speak to his carers as it aided his understanding. Michael initially indicated a preference for professionals to speak with his carer, but when presented with the option of 'both' stated "*both, yeah*". Beverly remarked that being excluded from a conversation was frustrating for James, and indeed he appeared to become frustrated when Beverly and the researcher spoke for long periods of time without making eye contact with him:

Beverly: So you saw how when you and I were talking but he didn't understand he starts getting ... flappy ... because he can hear us talking and we've got eye contact and he's not part of it. It's quite stressful, isn't it James?

James: Stressful.

Kira reflected that there were instances where she would prefer to speak to professionals without Tasha present, for example when meeting with an occupational therapist to discuss how to restrict Tasha's spitting behavior:

I felt it was better that we talked alone, because that didn't put ideas in her mind ... so if you start talking about something like that, like doing the [lowers voice] spitting, she thinks it's a laugh, so she starts doing it.

There was acknowledgement that being respectful and person-centred while gathering necessary information was challenging. Suggestions for how to manage this tension included switching eye contact between all parties, occasionally seeking confirmation from carers, and offering people with learning disabilities choice.

The lack of respect demonstrated in numerous communication interactions was a source of frustration for carers, who felt that professionals "*should know better*", as outlined by Jadzia:

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It makes me very cross because ... these are people who are supposed to know what they're doing and they don't ... I think, well, how did you get to this position in your life and not know that you have to treat people as people regardless?

Both Miles and James indicated they felt like children when professionals spoke to them; although they were not asked how they felt about this, they both appeared to smile as they selected the option. Michael indicated that he felt like an adult at health and social care appointments, and Leonard stated that professionals took him "*seriously*". Kira suggested that speaking to Tasha at the level of a toddler or baby was most appropriate, recognizing that this might be considered a "*controversial*" opinion.

Although family carers acknowledged that it is not always easy to interact appropriately with the people they care for, they all identified, with a level of resignation and frustration, the disrespect and poor communication they were met with throughout their interactions with professionals.

## **Discussion**

The findings highlighted the impact of poor communication on healthcare access, reflecting literature indicating, for example, explanations of pain being ignored (Dinsmore, 2012), parents' expertise of their child's medical condition being dismissed (Iacono & Davis, 2003), and people with disabilities not being told how long they would have to wait (Castles et al., 2012; Cumella & Martin, 2004), or even what procedure was being undertaken (Mencap, 2018). The findings highlighted that there is not one singular preferred method or form of interaction that is universally acceptable and preferred by people with learning disabilities and their family carers, and that the social and political environment communication takes place in plays an important role.

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The key contribution that this study makes is to suggest that professionals must examine their own behavior and unconscious bias, recognize their own structural power and complicity in a political system that does not view people with learning disabilities as *normal*. Communication needs to be negotiated continuously in order to construct what Ginsburg and Rapp (2017) called accessible futures for disabled people; i.e. a future where disabled people are afforded the full rights of citizenship within societies that respect difference- in this case, different ways of communicating.

### **Normalization and power**

The language and communication style used reflect and recreate an oppressive social order. Voloshinov (1986), a key theorist on the intersection of language and society, argued that language and other forms of communication do not exist in a social vacuum; rather, language is a critical part of the relationship between the economic and social base of a society, and the superstructure that keeps this society operating. This relationship is maintained by what is called ideology, described by Gramsci as a terrain of practices, principles, and dogmas that influence how individuals behave in a social and economic context (Ramos, 1982). Voloshinov (1986) argued that while language and communication reflect the dominant ideology of a society, they also have the power to reinscribe and create new social norms.

This is evident in the medicalised language used to define learning disability; it is described as a cognitive impairment and is often assumed to be a static, biological fact (Goodley, 2001). However, as Inglis (2013) reflected, changes in the diagnostic threshold (from 85 IQ points to 70) meant that hundreds of thousands of people were *cured* overnight of their learning disability and were suddenly not disabled. This example demonstrates that

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learning disability is not an incontestable fact but a socially constructed way to classify a way of being that deviates from the norm.

Questions of normalization necessitate considering the works of Foucault (2012; 2003), who wrote at length on the complex nexus of communication, language, power and stigma. Foucault argued that unlike feudalist societies, post-modern societies do not wield power in an explicitly unidirectional fashion. Rather, power is diffused in society and is expressed in three key ways: surveillance, normalization, and examination (Foucault, 2012).

The communication between professionals and people with learning disabilities is a clear example of Foucault's theory of power; people with learning disabilities have already been examined by the medical gaze (Foucault, 2003), their bodies and minds deemed outside of the norm and thus requiring treatment. People with learning disabilities continue to be under the surveillance of professionals through capacity assessments, appointed social workers, detention under the Mental Health Act (1983), and so on. The key factor at play in the communication interactions outlined in this study is *normalization*; a process whereby power structures in society lead to a small series of actions that contribute to the emergence and maintenance of a discourse of what is normal and what is not; certain groups of people are constructed as 'other', sitting outside of the acceptable social norm (Foucault, 2012). Little by little, the entire social system creates an environment where the worst abuses of power can take place towards people with learning disabilities, without explicitly wielding this power (Ryan, 2017). In isolation, the examples of poor and disrespectful communication outlined by participants appears relatively innocuous; however, small actions like not bringing communication aids to an appointment imply that people with learning disabilities do not need communicating with.

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People with learning disabilities are often viewed in simplistic binary categories of either *inspirational* or *challenging* (Inglis, 2013). If this is the starting point for interactions, it is easy to see how they can have their pain ignored by healthcare professionals who do not understand their atypical expressions of it (Regnard et al., 2003), or to see how consultants could argue that a woman with Down’s Syndrome and severe learning disabilities had such a poor quality of life that he would place her on a Do Not Attempt Resuscitation order over and above the wishes of her family (Mencap, 2007).

At no point in these examples has the entire system of normalization and power ever revealed itself in its *murderous splendour* (Foucault, 2012); instead, it has made several small, bureaucratic gestures that silently work together to create a society where people with learning disabilities are implicitly treated as *less than human*, unless they behave in a way that those designated *normal* can understand, and the end results are viewed as an unavoidable tragedy, or personal failure on the part of a single professional, rather than an avoidable death in state care (Ryan, 2017). As Curran (2016:435) argued, *these are not examples of ‘poor practice’ or types of individual but the effects of continuous normalising strategies that contribute to wider societal discourses*”. Each poor communication interaction does not simply reflect the views of society, but because it is performed by professionals with social and political power, each communication interaction reinscribes these ways of conceptualizing people who fall outside the norm.

### **Learning the language**

While, as participants in this study suggested, communication is always possible, how this can be facilitated is debatable. Godsell and Scarborough (2006) argued that the responsibility to adapt and find a suitable method of communication rests with the more *competent* communication partner. The idea that either conversational partner is more

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competent is, however, disputed. As disability advocate Amanda Baggs (SilentMiaow, 2007), stated:

I find it very interesting ... that failure to learn your language is seen as a deficit but failure to learn my language is seen as so natural that people like me are officially described as mysterious and puzzling, rather than anyone admitting that it is themselves who are confused.

Attempting to *learn the language* of people with learning disabilities, through using resources and forms of communication that they can understand, could be an effective strategy. People with learning disabilities may interpret an unwillingness to use pictures or easy read as a sign that professionals are embarrassed or uncaring (O'Halloran et al., 2008). In Morton-Nance and Schafer's (2012) study, nurses recalled working with people who had no verbal language and did not mention attempting any other form of communication, instead defaulting to speaking with their carer. Although accessible information is produced by hospital trusts, there is no national scheme co-ordinating its design or delivery and it is often not used during appointments with people with learning disabilities (Brown et al., 2017).

Reading and interpreting non-verbal communication is undoubtedly challenging. People with learning disabilities can find that under-engagement is misinterpreted as an expression of contentment and over-engagement is pathologized as *challenging behavior*. This is apparent in the case of pain, where atypical responses to pain, such as laughter or aggression, mean that non-verbal communication may not be listened to or explored (Regnard et al., 2003).

Despite the challenges, there is an onus on professionals to continue evaluating their communication skills. Where a complex explanation is not possible, simple choices can be

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offered. Finlay and Antaki (2012) provide an example of a person with learning disabilities choosing a day centre to attend by pointing to a support worker's hand, where each hand signified a different day centre.

Participants preferred a relaxed, friendly approach and for professionals to joke and smile, echoing the existing literature (Finlay & Antaki, 2009; Flynn et al., 2016). Although participants recommended the beneficial effects of the use of humour, as did existing literature (Finlay & Antaki, 2009), this was not frequently mobilised. In exploring nurses' avoidance of using humour with patients without learning disabilities, McCreddie and Payne (2012) suggested this might be linked to risk aversion. Bell and Cameron (2003) demonstrated that gentle humour is appropriate even in discussions that professionals consider taboo, including those surrounding sexuality. However, as a third of people with learning disabilities report being made fun of for how they look or act (Chadwick & Platt, 2018), a delicate balancing act is necessary to avoid appearing to laugh *at* rather than *with* them.

The use of touch, which was rated favourably to varying degrees by participants with learning difficulties, is a key example of the conflict between professionalism and person-centred communication. A reflection published in a leading nursing journal details a first-year student's struggle with people with learning disabilities wanting a 'cuddle'; the author explained how she learnt to divert hugs into more *professional* handshakes and high-fives (Nutting, 2010). Although setting and adhering to personal boundaries is an important facet of communication, it appears unquestioningly accepted that 'cuddles' are not appropriate. As Gale and Hegarty (2000) pointed out, the avoidance of expressive touch (i.e. that which is not required to provide care) can be interpreted as "*I only touch you when I have to*". In contrast, the use of expressive touch can communicate "*I don't have to touch you, but I want to*" (Gale

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& Hegarty, 2000:103). Expressive touch, such as hugs, is of course not always appropriate, and its association with unwanted physical attention or sexual abuse cannot be disregarded. However, it might also be problematic to exclude it as a means of communication, especially from those who may not have many other forms of communication available.

### **Limitations**

The sample were all white apart from one mother who identified as mixed race, reflecting the under-representation of black and ethnic minority people in healthcare and disability research. We could not, therefore, explore the structural disadvantages in interactions with health and social care professionals due to the intersections of race and disability (Dunham et al., 2015). While it was necessary to adapt the style of questioning according to the needs of each participant, on reflection the symbol exchange questions provided to two participants could have included questions with more depth. For example, the participants were asked whether they felt like a child or an adult when communicating with professionals; they could have subsequently been asked whether this was a positive or negative experience.

### **Recommendations**

Facilitating appropriate communication in health and social care settings can lead to improved access to care, contributing towards reducing the existing health inequalities experienced by people with learning disabilities. The following list presents some recommendations for the facilitation of more effective communication, and thus better access to health and social care for people with learning disabilities, based on the findings of this study.



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- Use of a variety of communication methods, including varying tone of voice, body language, and maintaining a positive facial expression.
- Easy Read literature needs to be made available at all appointments. If this literature is not provided, professionals should advocate for the provision of this resource or create their own resources.
- Use of communication aids such as pictures and symbol exchange needs to be promoted, according to the needs and wishes of people with learning disabilities.

Speaking simply and clearly (Broughton & Thomson, 2000), has been found to facilitate communication and could be achieved through using one subject per sentence, emphasizing the key words in each sentence, giving people with learning disabilities time to reply, and rephrasing the question, if necessary (Godsell & Scarborough, 2006). England (2012) advocated breaking complex information into smaller pieces, and regularly checking people have understood.

Providing extra time for people with learning disabilities during appointments, getting to know them before conducting assessments, and allowing them to ask questions have been highlighted as crucial by people with and without learning disabilities (Arrey, 2018; Smith, 2016). This, of course, might be difficult to achieve given that over 30% of National Health Service (NHS) staff report they always or often feel they have unrealistic time pressures, meaning this ideal may be hard to implement in practice (NHS England, 2018).

Authors with and without learning disabilities recommend Easy Read resources be available at all health and social care appointments and during hospital stays (Brown et al., 2017; Smith, 2016). In Easy Read, plain English sentences are presented next to photographs or drawings illustrating their meaning (Department of Health, 2010). Chinn (2017) argues that available Easy Read resources often place an emphasis on the creation of docile service

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users, by teaching people with learning disabilities how to integrate into existing health care services, rather than detailing risks and ways for them to be involved in their care.

Furthermore, a greater focus is needed on evaluating and distributing these resources; currently, much time is invested in producing them but far less in ensuring people can access them (Sutherland & Isherwood, 2016). This is a worrying trend; people with learning disabilities who have not been presented with information about their care in an accessible format may be denied their right to give informed consent (Barber, 2014).

The location and timing of appointments can also impact on communication (Arrey, 2018). Arranging appointments at quieter times of day and the use of a 'do not disturb' sign for examination and treatment rooms can contribute to a calm and quiet environment (Barber, 2014; Wilkinson, 2018). Even a calm environment can be anxiety-inducing if it is unfamiliar; Barber (2014) advocate introducing people with learning disabilities to a named professional and giving a tour of the clinical or social care area where possible.

While lack of training is clearly a key issue for professionals, it is important to consider that people with learning disabilities vary in their expression and worldview. There is no single structured training programme that can unlock the secret to working with people with learning disabilities. Perhaps the largest contribution professionals can make is to treat people with learning disabilities with respect.

## **Conclusions**

Communication was found to be an area of concern for people with learning disabilities and their carers, affecting their access to health and social care. Participants reported instances of ineffective and disrespectful communication and identified a desire for professionals to use different forms of communication rather than relying on verbal language alone, to relax their professional demeanour and focus on generating a fun and enjoyable

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communication experience for all parties, and to treat people with learning disabilities with respect.

Considering the social position that professionals occupy, it is important to explore how their communication style, language, and willingness to attempt to speak the language of people with learning disabilities can either reflect and recreate, or resist the existing social order. Examining one's own position of power, and being willing to show greater vulnerability and creativity in communication, is a key contribution that professionals can make towards the construction of a more appropriate and accessible care for people with learning disabilities.

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