

# Caregivers' experiences of supporting clients in healthcare settings – communicating with health professionals

Jane Greaves, M.Sc., Ph.D. RGN. Associate Professor<sup>a</sup>

Meaghan Grabrovaz, Senior Research Assistant<sup>a</sup>

Andrew Gibson, Consultant Neurologist<sup>b</sup>

Petra Mandysova, MSN, PhD. Deputy Dean<sup>c</sup>

Sam Browning, B.Med.Sci. BM/BS, MRCGP General Practitioner<sup>d</sup>

Julie Alderson, M.Sc. B.Sc. RGN. Senior Lecturer<sup>a</sup>

Alison Steven, RN, BSc, PGCRM, MSc, PhD. Professor<sup>a</sup>

- a. Faculty of Health and Life Sciences, University of Northumbria, Newcastle Upon Tyne, UK
- b. Consultant Neurologist, Royal Hallamshire Hospital, Sheffield
- c. Faculty of Health Sciences Department of Nursing, Palacky University, Olomouc, Czech Republic
- d. Clinical Lead for Learning Disability, Leeds CCG, Leeds

## Author contributions

JG, MG, AS, PM and JA were responsible for the study conception, design, and data collection

throughout the study. MG and JG performed the analysis. JG drafted the manuscript and all authors

commented on drafts of the manuscript and approved the final version. AG assisted with the writing

of the manuscript. JG was principal investigator for the stud

## Key words:

Learning Disability; Caregivers; Communication; early warning scores; RESTORE2 mini; thematic analysis; qualitative research

# Abstract

## Background

Caregivers often assist persons with learning disability, in their dealings with primary and secondary healthcare. Outcomes from acute illness are worse for people with learning disability than the population averages, and it is probable that difficulties with communication contribute to this problem.

## Aims

The aim of this study was to investigate and understand the experiences of caregivers who support persons with learning disability in healthcare settings such as general practice surgeries, emergency departments, hospital outpatient departments and hospital wards.

## Methods

Online, semi-structured interviews with caregivers in the learning disability sector were recorded and transcribed. The transcripts were thematically analysed to identify data about the caregivers' experiences of communicating with the wider primary and secondary health services. Analysis was an iterative process that searched for meaning in the data.

## Findings

Six themes emerged from the data. Six categories contributed to the theme "The Caregivers' Status, Skills, and Knowledge", and were significant to understanding the caregivers' interactions with health professionals. This theme and its significance for practice are discussed in detail.

## **Conclusions**

The full participation in clinical consultations by caregivers for people with learning disability is often necessary, but the caregivers report that on many occasions health professionals do not engage with them in a way that allows them to contribute fully.

## Introduction

This study reports the experiences of the caregivers of persons with learning disabilities, in encounters with the broader health services. A caregiver is a family member, or paid helper, who regularly looks after someone who needs support to cope with daily living.

The caregivers of people with learning disabilities are a heterogeneous community. Many people with learning disability live with family and friends who are described as family, or informal caregivers (Mencap, 2020). Many other caregivers are employees of local authorities, residential homes, and private care companies.

Caregivers have skills and knowledge of social care. Except for a few with incidental professional qualifications, caregivers in learning disability may have little knowledge of acute healthcare (Haigh and Garside, 2021) and have often acquired their skills and knowledge directly from their experience of caring without any formal teaching (McDonald et al., 2016).

## Background

People with learning disabilities die younger than the general population and often have chronic health problems (Cummins et al., 2021, Heslop et al., 2020). Recently, attention has been paid to the fact that people with learning disabilities have unexpectedly poor outcomes from episodes of acute illness (Badcock and Sakellariou, 2022, Glover and Ayub, 2010). In 1917 the LeDeR review of deaths of all persons with learning disabilities or autism aged over 4 years was established in England (LeDeR, 2020). In the UK these concern over poor outcomes has led to learning disability training for all healthcare professionals (eLearning for Healthcare, 2022) named for Oliver McGowan, a patient who tragically died during hospital admission (McGowan, 2022), and whose LeDeR inquiry was found to be flawed (NHS England, 2020). Oliver's difficulties were partly caused by the health professionals concerned with his care disregarding information provided by his family.

People with learning disabilities often require the services of community and secondary health services. Many people with learning disabilities are unable to explain their needs, the nature of their problems, or their symptoms. Their caregivers assist them and speak for them in these situations.

Problems of communication have long been recognised to be a factor contributing to service inequalities. In 1995 Simpson suggested that when people with learning disabilities require hospital services:

*“Staff from community learning disability teams ... could support the person during the interview, acting as an interpreter to help the person understand the doctor and vice versa.”*  
(Simpson, 1995)

There have been a number of studies of problems of communication between healthcare professionals and people with learning disabilities from the point of view of health professionals (Drozd and Clinch, 2016, Morton-Nance and Schafer, 2012). The study presented here is an analysis of the experience of caregivers as they advocate for those with learning disabilities.

This study took place in the context of a national initiative by NHS England to introduce RESTORE2 Mini (Anderson and Douglass, 2021) to the Learning Disability community. RESTORE2 Mini is a scoring system to help in the early diagnosis of acute illness by identifying “soft signs”. These are minor changes in behaviour that are often seen before the patient’s vital signs become abnormal.

## Study aims

The aim of this study was to understand the experiences of caregivers who support persons with learning disability in healthcare settings such as general practice surgeries, emergency departments, hospital outpatient departments and hospital wards.

## Method

### Study design

Semi-structured interviews were used to explore, and evidence, the lived experience of caregivers from the learning disability sector, in encounters with health professionals. The Consolidated Standards for Reporting Qualitative Research checklist was used to report this study (Tong et al., 2007). Verbatim quotes from the caregivers are used to exemplify and add verisimilitude to aspects of the analysis.

### Ethical Approval

This study was carried out according to the Declaration of Helsinki and received ethical approval from the University of Northumbria Research Ethics Committee. The project was monitored by a multidisciplinary steering group.

### Recruitment and consent for Interview

Participants were caregivers for adults with learning disabilities who had attended RESTORE2 Mini training. The background of caregivers recruited for the overall study is shown in table 1.

*Table 1 Numbers and categories of participants*

	Family caregiver	Salaried caregiver	Shared Lives carer*	Healthcare professional for learning disability	Total
Number of participants	8	8	3	14	33

\* Is where an adult with learning disability either lives with or regularly visits a shared lives caregiver in the home of that caregiver and shares in the family and community life of that caregiver.

A mix of paid and unpaid caregivers who provided care at home, in supported care environments, or in care homes were recruited using convenience and purposive sampling. Thirty-three caregivers took part in the study. A telephone discussion of the research preceded the agreement to consent to participation. No volunteers withdrew from the study.

## **Data collection**

Data collection took place between February and April 2021. Semi-structured Interviews using a discussion guide were recorded, using Zoom. The focus was the caregivers' experiences of communicating with health professionals.

## **Analysis**

The interviews were transcribed, and data were held and organised using NVivo™ software. Braun and Clarke's (2006) flexible six-step guide was adopted to explore the interview transcripts (Braun and Clarke, 2006). Data relating to caregivers' communications with the wider primary and secondary health services were extracted to nodes. Analysis was an iterative process that searched for meaning in the data. These were allocated to 30 categories which were then combined into six themes (Guest et al., 2012).

## **Findings**

The interview data were mapped to six themes which are shown in Table 2. The first is "Caregivers' Status, Skills, and Knowledge". Six categories contributed to this theme (Table 3). Here we discuss these issues relating to the status, skills, and knowledge of the caregivers. A report of all the findings, including the verbatim quotes, is available online (Greaves, 2021).

***Table 2: The six themes to which the data mapped***

• Carers' Status and Skills
• Carers' emotions and stress levels
• Carers' previous experiences
• Carers' working or caring environment
• Health professional related
• Health care system structural or procedural issues

**Table 3: The six nodes contributing to the theme "Caregivers Status Skills and Knowledge"**

Theme	Categories
Caregivers' Status, Skills, and Knowledge	<ul style="list-style-type: none"> <li>• Health professionals often do not listen to caregivers</li> <li>• Health professionals mistakenly presume the caregiver has medical knowledge</li> <li>• Health professionals discount the caregiver's insight into the patient's condition</li> <li>• There is ambiguity about the caregiver's role in acute healthcare environments</li> <li>• Problems with advocacy roles</li> <li>• The stigma of the anxious/pushy parent or time-waster label</li> </ul>

## The caregiver's Status, Skills, and knowledge

### Health Professionals do not listen to the caregivers

This study showed that whilst carers often *do* have valuable information about the person they are caring for, this is sometimes not valued or recognised by health professionals. Caregivers identified their lack of professional certification, lack of technical language, and low-pay status as contributing to this problem.

In secondary care, health professionals have established routines that they follow. This is often not possible in the case of an individual with learning disabilities. An example is in establishing a medical history. People with learning disabilities may not reveal symptoms for a number of reasons: not understanding the question, being frightened to admit symptoms, wanting to tell the doctor what



they want to hear, or to being a person who gives a stereotyped response - such as always repeating the question. Caregivers report that they are not listened to when they attempt an explanation of best to communicate with the individual with learning difficulties.

*“I think they understood why we were concerned. I’m not sure how much value they placed on the data that we were providing.” Caregiver 2*

Several carers described incidents where they tried to pass on information, essential for appropriate care and treatment, but they were ignored. They reported that health professional seemed unwilling to 'listen' or 'hear' information that was not what they were expecting or are used to hearing in similar situations.

For one carer, a former health professional, it felt like a reluctance of some health professionals to adopt a different perspective.

*“It’s all about perspective. How do you actually get them to switch onto the same page as you are on...Because they’re working to their own agenda...You tend to know their needs far better than anybody that’s... but they think, ‘I know better than you because I’m a trained healthcare practitioner’” (Shared Lives carer, former health professional)*

One family caregiver, who is a practicing health professional, reflected on their own clinical training remembering how they were trained in a specific approach so that it became deeply ingrained.

*“Health professionals may be working in a dynamic, often life or death environments, working within protocols, all of which can lead to heuristic ways of thinking and processing information. This may mean that for some health professionals dealing with information that is different, or is presented in a different way, to ‘normal’ takes additional energy and mental effort to process and incorporate into their decision-making process.” (Family caregiver 1)*

In primary care, caregivers have a particular problem in getting access to services.

*“We have a very good relationship with our GP surgery that we’ve built up over many years. Which is a big advantage. But... trying to get through the receptionist, it’s not*

*always easy. Sometimes we just need a conversation with the GP but trying to explain that to a receptionist can be a battle.” (Parent carer 2)*

Patients with learning disabilities do not conform to the usual ways of getting access to a doctor. The caregivers need the service to be flexible, but the participants in this study reported that adherence to customs or protocols complicates the care of people with learning disabilities.

*“Yeah, I would say the most challenging part - and I feel horrible saying this – is, sometimes, receptionists. Because when you’re phoning up for an emergency... You really have to come across almost as stroppy, and say, ‘Look! No! It’s an emergency!’. Or I end up having to say sometimes, ‘I’m not prepared to, you know, talk about this - I want a doctor’”. (Parent carer 1)*

### **The carers' special skill in supporting people with learning disabilities is not recognised**

Not understanding that caregivers have valuable skills and knowledge was identified as a key issue contributing to health professionals’ attitudes.

*“I think people who work in hospital find it very hard to differentiate between the very specialist support that people... with learning disability experience are able to offer. And the kind of generic support that it’s assumed that elderly people get”. (Manager, care provider organisation).*

Caregivers felt that their work required person-centred care, as opposed to task-orientated care.

Thus, getting to know people well, and being able to interpret subtle, variable, and confusing communication signals, health cues, and behaviours are part of a distinct caring skills set.

*“I think, ... we need to recognise the skill of support workers, as opposed to care assistants. I think that knowing and understanding somebody with a learning disability is a really skilled job.” (Family Caregiver 2).*

A person with a learning disability can exhibit unexpected behaviour when confronted with new situations, and the abnormal sensations of an illness. The caregivers felt that their special insight at these times would facilitate investigation and treatment. Furthermore, they found that many health

professionals did not understand that an underlying diagnosis of a learning disability could significantly change the presentation and symptoms of an episode of acute illness.

Caregivers reported that avoidable difficulties arose from their being unable to explain to healthcare professionals that the person with learning disabilities could be predicted to respond badly in some situations, often by becoming distressed. This distress was often focused on the caregiver and rather than being asked to help, caregivers said they were often asked to leave, which further exacerbated the distress.

A caregiver described how a situation escalated to violence when the health professionals ignored her advice. They explained that the individual would not accept having stitches removed at home and had to go to hospital:

*“We tried to do it at home... And we said, ‘We’re going to have to take him to hospital, sedate him, and then take the stitches out’. ... the GP explained it...But by the time it got to the afternoon, the shift had changed... And the doctor was like (sic), ‘This is a waste of my time! I don’t see why I have to do this!..... And he got up in this guy’s face and he really didn’t like it. And I said, ‘Look, you’re going to have much more success if you approach him from the side’. .. And he got a right hook! And luckily.....we managed to sedate him, and we managed to get the stitches out.” (Manager, care provider organisation).*

Situations like this were reported to lead to instances of the patient being given sedatives unnecessarily or being sent away without treatment.

### **Health professionals mistakenly assume that the caregiver has “medical” knowledge**

Health professionals often use technical ‘medical’ terminology when speaking to caregivers and caregivers reported that when they used ‘The wrong words’ healthcare professionals discounted what they were trying to express. Caregivers were sometimes told things they needed to know in language that they could not understand. This is a serious problem when the caregiver is responsible for continuing care - such as medication.

*“You see... I’ve not got the language. Sometimes they explain things using medical terms that I don’t understand and they look at me as though I’m daft when I say, “What do you mean” (Family Caregiver 3)*

### **Health professionals discount the caregiver’s insight into the patient’s condition**

Caregivers described how they were able to recognise the signs of early acute illness in the people for whom they care, but that their opinion was not listened to by the health professionals.

*“Sometimes – particularly during COVID, I’ve recognised the signs of deterioration and people haven’t taken me seriously.” (Health professional, Nurse practitioner, Care home Support Team)*

A further problem is that the symptoms and signs of acute illness in a person with learning disabilities can sound quite bizarre.

*“Saying the person I support is squeaking high... a high-pitched squeak, when usually he makes low-pitched squeaks – it’s quite difficult for someone else to understand what that really means” (Care support manager).*

*“I’m just thinking, there’s one gentleman, about whom I used to have a regular conversation with a GP..... He used to have regular chest infections.... And the first sign of them that we used to get was he would shout. You needed earplugs because he could shout for 24 hours, really, really, loudly. And I knew this was the first sign of a chest infection. .... I don’t know how you would even write that out. Because you would never go to a doctor and say, ‘Well, the symptom of a chest infection is shouting!’” (Care Home Caregiver).*

### **The caregiver’s role in acute healthcare environments such as hospital wards is misunderstood**

Many people with learning disabilities manage their own personal care and hygiene. In hospital, the nursing staff sometimes ask the caregiver to help with a variety of nursing tasks that they do not normally undertake. The caregiver often does not have the required expertise and their relationship with the person for whom they care does not normally include intimate treatments which may not be acceptable to either the caregiver or the patient.

*“One time the nurse asked me to help wash him and he was not used to me seeing him undressed and was distressed. Then she got annoyed because I didn’t know what to do – with washing in bed. He lives on his own and copes usually, so what she was wanting was not the same as helping him with his shopping! (Family Carer)*

### **Problems with advocacy roles**

Experienced caregivers talked about how, over time, they had developed the confidence to speak effectively for the people for whom they cared.

*“Not everybody is comfortable disagreeing with a doctor. And that’s cultural. That’s generational. That’s about being marginalised and all that stuff. Experience helps you speak up”. (Manager, care provider organisation).*

There was ambiguity in the role of the caregiver. Communication with people with learning disabilities can be difficult and they often look to their caregiver for reassurance, and for explanations about what is happening to them. The caregiver may be needed to interpret the person's response to examination and treatment. The carer’s insight may be necessary to prevent the diagnostic overshadowing that occurs when a health professional attributes all their symptoms and signs to their learning disability.

*“I had to say, ‘No, that’s not a feature of her learning disability. It’s something new’”. (Care home Caregiver)*

### **The stigma of the anxious/pushy parent or time-waster label**

Caregivers of all types and from all backgrounds spoke about their experiences and the effect of being labelled as ‘time wasters’ or as ‘anxious’, neurotic’, or a ‘pushy parent’. This was particularly a problem for family carers.

*“I’ve found that some think that you’re just over-protective. Or, you know, you’re a worrying mum”. (Shared Lives carer 2)*

## Discussion

It has been reported that half the caregivers of people with mild to moderate learning disabilities felt that they, and the person with learning disabilities, had been unfairly treated by the health professionals responsible for their care (Ali et al, 2013). Mastebroek et al. (2016) found that impaired doctor/patient communication, and the role of caregivers in facilitating consultations, were important themes in a qualitative study of health information exchange in General Practice. Ryan et al. (2017) conducted a focus group study of people with learning disabilities and found that the desire to be heard was high in their requirement for health service encounters). Gregson et al. (2022) reviewed the literature relating to consultations with persons with learning disabilities and discovered an overarching theme “Include me” expressed by caregivers and by the persons with learning disabilities themselves.

The study here reported, confirms that, from the perspective of the caregivers, communication with health professionals is often poor. The persistent complaint of the caregivers is that they are not included in discussions, and that their contribution is disregarded. This is significant because people with learning disabilities *do* have worse outcomes than would be expected (Louch et al., 2021), and many of their problems start with communication between professionals (Tuffrey-Wijne and Hollins, 2014, Tuffrey-Wijne et al., 2014).

### **The Role of Caregivers**

Communicating with persons with learning disabilities is challenging for health professionals. Some individuals with learning disabilities seem to respond in ways that show they understand. The caregiver may know that the person is using a ‘stock’ response and has not understood. Others with learning disabilities may respond in ways that are meaningless to the health professional, but that the caregiver understands. Many persons with learning disabilities only function adequately in a healthcare environment with the constant assistance of their caregiver. The presence of the

caregiver should be accepted as a 'Reasonable Adjustment'(NHS England, 2016) to the management of many people with learning disabilities (Heslop et al., 2019). The caregiver gives the person with learning disability a voice - allowing them to participate in decision-making. A study of medical practitioners found that though they recognised the value of carers and family in facilitating communication, they did not identify that the carer's presence should be encouraged, as a 'reasonable adjustment' (Redley et al., 2019).

Lewis et al (2017) reviewed the literature relating to nurses' difficulties in dealing with patients with learning disabilities. Along with communication difficulties, they identified that nurses have "Ambiguous expectations of paid and unpaid caregivers" (Lewis et al., 2017). Health professionals are used to working with healthcare assistants and see the caregiver as filling this role. They do not recognise that the learning-disability caregiver brings insights, skills, and knowledge that are essential to the smooth management of care.

### **Caregivers' contribution to practice is overlooked by Health Professionals**

It was a salutary experience to hear how caregivers were sometimes treated by health professionals in acute care. These interviews revealed multiple stories of caregivers' concerns and opinions being disregarded by health professionals. All staff groups were guilty of this, including senior doctors. There were a number of reports of incidents where the caregiver believed that a patient was harmed by their concerns being ignored. The caregivers also believed that health professionals, with little experience of learning disability, expect the symptoms and signs of disease to be unaffected. Their expression can be very altered by the individual with learning disabilities response, close experience of that individual is necessary to recognising their changed behaviour. People with learning disabilities may also respond very differently to the use of routine, relatively unthreatening medical devices. A caregiver is accustomed to gentling and cajoling towards cooperation and understands that even a spoon can be scary.

## Limitations of this study

### Strengths:

This study explored the lived experience communicating with health professionals by paid and unpaid caregivers working in all settings of learning disability care throughout England. In-depth qualitative interviews gave participants the opportunity to clearly explain their encounters with health professionals. They were able to make clear their frustrations and their anxiety when they felt they were being disregarded.

### Weaknesses:

There were limited numbers of interviewees from each care sector and only the perspective of caregivers is explored. The COVID-19 pandemic obliged the team to conduct all interviews online.

## Conclusions

This study indicates that caregivers believe they can facilitate clinical care by assisting communication between the person with learning disabilities and health professionals and by understanding how their usual behaviour has changed. When a person with learning disabilities needs the attention of healthcare services their caregiver acts as their supporter, interpreter, and advocate. A person with learning disabilities denied the presence of a caregiver who understands them, loses their voice just as surely as does a person dependent on sign language when no one knows how to sign.

Caregivers expressed their conviction that their advocacy on behalf of the person with learning disabilities can be inhibited by the cultural norms relating to the perceived relative status of members of the healthcare team (Green et al., 2017). These can be real impediments to caregivers speaking up for the people they care for. For family carers, who do not have the support and encouragement of colleagues and managers to legitimise their concerns and actions, it can require



persistence in the face of quite an active dismissal by health professionals to get the response they need. Caregivers, despite often being the only person who really knows and understands the person with learning disabilities, have no official place in discussions.

Prompt, appropriate management of persons with learning disabilities who present with acute illness should be improved by recent initiatives to teach caregivers how to recognise the clinical signs of deterioration. These programmes also provide caregivers with a vocabulary that will improve their communication with health professionals. The findings from the current study demonstrate that the hesitancy of healthcare professionals to recognise the special role of caregivers is another barrier that needs to be overcome.

## Implications for Practice

- Caregivers must be recognised as having a specialised role in the care of persons with learning disabilities.
- Health professionals should recognise that caregivers for persons with learning disabilities have valuable skills in understanding and communicating with the people for whom they care.
- The active participation of caregivers is essential for persons with learning disabilities encountering healthcare professionals.
- Caregivers may not have the clinical and personal care skills of healthcare assistants.

## References

ALI, A., SCIOR, K., RATTI, V., STRYDOM, A., KING, M. & HASSIOTIS, A. 2013. Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PloS one*, 8,e70855.

- ANDERSON, A. & DOUGLASS, E. 2021. Developing a personalised tool to detect physical deterioration in adults with learning disabilities in community settings. *Learning Disability Practice*, 24.
- BADCOCK, E. & SAKELLARIOU, D. 2022. "Treating him... like a piece of meat": poor communication as a barrier to care for people with learning disabilities. *Disability Studies Quarterly*, 42.
- BRAUN, V. & CLARKE, V. 2006. Using thematic analysis in psychology. *Qualitative research in psychology*, 3, 77-101.
- CUMMINS, L., EBYARIMPA, I., CHEETHAM, N., TZORTZIOU BROWN, V., BRENNAN, K. & PANOVSKA-GRIFFITHS, J. 2021. Factors associated with COVID-19 related hospitalisation, critical care admission and mortality using linked primary and secondary care data. *Influenza and Other Respiratory Viruses*.
- DROZD, M. & CLINCH, C. 2016. The experiences of orthopaedic and trauma nurses who have cared for adults with a learning disability. *International journal of orthopaedic and trauma nursing*, 22, 13-23.
- ELEARNING FOR HEALTHCARE. 2022. The Oliver McGowan Mandatory Training [Online]. London: Health Education England. Available: <https://www.e-lfh.org.uk/programmes/the-oliver-mcgowan-mandatory-training-on-learning-disability-and-autism/> Accessed 21<sup>st</sup> Nov 2022
- GLOVER, G. & AYUB, M. 2010. How people with learning disabilities die. *Learning Disabilities Observatory*, 2010, 1-55.
- GREAVES, P., STEVEN, A., ALDERSON, J., GRABROVAZ, M. 2021. An exploration and evaluation of mechanisms to aid recognition of acute deterioration in people with learning disabilities: "What do I need to know?". In: UNIVERSITY, N. (ed.). Northumbria University: Northumbria University.

Available at:

<https://nrl.northumbria.ac.uk/id/eprint/50112/1/Acute%20deterioration%20report%20Nov%202021%20Northumbria%20Uni-1660905614.pdf> Accessed 7<sup>th</sup> Dec 2022

GREEN, B., OEPPEN, R., SMITH, D. & BRENNAN, P. 2017. Challenging hierarchy in healthcare teams—ways to flatten gradients to improve teamwork and patient care. *British Journal of Oral and Maxillofacial Surgery*, 55, 449-453.

GREGSON, N., RANDLE-PHILLIPS, C. & HILLMAN, S. 2022. People with intellectual disabilities' experiences of primary care health checks, screenings and GP consultations: a systematic review and meta-ethnography. *International Journal of Developmental Disabilities*, 1-17.

GUEST, G., MACQUEEN, K. M. & NAMEY, E. E. 2012. Introduction to applied thematic analysis. *Applied thematic analysis*, 3, 1-21.

HAIGH, S. M. & GARSIDE, J. 2021. Effects of the Care Certificate on healthcare assistants' ability to identify and manage deteriorating patients. *Nursing Management*, 28.

HESLOP, P., BAKER-GLENN, E., FLEMING, P., KNIGHT, M., MASON, M., TURNBULL, P. & WADE, C. 2020. The impact of the national clinical outcome review programmes in England: a review of the evidence. *Clinical Medicine*, 20, e52.

HESLOP, P., TURNER, S., READ, S., TUCKER, J., SEATON, S. & EVANS, B. 2019. Implementing reasonable adjustments for -disabled people in healthcare services. *Nurs Stand*, 34, 29-34.

LEDER 2020. Learning Disability Mortality Review (LeDeR) programme: Action from Learning Report 2019/2020.

LEWIS, P., GAFFNEY, R. J. & WILSON, N. J. 2017. A narrative review of acute care nurses' experiences nursing patients with intellectual disability: underprepared, communication barriers and ambiguity about the role of caregivers. *Journal of Clinical Nursing*, 26, 1473-1484.

LOUCH, G., ALBUTT, A., HARLOW-TRIGG, J., MOORE, S., SMYTH, K., RAMSEY, L. & O'HARA, J. K. 2021. Exploring patient safety outcomes for people with learning disabilities in acute hospital settings: a scoping review. *BMJ Open*, 11, e047102.

MASTEBROEK, M., NAALDENBERG, J., VAN DEN DRIESSEN MAREEUW, F. A., LAGRO-JANSSEN, A. L. & VAN SCHROJENSTEIN LANTMAN-DE VALK, H. M. 2016. Experiences of patients with intellectual disabilities and carers in GP health information exchanges: a qualitative study. *Family practice*, 33, 543-550.

MCDONALD, J., MCKINLAY, E., KEELING, S. & LEVACK, W. 2016. Becoming an expert carer: the process of family carers learning to manage technical health procedures at home. *Journal of Advanced Nursing*, 72, 2173-2184.

MCGOWAN, T., MCGOWAN, P. 2022. Oliver McGowan's Story [Online]. Oliver's Campaign. Available: <https://www.olivermcgowan.org> [Accessed 15/11/2022 2022].

MENCAP. 2020. *How common is learning disability* [Online]. Mencap. Available: <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability> [Accessed].

MORTON-NANCE, S. & SCHAFER, T. 2012. End of life care for people with a learning disability. *Nurs Stand*, 27, 40-7.

NHS ENGLAND. 2016. *Reasonable Adjustment* [Online]. NHS England. Available: <https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/>

NHS ENGLAND. 2020. Independent Review into Thomas Oliver McGowan's LeDeR Process: phase two [Online]. London: NHS England. Available: [https://www.england.nhs.uk/wp-content/uploads/2020/10/Independent-Review-into-Thomas-Oliver-McGowans-LeDeR-Process-phase-two-\\_20-October-2020.pdf](https://www.england.nhs.uk/wp-content/uploads/2020/10/Independent-Review-into-Thomas-Oliver-McGowans-LeDeR-Process-phase-two-_20-October-2020.pdf) .

REDLEY, M., LANCASTER, I., PITT, A., HOLLAND, A., THOMPSON, A., BRADLEY, J. R., GLOVER, G., THOMSON, K., JONES, S. & HERBERT, B. 2019. "Reasonable adjustments" under the UK's Equality Act 2010: An enquiry into the care and treatment to patients with intellectual disabilities in acute hospital settings. *Journal of Applied Research in Intellectual Disabilities*, 32, 1412-1420.

RYAN, S., HISLOP, J. & ZIEBLAND, S. 2017. Do we all agree what "good health care" looks like? Views from those who are "seldom heard" in health research, policy and service improvement. *Health Expectations*, 20, 878-885.

SIMPSON, N. J. 1995. Bridging primary and secondary care for people with learning disabilities. *Advances in Psychiatric Treatment*, 1, 207-213.

TONG, A., SAINSBURY, P. & CRAIG, J. 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care*, 19, 349-357.

TUFFREY-WIJNE, I., GOULDING, L., GORDON, V., ABRAHAM, E., GIATRAS, N., EDWARDS, C., GILLARD, S. & HOLLINS, S. 2014. The challenges in monitoring and preventing patient safety incidents for people with intellectual disabilities in NHS acute hospitals: evidence from a mixed-methods study. *BMC Health Services Research*, 14, 1-13.

TUFFREY-WIJNE, I. & HOLLINS, S. 2014. Preventing 'deaths by indifference': identification of reasonable adjustments is key. *The British Journal of Psychiatry*, 205, 86-87.