

# Breaking the cycle of inequalities for people with a learning disability

A woman with a learning disability is likely to die from similar causes to the general population, but on average 20 years earlier than a woman without a learning disability; a man with a learning disability is likely to die on average 13 years earlier.<sup>1</sup> A learning disability is not a life-limiting illness and yet it continues to be associated with significant health inequalities.

During the pandemic, adults aged 18–34 years with a learning disability were 38 times more likely to die of COVID-19 than young adults in the general population.<sup>2</sup> Initial National Institute for Health and Care Excellence guidance (NG159) categorised many people with a learning disability into frailty categories, lowering their prioritisation for emergency triage, a situation exacerbated by the use of ‘do not resuscitate’ notices, sometimes without consultation.<sup>3</sup> It wasn't until February 2021 that people with a mild or moderate learning disability were placed in the vaccination priority groups: until then, carers of people with a learning disability were being invited for vaccine before those that they cared for.

Experience of this pandemic-related inequality and injustice has broken the fragile trust many people with a learning disability and their families had with the NHS.

Change is coming: a new digital flag for reasonable adjustments on all summary care records (currently piloting) and the roll-out of the Oliver McGowan mandatory training on learning disability and autism for all health and social care staff.<sup>4</sup> The Department of Health and Social Care will be publishing a Code of Practice for the training next year. In anticipation, there are changes that can be made now, in clinical practice and in the way we conduct our research.

### CHANGES TO CLINICAL PRACTICE

I will take diabetes as an exemplar. Primary

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care management of diabetes for people with a learning disability is not preventing emergency admissions for diabetic complications,<sup>5</sup> for several reasons. The first is learning disability registers. Coding is variable in primary care.<sup>6</sup> It is suggested that only 25% of people eligible to be on the register are on it.<sup>7</sup> In one clinical commissioning group we found 16 people whose records contained coding for Down syndrome yet they were not on the learning disability register.<sup>6</sup> The code 918E is recommended and we should be using it now. It can ensure that the individual will be invited for a learning disability health check, diabetes care plan, and any relevant vaccine priorities.

### LEARNING FROM A RANDOMISED CONTROLLED TRIAL

During a randomised controlled trial on the management of type 2 diabetes we spoke to 172 people with a learning disability and diabetes in West Yorkshire. Twenty-five were not eligible for the study. For nearly half this was because their diabetes was not type 2; the people caring for them had referred them because they didn't know the difference.<sup>8</sup> This highlighted a significant need for better understanding of diabetes in paid and family supporters.

We interviewed every person in that trial about their learning disability and about their ability to read. Not one person took offence. These conversations need to happen in primary care to establish people's communication needs and the outcome

must be recorded.<sup>9</sup> Many people told us that they couldn't read and saved up letters with NHS logos on them until a time when they could get support to read them, sometimes missing appointments as a result (Amy M Russell, unpublished data, 2018). Therefore, when people miss appointments, consider if you have communicated appropriately about their appointment: is your letter in a pile waiting to be read?

Over half of the participants had a mobile phone, but very few had a smart phone. Only 22% used the internet, a third of whom needed help to do so.<sup>8</sup> Any purely web-based service can perpetuate inequalities in adults with a learning disability.

Our trial found that glycaemic control in people with a learning disability was comparable with the general population of people with type 2 diabetes, but there were high levels of obesity and low levels of physical activity in this group. When planning activity interventions, we found that high levels of fear and experiences of hate crime inhibited people's capacity to exercise in public close to home.<sup>8</sup> Safety and transport therefore require discussion in any conversation about physical activity so that unwarranted assumptions are not made. All activity-based interventions need a discussion of wider social and economic barriers.<sup>10</sup>

### WHERE TO START MAKING REASONABLE ADJUSTMENTS IN CLINICAL PRACTICE

General practices were willing to change but didn't always know where to start to improve their care. We created a suite of resources to support clinicians, available on the Diabetes UK website,<sup>11</sup> including a co-produced easy-read guide on how to support informed diabetes management.<sup>12</sup> The site is updated with new resources as we develop them.

We evaluated these resources. We found that clinicians believed they needed specialist training to work with people with a learning disability, and that coding and making

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reasonable adjustments were perceived as someone else's role. We need to dispel these myths; addressing this inequality is everyone's business, and special training is rarely needed for general support.

A scoping review of access to health care and public health interventions for persons with a disability found evidence of disabling attitudes towards people with disabilities within clinicians, for example, the belief that people with a disability weren't suitable for certain services, wouldn't engage with certain treatments, or didn't have a quality of life worth investing resources in.<sup>13</sup> Decisions were often made without consulting with the person or their family. Data evaluating the effects of disability on healthcare interventions are also lacking and we are calling for all researchers and clinicians to record disability, and particularly learning disability as standard, to improve the quality of these data.

### CHANGES TO RESEARCH PRACTICES

Current research suggests people with a learning disability are excluded from 90% of health research automatically.<sup>14</sup> Yet there is an increased and timely interest in community engagement and co-production. To capitalise on this zeitgeist, we must place greater value on stakeholder engagement, recognising it as a research skill, and sustainably employ researchers in a way that allows them to build enduring relationships with community groups, including groups of people with learning disabilities. We must cost for, and

pay, these community groups properly for contributions throughout the research cycle from grant development to dissemination. We must design inclusivity into our research: in our materials, processes, and recruitment strategies. There are resource implications, but now is the time to ask for this funding. The door is open to such requests in ways it hasn't been before.

We need to go beyond blanket exclusions about people who lack capacity and investigate what people need to enable their informed consent. Crucially, we need to support researchers in the field who often struggle to implement capacity assessments and often, therefore, err on the side of caution. These actions will help address inequalities through increased involvement of historically excluded groups.

### CONCLUSION

Inequalities in health for people with a learning disability raise questions about our systems of care. Inequalities in our evidence base raise questions about the inclusivity of our systems of research design, funding, and approval; systems we must begin to question. While that conversation takes place my message is simple: small changes in clinical practice and research design can make a big difference to people with a learning disability.

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