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An exploration and evaluation of mechanisms to aid recognition of acute deterioration in people with learning disabilities:

“What do I need to know?”

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Glossary

Paid carer	– Someone who is employed to provide care on a paid basis
Shared Lives carer	– Shared lives schemes support adults with learning disabilities, mental health problems or other needs that make it harder for them to live on their own. The schemes match someone who needs care with an approved carer. The carer shares their family and community life and gives care and support to the person with care needs.
Unpaid carer	– Anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. Family carers may be in receipt of Carer’s Allowance but are considered as unpaid carers in this study

Abbreviations and notations

GDPR	General Data Protection Regulation
DNACPR	Do not attempt cardiopulmonary resuscitation
LeDeR	Learning Disabilities Mortality Review
EWS	Early Warning Score
NEWS	National Early Warning Score
NEWS2	National Early Warning Score version 2
PMLD	Profound and Multiple Learning Difficulties

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“My son was 15 at the time. And developed quite a life-threatening situation, because I wasn’t listened to. He had appendicitis. He’d been away, and he came back. And my son has a really high pain threshold, ridiculously high. So, I phoned my GP. My GP was amazing, because they know my child. And, for my child to say that he’s hurting, you know there’s a bad pain. Because he’s got a bowel condition as well. And he said, my tummy hurts. So, I gave him his medicine. And he came back down and said, that hasn’t worked. And I thought, “Oh, keep an eye on this.” And then it didn’t work. So, I phoned my GP. And my GP said, “No, something is wrong. Get him, come down to the surgery, get the letter and go to A&E.”

Once I walked into A&E, I may as well have been invisible. And because my son wasn’t screaming the place down, they were saying, “No, it’s just a food bug.” They gave him anti-sickness because he couldn’t keep anything down. To the point when they discharged us. He threw up blood in the A&E... The main A&E! And they still sent me home. Saying, “Oh, it’s anti-sickness - it doesn’t stop you being sick.” So, the next day we went back, which was the Monday. I then refused to leave. That’s what I was saying about being a pushy parent, because that’s how I was labelled at that time. Because I staged a sit in. You know, I was not leaving. Luckily, his consultant for his bowel problem worked at the same hospital. So, when his consultant then came up, and he said... In the middle of A&E....much to my son’s dismay, “I had a camera up his... Because he had to have a colonoscopy about four weeks before. He said, “I had a camera up his bum and he didn’t even ask for a painkiller.” He said, “If this kid tells you he’s in pain, he’s in agony. And it took them five days to find out he had appendicitis. And by the time they operated, it was bursting. So, then they had to remove part of his bowel. Now, it was because... I stand by this.....I wasn’t listened to. I was classed as a neurotic parent. And that’s what I’m saying - it’s how you’ve asked him the question. So, if you said to him, “Does it hurt there?” And then you pressed there... If you didn’t say to him, “Does it hurt there?” He wouldn’t think to say... But because he’s so articulate, people thought it was just me being fussy”. (Parent carer, 31031200).

“I can remember one when I was first a support worker. So, I’m like 23, 24... And I was really, really new and green. And... I had a gentleman... And I think I took him to the doctors on the Friday for medication review. And he had epilepsy. And I knew nothing at this point. And the doctor said, “Oh, he’s on the wrong medicine”. And she cut a load of his epilepsy drugs there and then. And... You know, I’m 23 - the doctor has told me to do this. I’ve written it down. I’m doing it. There’s a letter to prove it. I go back... He comes down to his mum’s for the weekend, comes back looking absolutely dreadful. He’s been seizing the whole time. And I called the doctor - and they said, “No, no - he’s just getting used to his medicine changing”. And I called again, and I think I called an ambulance the next morning, and he went into hospital. And he was really, really ill. He really should not have had those meds dropped. And certainly not that quickly. And that’s the first time I remember getting really angry that I could see something was wrong, and I was treated like I was stupid. And actually the person was put in danger”. (Learning disability health professional, 16020930).

Executive summary

Background

Many people require help with everyday life and the management of their healthcare. One such group is people with learning disabilities. They may be cared for in their own homes, in care-homes or nursing homes. They are not ill, though they often have chronic health problems, but are as susceptible to acute conditions, such as Covid-19 and sepsis, as the rest of the population. It is known that persons with Learning Disability have worse outcomes from acute illness than average. This was highlighted recently by their worse outcomes from Covid-19 infection than other population groups.

Most adults, when they develop an acute illness can make clear that they are feeling unwell and are able to communicate their symptoms. They can trigger the healthcare system to provide the support, investigation, and treatment appropriate to their condition. Children, elderly people with cognitive decline, and people with learning disabilities are less able to do this. When they become ill, they are more dependent upon those around them recognising that there is a problem, and this can often be difficult as their behavioural and emotional responses are sometimes understandable only to those who are familiar with their 'usual'.

In acute care settings Early Warning Scores (EWS) are used to identify the signs of deterioration. These use a score derived from the usual monitoring information that is recorded routinely. Recently EWS has been introduced in community settings where people do not normally have their vital signs monitored. Some EWS require monitoring of the patients' vital signs (Pulse, Blood Pressure, Oxygen Saturation, Respiratory Rate and Conscious Level) whereas others depend on small changes in behaviour and do not require the use of any equipment.

Study aims and design

Aim:

1. To investigate and evaluate the current use, the potential for future use and the impact of routine use of Early Warning Systems to identify acute deterioration in people with a learning disability. Design: A qualitative approach to explore and evidence the lived experiences and knowledge of paid and unpaid carers with respect to the following topics:

- **Their ability to recognise the early signs of illness and deterioration in the condition of adults with a learning disability**
- **Their experiences of escalating their concerns to get timely help and treatment**
- **Their thoughts and opinions about the usefulness of such tools and education**

2. To review the variety of EWS being used outside of acute care in England.

3. To identify the range of soft signs recognised by the participating carers.

The Sample

During the development stage of the project, we were also asked to evaluate an NHS England project to teach the use of Restore2 Mini to carers for people with learning difficulties. This review became the source of the sample of carers interviewed for the overall study. This decision was partly a response to the difficulties presented by the onset of the pandemic that complicated the use of a general sample of carers.

Thirty-three participants were recruited from the training sessions: 10 family carers (unpaid); 10 paid staff members working for care provider organisations (paid carers); 4 Shared Lives carers (paid carers). Nine participants were recruited from super-trainer sessions.

Semi-structured interviews with the carers were transcribed and analysed for significant themes.

Results

The carers' concerns

- Health professionals do not value the knowledge and skills the carers possess in their role and disregard their contributions. Carers report that this sometimes results in unnecessary clinical complications.
- Carers themselves accept that they do not have the necessary technical language for communicating with health professionals.
- Primary and secondary care 'gatekeepers' often lack the knowledge to recognise the urgency of an issue raised by carers. This can lead to delay in securing appropriate treatment.
- Some patients do not have their learning disability registered with their GP. This complicates issues of access and entitlement to services.
- Carers lack confidence in their capacity to undertake clinical tasks – such as making vital signs observations.

Training for Restore2Mini

- Those carers who had attended training sessions in the use of Restore2 Mini liked the format of the training and found the content useful.
- Carers who attended training for Restore2 Mini were subsequently more confident in making assessments
- Carers endorsed the Restore2 Mini as providing them with appropriate language to describe acute illness.
- Carers endorsed the use of an early warning score that included vital signs, where it provided baseline values that were useful in the interpretation of subsequent episodes of deterioration.
- Carers believe that without Learning Disability awareness training for acute sector medical professionals the potential benefits of Restore2 Mini will not be realised.
- Carers believe that if those managerial and administrative staff who control access to primary and secondary care gatekeepers do not have training in the use and language of Restore2 Mini its potential benefits will not be realised.

Scoping review of tools in use in England

A wide range of EWS tools were identified. Carers favour those that do not require the use of equipment for measuring the individual's vital signs. The reasons for this were that the high rate of staff turnover and the heterogenicity of background of carers makes the more complex training for making physiological measurements difficult, that many people with learning disabilities find procedures such as blood pressure measurement frightening, and that the use of soft signs indicators endorses and augments the carers intuitive evaluation of their clients.

Soft signs

Soft signs are changes from an individual’s usual behaviour that indicate that an individual may be becoming unwell. This study identified a wide range of types of soft signs that those caring for people with a learning disability have encountered. Soft signs are highly variable and, in the case of those with learning difficulty, sometimes unusual; thus, it can take time and personal knowledge of the individual for carers to become experienced in their recognition.

"At the GP's when we asked about her ears – because she had an ear infection at the time – he did a swab There was no information given to us about when we would find the results of the swab, whether there was an infection. Nothing. It was a ridiculous situation. So, she had this ear infection – he took the swab. He did his learning disability check.

And then we never actually got the results back from this swab that he took for her ear. Three days later, because of her autism and her learning disability, she found it very difficult to tell people stuff without them actually targeting, and pinpointing specific areas. So, unless I said to her, "[name], how are your ears today?" She wouldn't actually tell me. I would say, "How are you today?" And then she would say, "Yeah, I'm fine." But, actually, her ears were killing her. So, we phoned up her doctors surgery, and said, [name]'s ears are absolutely killing her, can we please see a GP, because we've already been prescribed the wrong antibiotics by another GP last week. I said, "We need something. She's crying her eyes out here. You know, she's in agony". And they said, "Oh, we'll get her GP to ring you back today." They never rang us back. And [name] actually has a job coach, and she had a job at our local hospital. Because she'd had untreated urine infections in the past, she'd had a lot of time off of work because of kidney pain. So, she was on a… on a written warning from work, for having too much time off. Because of that, she couldn't take time off of work, this day – when she was in pain. So, she went into work in agony. I was waiting for a phone call – I kept ringing the doctor's surgery to say, "Look, I really need to speak to the doctor before she goes into work, because I need to get her medication sorted out before everywhere shuts, you know." And… they didn't ring me back. Anyway, eventually – she went to work. They did ring me back at… It was 6:30. I picked the phone up, and then they put the phone straight down on me. And I phoned back immediately – the doctors surgery. And I said, look, somebody has just rung me, and they've put the phone down – and it was then the receptionist You know, after you'd been through the whole press 1, press 2, press 3… Oh, she said. I'm so sorry. I'll send a message to the GP now and tell him to ring you back immediately. Well, he never rang. So, I was then left with this young lady who's got a learning disability and autism, at work, in agony with her ear infection. No doctor. She'd… Incidentally, she'd been shielding for the previous, I think, six weeks. And it was her first day back at work from shielding. So, I rang 111 – that was the advice I was given. I rang them up. They organised, what they told me was, an appointment at A&E. You know… to go and see a GP. So, we got up there, after she'd finished work at eight o'clock. We walked into the waiting room. They knew nothing about any appointment. They told us just to wait to see the doctor, and hopefully the doctor at A&E would see us before he finished at 9:30. So, we waited in a packed waiting room – obviously with this COVID around – and we waited for an hour and a half. And then we saw the doctor come out of his office, and I then sort of shouted out, excuse me… I said, "Are you the GP who's working in here today." He said, "Yeah, are you leaving now?" And he said, "Yeah." And I went, "We're desperate to see you." And he said," I'm so sorry. I'm finished for the day." He said, "You'll have to wait now and see one of the doctors, you know, in A&E. You know, through the doors, I suppose". So, this was now half past nine. And to cut a very long story short, we got out of that hospital at half past three the following morning, having seen a doctor, who looked in [name]'s ear and said, you definitely need to be seen by a specialist. You need somebody to looking in your ears. I'm going to give you a prescription. So, they gave us the prescription for some medication. They didn't give us any medication there and then, which is what we wanted. They did give us some… Oh, I can't remember the name of it. It was a really, really heavy pain relief. It began with an N. Which got her through the night. The next morning, I phoned 22 different pharmacists, who didn't stock this medication. Because they said they no longer could get it. They've stopped, sort of, issuing it. And all these pharmacists that I spoke to said you need to get some [medication name]. So, I said, right, how do I get this ___? Oh, you're going to have to go back to the doctors again. So, we started the whole rigmarole again of phoning the doctor, trying to get an appointment". (Shared Lives carer, 08041100).

1 The Study

1.1 Introduction

This study gave a voice to those who care for people with learning disability. They support the lives of people who, owing to learning disability, are unable to cope with some, or all aspects of independent life. Some of the people they support cannot talk, and struggle to communicate by any means at all. Others, can live lives in society, marry, have children, and go out to work; but none of them can do what they do without some level of support. The interviews reveal an extraordinary level of commitment. Many carers are unpaid, some earn the minimum wage, many are family members, many are as dedicated as if their charges *were* their own family. This research has given them a voice, and as you read the verbatim quotes you will see the matter-of-fact language with which they describe almost insurmountable problems. You may be surprised by their perception that their concerns are dismissed, belittled, and misunderstood by members of the acute healthcare workforce. We have used verbatim extracts from the interviews more liberally than many will think is necessary but having given the carers a voice we feel a responsibility to let them be heard in their own words.

The NHS definition of a learning disability is that it affects the way a person understands information and how they communicate (NHS, 2018). There is a wide range in the type and severity of Learning Disability, which can be mild, moderate, severe, or profound, and the level of support people need varies accordingly. Profound and multiple learning disability is the occurrence of a severe learning disability along with other disabilities, resulting in complex health and social care needs. Autism spectrum conditions are not classed as learning disabilities, however, approximately 20-30% of people with a learning disability also have autism (NHS, 2019).

People with learning disabilities are not ill, though they often have chronic health problems and are no less susceptible to acute conditions than the rest of the population. When people with learning disabilities start to deteriorate with a sudden illness, such as Covid-19 or sepsis, because communication difficulties and intellectual impairment complicate evaluation, appropriate recognition and treatment may be delayed (Louch et al., 2021; Tuffrey-Wijne & Hollins, 2014). Research has demonstrated that people with Learning Disability have worse outcomes than patients with average communication abilities (Heslop P, 2013; NELA Project Team, 2019; Mencap, 2007, 2012). There may be many reasons for this phenomenon (Figure 1). Some causes of delay in recognising deterioration are shown in (Figure 2).

FIGURE 1: POSSIBLE REASONS WHY PEOPLE WITH LEARNING DISABILITY HAVE WORSE OUTCOMES THAN AVERAGE

- When people with learning disabilities become suddenly ill, co-existing medical problems may add complexity to the manifestation, recognition, progression, and treatment of the disease. It is known that people with learning disabilities have higher incidences of common problems such as constipation, acid reflux and aspiration and ischaemic heart disease. They may also have developmental abnormalities such as neurological disease and chromosomal disorders such as Down's syndrome that are in turn associated with health problems (Bromley CCG, 2016).
- People with cognitive dysfunction or a learning disability may not express symptoms in a recognisable way and their emotional response, whether exaggerated or reduced, may confuse interpretation. Furthermore, when the carer seeks to explore what the person is feeling, their responses may be confusing.
- People with cognitive dysfunction or a learning disability may be cared for in their own homes, in care-homes or nursing homes. Most recipients of care do not undergo routine physiological monitoring. If an adequately qualified carer suspects that their client has an acute health problem, they are likely to measure their vital signs. Many vulnerable, looked-after people have chronic illness or physical developmental abnormalities associated with their status that cause abnormalities in their vital signs. A single set of observations are therefore more difficult to interpret. In recognition of this problem some medical teams have instituted infrequent, but regular, measurement of vital signs to provide a baseline.
- Carers may have rudimentary medical knowledge and the routine care needs of the group of people under discussion do not usually require the skills of trained nurses and the bulk of the care is carried out by relatives in the home or by care assistants in institutional settings. Hospitalisation of the person with learning disability may however be delayed because, amongst other reasons, the carers are concerned about the emotional state of the individual, and the gatekeepers for escalating care overestimate the resources of the care home.

FIGURE 2: SOME REASONS FOR DELAY IN RECOGNISING ACUTE ILLNESS (BROMLEY CCG, 2016)

- Lack of staff training in the recognition of patient deterioration in care homes
- Lack of staff training in the recognition of patient deterioration in the acute sector with people with a Learning Disability
- Delay due to organisational factors specific to the care of 'looked after' people
- Issues related to high turnover of staffing in this health/social care sector
- Delay due to failure of communication
- Lack of reporting in a acute and primary care setting that a patient has a LD
- Lack of experience of acute illness and deterioration in the community and care-home setting

1.2 Study aims

- ***To investigate and evaluate the current use, the potential future use, and the impact, of the routine use of Early Warning Systems to identify acute deterioration in people with a learning disability.***
- ***To investigate and evaluate the use of educational initiatives for families and non-clinical care home staff around spotting signs of patient deterioration and escalating concerns.***

1.3 Method

1.3.1 Study design

The study adopted a qualitative approach to explore and evidence the lived experiences and knowledge of paid and unpaid carers with respect to the following topics:

- recognising the early signs of illness and deterioration in the condition of adults with a learning disability
- experiences of escalating their concerns to get timely help and treatment
- previous experience using education tools or training that help them to assess the condition of adults with Learning Disability or autism
- thoughts and opinions about the usefulness of such tools and education

1.3.2 Ethical Approval

Ethical approval for the study was secured from the University of Northumbria.

1.3.3 Selection criteria for participants

The selection criteria for participation were that participants should be carers for adults with learning disabilities. No gender, age, paid or unpaid carer status, or any other personal characteristic precluded carers from participating.

1.3.4 Recruitment of carers for Interview

Convenience and purposive sampling were used to recruit paid and unpaid carers who provided care at home, in supported care environments or care homes. Owing to the difficulties presented by the pandemic all the participants were recruited from the cohort of carers who participated in training sessions for RESTORE2 Mini initiated by NHS England. One thousand trainers were trained during the first phase (super-trainer sessions) of this roll-out, each of whom were required to train a further 5 carers (phase 2), resulting in five thousand paid and unpaid carers being trained in the use of RESTORE2Mini. Training was free for all participants, and the roll-out was administered and funded by the LeDeR Programme, Learning Disability & Autism Programme, NHS England & NHS Improvement.

Convenience sampling, drawing on professional contacts within Learning Disability and autism networks, facilitated the dissemination of study information to unpaid carers at home, and paid carers in care homes and supported living settings for example. Information was provided to professional contacts for inclusion across their own networks in newsletters, emails meetings for example. Contact details for further information were included and potential participants were sent further information to help them decide whether to participate.

The numbers of each type of carer in the range of settings identified above was monitored to ensure carers of all types and from all settings were included. Where necessary, purposive snowball sampling i.e., recommendations for potential participants from existing participants forwarding project information and researcher contact details was used to ensure inclusion of carer types and settings.

Researchers participated in roll-out delivery planning meetings, as part of the Evaluation Sub-Committee. We evaluated the training, delivered by Wessex Academic Health Science Network (Wessex AHSN) (who also delivered the super-training sessions) and the impact on carers, of access to the tool. Research study information (slide, contact details, email text content), was distributed to all super-trainers as part of their training materials pack, for inclusion and dissemination in their phase 2 training sessions. Researchers also participated in a total of ten super-trainer sessions, giving a brief overview of the research project and the selection criteria and inviting attendees to contact the researcher for further details.

Researchers also attended five phase 2 training sessions, two family carer training sessions and three training sessions run by a super-trainer, presenting the research information session at each training session. Participation in these training sessions and dissemination of research study information through super-trainer's own sessions facilitated convenience sampling of training session participants, who self-identified as either paid or unpaid carers.

1.3.5 Types and numbers of Carers Participating

Table 1 summarises the types of carers who participated in this study.

TABLE 1 TYPES AND NUMBERS OF CARERS INTERVIEWED FOR THIS STUDY.

	Family carer	**Paid carer**	**Shared Lives carer**	**Learning Disability professional**	**GP**	**Learning & Development role in care provider organisation**	**Total**
Number	10	10	4	4	2	3	33

Carers can be of any age and gender, of the 33 participants in this study, 25 (76%) were female and 8 (25%) were male. Carers were not asked about their age, although six participants volunteered their age as part of describing themselves and the person they cared for.

Carers may themselves have physical, mental, or learning disabilities, and although participants were not asked about this, some included the information when asked to talk about themselves and the person(s) they supported. Two participants talked about their own learning or physical disabilities.

1.3.6 Data collection

Data collection took place between February – April 2021. Given the COVID-19 pandemic management measures in place at the time, interviews were conducted remotely using either Microsoft Teams or Zoom, in accordance with Northumbria University policy and government guidance. Where permission to record was granted by participants, interviews were recorded by placing a digital recorder close to the computer speaker. Interviews were conducted using a discussion guide, adapted to the type of carer.

1.3.7 Data analysis

Interviews were transcribed 'intelligent or clean verbatim' (repeated and filler words and sounds that do not add meaning omitted, capturing what is said but not how it is said). Data was managed and thematically analysed using NVivo software to identify themes and provide evidence of the issues carers face in spotting acute deterioration, escalating their concerns, the range of soft signs carers use to spot acute deterioration, any prior experience of EWS tools and training and the impact such training and tools have for them.

2 Results

To evaluate the impact of the EWS it was necessary to identify the problems carers encounter when attempting to escalate concerns to the healthcare sector, then to identify whether the use of an EWS has any positive effects on these as well as identifying whether EWS implementation creates new challenges. The results have therefore been organised and presented in two parts:

PART 1. Escalating care to primary or secondary health sectors

PART 2. Early experience of the use of Early Warning Systems when escalating care to primary or secondary health sectors

The data relating to the relationship of Learning Disability carers with health care professionals was allocated to 33 nodes according to topics and these were then sorted into six themes. The Framework for analysing the data is shown in Table 2.

Carers’ Status and Skills	• **Health professionals do not value the skills of social carers** • **Health professionals have pre-conceived socio-cultural values about the status of carers** • **Carers’ reluctance to undertake work seen as 'Clinical'** • **Lack of funding/access to training** • **Advocacy skills and experience** • **The stigma of the anxious/pushy parent or time-waster label.** • **Cultural norms** • **Language and communication**
Carers’ emotions and stress levels	• **Effect on effective information flow of the fear and anxiety that carers experience** • **Effect of additional life stresses related to caring on carers effectiveness in conveying key information**
Carers’ previous experiences	• **Carers’ knowledge or concerns overlooked** • **Previous serious or fatal outcomes**
Carers working or caring environment	• **Staff turnover** • **Workload** • **Organisational procedures in care organisations** • **Lone working**
Health professional related	• **Ability and willingness of health professionals to 'hear' and listen to information** • **Ability and willingness of health professionals to make adjustments to their communication, appropriate to the needs of the individual with a learning disability** • **Ability and willingness of health professionals to make appropriate adjustments to care and treatment of the individual with a learning disability** • **Lack of knowledge, understanding and training for health professionals about learning disabilities** • **Expert status of health professionals** • **Workload** • **Carers’ perceptions of how they are valued by health professionals** • **Health professional related summary**
Health care system structural or procedural issues	**Primary care:** • **People are not registered as having a learning disability** • **GP receptionist gatekeepers, and GP triaging and appointment systems** **Secondary care:** • **Hospital passport not read or too complex** • **111 algorithmic approach to triage** • **Ambulance service/paramedics and policy issues** • **Procedural or policy issues** • **Direct Access during Secondary care** • **Consent and/or next-of-kin issues affecting information flow**

Table 2 Nodes and their allocation to themes

2.1 PART ONE: Carers experiences of escalating concerns to the primary and secondary health sectors.

2.1.1 Carers Reflections on their relationships with health professionals

Carers were asked about their experiences when trying to escalate their concerns. This identified obstacles, organised into eight themes, summarised in table 3.

The carers reported a barrier to communication, due to perceptions of their status, when they attempt to express their concerns to other health professionals, and even, sometimes, to other carers. This results in important information that health professionals need for the diagnosis, treatment, and care of people with a learning disability being either:

- excluded by the health professionals
- not communicated by carers.

Table 3 summarises contributing factors identified in this study related to impediments to escalating carer concerns arising from carers' perceived status or skills and knowledge.

Factor	Barrier	Contributing factors	Negative consequences
Carers' status and/or skills	Health professionals do not recognise skills of social carers	• The expertise of carers for people with learning disabilities is not acknowledged • Time it takes for carers to develop expert knowledge of person, the manifestation of their learning disability(s) and the range of normality for them	• Important knowledge and information offered by carer (or available if asked for) is overlooked or discounted • Health professionals are unlikely to have same level of expert knowledge of person as carers • Health professionals do not understand that they need to know the information carers are telling them
	Health professionals have socio-cultural preconceptions about the status of carers	• Unrecognised skill level of carers for people with learning disabilities • Low pay levels in care sectors	• Important knowledge and information offered by carer (or available if asked for) is overlooked or discounted
	Carer-clinical boundaries	• Minimum pay • Little formal health education • Social carers have expertise in the person/people they care for, not health care	• Carers feel they are being asked to take on responsibility beyond what they are being paid for • Carers feel they are being asked to make clinical decisions, beyond their role
	Lack of funding/access to training	• Care support workers and Shared Lives carers may only access mandatory training • Family carers may not be part of networks which provide training	• Carers may not have access to latest knowledge and skills that could help spot deterioration and escalate concerns earlier
	Willingness and ability to advocate for the patient	• Health professionals often do not include carers in decision making	• Carers do not know they can challenge outcomes or insist on asking for help • Carers do not know they are experts on the person they care for • Carers are inhibited or intimidated by cultural norms about the status or expertise of health professionals
	Fear of the 'Anxious parent' or 'time waster' label	• Carers need to build their knowledge and experience over time, so will be more anxious when less experienced or facing new situations • Carers working or caring context may mean they have to ask for help to come to them	• Carers hesitate to escalate concerns or advocate if they do not get the help they are seeking

Factor	Barrier	Contributing factors	Negative consequences
Carers' status or skills	Cultural factors	• Generational, ethnic or other social norms e.g. class, relating to status of health care professionals • Caring offers paid employment accessible to people who themselves are marginalised by society e.g. through disability, educational attainment, disrupted lives • Carers' experience or expect disdain from health professionals	• Carers feel unable or unwilling to challenge health professionals or to insist on appropriate help and treatment • Carers have low expectations about health professionals' willingness to listen or recognise the value of the information carers have
	Language and communication	• English may not be first language of carers (or health professionals) • Vernacular (non-medical) language of carers • Emotional state affects carers communication • Inexperience/reluctance to communicate via spoken word on phone or in person (especially younger people)	• Carers do not use language that elicits desired outcome • Important information being conveyed by carers is discounted by health professionals

TABLE 3 IMPEDIMENTS TO ESCALATING CONCERNS RELATED TO CARERS STATUS OR SKILLS.

2.1.1.1 Health professionals do not value the skills of social carers

Several carers expressed their disappointment that their skill and knowledge in learning disability was not acknowledged as useful by the health professionals they encountered. Further, they believed that many health professionals did not understand that an underlying diagnosis of learning disability could significantly change the presentation and symptoms of an episode of acute illness.

Carers, and health professionals, who participated in the project, talked about the complexity of caring for people with learning disabilities. Carers acquired detailed, in-depth, expert knowledge about the condition of the people they cared for, and the idiosyncrasies of the manifestation of condition and early signs of illness. For some carers, their knowledge of the person they care for, and their learning disability and other health conditions is more expert and detailed than the health professional is likely to have, particularly for carers of people with rare or complex multiples of physical health, mental health and learning disabilities.

At the same time health professionals often assumed incorrectly that carers possessed general medical knowledge beyond what they acquired through their work. The carers understood that their skills relate to social care, not health care, but this was not always appreciated by health professionals, who often assumed carers understood technical health care language, and knew (or should know) about health care related issues.

Carers felt that the nature of caring for someone with a learning disability centres on person-centred care, as opposed to task-orientated care. Thus, getting to know people well, being able to interpret subtle, variable, and confusing communication signals; health cues: and behaviours are part of a distinct caring skills set. These skills are needed to identify a person's needs and wants, and to support them in achieving these. One carer explained how important it was to attend to details such as appearance. They felt that the person with LD's dignity and self-respect required that they were 'well kempt'.

> *"I would hate somebody else putting his socks on, and not being able to straighten them. It's that kind of thinking. Whereas I've seen people get people dressed in ten minutes, and I'm thinking you haven't fiddled around with where the seam of their socks is, though, have you?" (LD health professional)*

One experienced care provider manager differentiated between the skills that carers for people with a learning disability needed and developed, compared to more generic or task-oriented care provided by other types of carers such as Health Care Assistants or care assistants for older adults. Carers for people with learning disabilities need the skill to able to imagine or think creatively about how to work with people with learning disabilities to make things possible for them, rather than focusing on what people cannot do.

> *"I always found the best support workers were people that came in with no expectations about what people could and couldn't do, because that meant that they didn't limit their imagination.......The key skill that you need to be a support worker is to be able to see people that you support as individuals. And then… Once you recognised that person as who they are, then you can build support around them as an individual." (Care provider manager)*

Asked to reflect on why carers skills, and therefore expert knowledge were often overlooked or dismissed by health professionals, carers referenced the lack of recognition for the skills of carers.

> *"I think, generally, one of the things that... .I've touched on is that 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..... And I think people work very hard to make sure that people that they're supporting aren't marginalised. And then somebody will come along and go, 'Well, you don't know what you're talking about'. (Care provider manager).*

In summary, in many situations where carers are trying to report their concerns, the health professionals are unlikely to have the same level of expert knowledge of people with learning disabilities as their carer does. Misunderstanding this, they may overlook or discount the information they are being offered that comes from the expert-knowledge, experience and skill-set of carers for people with a learning disability.

2.1.1.2 Health professionals have pre-conceived socio-cultural values about the status of carers

Carers and some health professionals in this study discussed how the status of carers could be one reason for this.

> *"Sometimes I'm discounted, honestly (despite being a trained health professional). So, I totally feel for them (carers). Because I've got the language, I've had education, and I know how far to push in the right way. But sometimes – particularly during COVID, I've recognised the signs of deterioration and people haven't taken me seriously. The ambulance crew, GP. So, I've got a massive empathy for the carers because... .. I don't know if it's just not an appreciation of another professional – because they are professionals. They might be low-paid carers, but they're professionals?" (Health professional, Nurse practitioner, Care home Support Team)*

Carers identified several factors that may contribute to this status-related effect which leads health professionals to discount carer expert knowledge including:

- Lack of certification of skills and knowledge
- Carers in the caring workforce are often from marginalised groups in society themselves
- Unpaid carers are conceptualised as parents, rather than carers, by health professionals

The lack of certification of skills and knowledge, along with a lack of understanding amongst health professionals about what social carers for people with a learning disability offered, was identified as a key issue contributing to health professionals' dismissal of carers expert knowledge. The support worker/carer was perceived as equivalent to a healthcare assistant, who would less often have an important contribution to make to patient management.

> *"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).*

Carers also identified that many support workers were individuals marginalised in society themselves, through their origin, ethnicity, social circumstances, and lack of formal education, and this contributed to a lack of recognition of their skill and knowledge by health professionals they encountered, and even by themselves.

> *"You come across a lot of support workers who do that job because they don't think they can do anything else. And, actually, they don't realise how skilled, and knowledgeable, and able they are." (Learning Disability health professional).*

Some interviewees observed that the general misunderstanding, that caring for people with learning disabilities involved complex and different skills to other types of caring, was evidenced by recent campaigns to attract people who had lost jobs during the pandemic into caring.

> *"I think that social, educational background and context of being a care worker is really, really overlooked. I mean, even the way the government is advertising for people now. It's kind of like… Anyone can do this, and we need you. And there's a government not understanding that this is a particular set of talents. … I mean, to actually get to using the RESTORE2 – it's got to occur to you that someone might be ill, and not just being naughty". (Learning disability health professional).*

One health professional described how difficult she felt carers jobs in the aged care homes she supported were, let alone the learning disability care homes she had recently begun to support.

> *"I've got some understanding of what the carers are up against.....I think if you've worked or supported care homes for any length of time, you would realise how very difficult their job is. It's just so difficult now. It's not genteel little old ladies, sitting and playing bingo. They lost their continuing care beds in [town name]. And they lost the rehab beds. And they've got everything – they've got everything thrown at them. And it's just crazy. And a lot of the girls that are RNs in there, are overseas nurses. So, they not only have to do a very difficult job, they've got to do it in a different language. And they've got to learn the structure of the community and the NHS. It's just mad. Honestly, it's mad". (Health professional, Nurse practitioner, Care home Support Team, 02031000).*

In summary, this study identified that carers often do have expert knowledge about the person they are caring for, but this is sometimes undervalued and unrecognised even by themselves, as well as by health professionals.

2.1.1.3 Carers' reluctance to undertake work seen as 'Clinical'

Many paid carers are paid the national minimum wage, despite the skill and knowledge level of their roles, some participants expressed concerns about being asked to take on responsibilities and decisions beyond what they are paid for. One health professional involved in delivering training to carers commented that there did need to be clarity in training about the difference between gathering information: and making decisions based on that information. However, for some carers, the responsibility of taking what are viewed as clinical observations, the fear of getting them wrong and the potential for litigation are clearly still impediments.

One trainer in a care provider providing training in an EWS tool that involved taking some measurements (RESTORE2) observed that there were some staff who queried whether they would be paid more for a more medicalised role and that there might more resistance when equipment to measure blood pressure was introduced.

Staff who trained carers to use an EWS commented that this initial resistance tended to fade once the tool was fully explained and carers gained experience of using it.

> *"Initially staff were worried about it being a medical tool and they were not trained clinicians or see it as part of the role – once the tool is explained and its ease of use, confidence grows". (Senior support worker, care provider staff)*

It was also observed that the advent of Covid-19 had changed some carers attitudes, familiarity, and willingness to use equipment to collect data about temperature, oxygen saturation levels and blood pressure as part of an EWS tool. Sometimes this had been because they themselves had contracted Covid-19 and used pulse oximeters on themselves.

However, for some people in the care sector, there are still reservations about role creep and whether people who are experts in social care should be asked to also start carrying out healthcare tasks. One manager in a care provider, who had attended a super-trainer session for RESTORE2Mini with a view to rolling the tool out within their organisation, commented that whilst they had not had feedback around taking on what might be perceived as clinical tasks, they themselves had reservations about it.

In summary then, for some carers there can be reluctance to take on what some of them view as medical tasks, normally carried out by people with higher status and pay. This is exacerbated by low levels of pay and lack of recognition for their skilled labour as social carers.

2.1.1.4 Lack of funding/access to training

Carers and health professionals in this study said that lack of funding acted as a barrier to carers being able to access training. Access to training was mentioned specifically by Shared Lives carers, who emphasised that although there was mandatory training that they were able to access, unless funding was provided to enable them to access other types of training, or the training was made mandatory, they would not be able to access it.

> *"…we have the opportunity to take other courses if we want them. But, generally speaking, the consensus of Shared Lives carers is if it's not mandatory, we don't do it. Because we don't get paid enough". (Shared Lives carer)*

Contributory factors to this barrier included care payment structures that meant that Shared Lives carers feel they are already significantly underpaid for the care for the people they cared for.

Being asked to give up further time, effectively unpaid, to participate in non-mandatory training as well as perceived grey lines of responsibility mean that Shared Lives carers can be wary of initiatives which feel as though more responsibility is being shifted onto them. The burden and costs of undertaking non-mandatory training was just one of a whole range of grievances that carers had about the structure of their working lives and their remuneration.

However, even for care support workers in care provider organisations, funding available for training can be an issue. One learning disability health professional reflected on their knowledge of the pricing structure for funded care packages, which may mean little funding available to provide training:

> *"Until we have a much tighter level of education for carers… I mean, it's there – there's a beautiful "Skills for Care" package that trains up apprentice carers, but… I think the actual funding is not there. I used to do care packages – if you're paying a company £15 an hour to look after someone, you know, by the time you've paid someone their, like, £10.20 or whatever it is – and the insurance and the tax and the training and put the holiday pay and the maternity leave in… Whatever – the admin and what have you in there, it doesn't cover it […] Like, the extra… you can do your manual handling and your infection control and your food hygiene, but you're probably not going to do the… the value-added-rich training". (Learning disability health professional).*

At the same time, carers felt the need for training may be increasing, driven by the high turnover of staff in the sector (30.4% average turnover rate in last 12 months Skills for Care, 2021) and the shift of labour into the sector from sectors adversely affected by the Covid-19 pandemic:

In summary then, funding to access training in EWS tools can be an issue for different types of carers, including Shared Lives carers and care support workers working in care provider organisations. Family carers did not specifically mention funding as a barrier but all of the family carers that participated in this study had accessed free training rolled out through NHS England & NHS Improvement funding.

2.1.1.5 Advocacy skills and experience

Experienced carers (both paid and unpaid) talked about how, over time, they had developed the confidence to effectively advocate for the people they cared for. Several issues were identified as driving the need to advocate including carers skills and expert knowledge being dismissed due to the professional status issues as discussed above.

> *"*Not everybody is comfortable disagreeing with a doctor. And that's cultural. That's generational. That's about being marginalised and all that stuff". (Manager, care provider organisation).

Diagnostic overshadowing is another barrier requiring carers to speak up for the person with LD. Diagnostic overshadowing occurs when a health professional, seeing that a person has LD, attributes all their symptoms and signs to this. The carer may have to say, "No, that's not a feature of their LD. It's something new. For example, one health professional recalled another carer talking in the EWS training session she had attended and describing having to really push for treatment of an acute episode, rather than this being dismissed as part of someone's degenerative condition.

Even minor issues can act as a barrier to effective advocacy such as young people not being experienced talking on the phone:

> *"I don't think anyone gets taught how to phone a doctor. That's mind blowing, isn't it? I'm just wondering… I'll ask the adult nurses if they've ever been taught how to phone a doctor". (LD health professional)*

One care home manager said that her team were generally older, experienced, and had worked in the care home together for some time. This had created a culture where they felt confident, and supported by managers, to escalate any concerns by just picking up the phone and calling the doctor. This care home manager was not aware of EWS tools and training but reflected that they had recently taken on a new apprentice, and this type of training and tool could be very useful for new or younger members of the team. She was not sure that younger people coming in would have familiarity and experience of using the phone, nor of confidently communicating with doctors, who might be conceived of being a higher-ranking type of person:

Other care provider staff also identified that cultural norms around the status of doctors or language barriers for people who do not speak English as a first language can act as real impediments for people developing skills and experience to advocate for the people they care for. Even experienced staff, or indeed, health care staff who are used to communicating on a professional-to-professional basis talked about difficulties they had fighting to get appropriate care, particularly during the Covid-19 pandemic:

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 active dismissal by health professionals to insist on getting the response they need.

In summary then, being able to effectively advocate for people with a learning disability involves

- having the knowledge and confidence in one's ability to notice soft signs/changes in 'normality' and know that concerns need to be escalated
- having the language skills to communicate concerns and related information
- being able to communicate clearly and assertively about the outcome carers are seeking
- confidence to insist if carers concerns are dismissed or the outcome they want is not forthcoming and they still believe there is an issue

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

Carers of all types and from all backgrounds spoke about their experiences and the effect of being labelled as an 'anxious, neurotic, or pushy parent', or as 'time wasters'. 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)*
>
> *"One of the issues that people would face is that of confidence (*to speak up*). And is this a problem? I've always said to my team, get the paramedics in – if they put in a safeguarding concern about wasting their time, I would prefer that to having to access somebody's "When I Die" booklet – do you see what I mean? I'm much happier to deal with… complaints about them being rung repeatedly. And we will continue to ring because we feel that there's a medical problem. (Team leader, care provider organisation).*

One carer, who cared simultaneously for several relatives with different health issues, described how her experiences varied according to whether she was trying to escalate concerns as a partner carer, carer for her mother with dementia or parent carer for her son with a learning disability. She also reported that other families in the parent carer forum she was a member of had similar experiences.

Parent carers who are health professionals themselves provide insight into the pejorative nature of the 'anxious parent' label, which leads to dismissal of concerns, and described how inhibiting this could be, in terms of escalating concerns:

> *"Yeah, I didn't want to be that mum who makes a fuss, just because she's got a disabled child. And I didn't want to be that person because I had met people like that. From a medical and a non-medical perspective. And that's not me. I'm usually quite together. Perhaps to the point where, actually, I wasn't doing the right thing" (Parent carer and health professional).*

Carers understand that there are times, especially at the beginning of their caring experience, when their concerns turn out to be unfounded, or that their own fear of the unknown can be part of what their concern is.

Carers were keen to be provided with information, specific to their situation, to enable them to assess whether it was appropriate to escalate concerns. One parent carer described how advice and information about what to look out for following an operation, would have helped her in the follow-up period after heart surgery.

The persistence carers described having to show, in the face of repeated dismissal of their concerns illustrates that it is often a multi-stage process. Getting timely help at one stage does not guarantee that the carer's concerns and expert knowledge will be listened to at subsequent stages. They may have to escalate, advocate and challenge repeatedly, both with the same and different people at every stage of the health care system, throughout the life of the person they care for.

In summary then, carers of all types can hesitate to escalate concerns because they are aware of being labelled as an 'over-anxious or pushy parent/carer' or 'timewaster'.

2.1.1.7 Cultural norms

Cultural norms relating to carers social, generational, ethnic or community contexts were mentioned by some trainers and carers as a barrier to escalating concerns. Carers from overseas sometimes came from cultures where disagreeing with a doctor was unacceptable.

> *"Not everybody is comfortable disagreeing with a doctor. And that's cultural. That's generational. That's about being marginalised and all that stuff". (Manager, care provider organisation).*

Other UK born carers drew attention to social, cultural and educational factors that made them reluctant to speak to individuals they perceived to be different to themselves and to speak up in meetings and case conferences.

2.1.1.8 Language and communication

Other trainers and carers commented that not speaking English as a first language could act as a barrier for some carers.

> *"And then there are others who don't have the language... And we have a lot of staff who English isn't their first language. So, getting the language barrier across anyway – it's a bit tricky. But we don't have the language to show how urgent it is, as well". (Learning & development role, care provider organisation, previously care support manager).*

One trainer pointed out that carers are not used to using clinical language to describe their concerns, as this is not part of their job or indeed training.

2.1.2 Carers' emotions and stress levels

Carers emotional response to fear and anxiety when the person they care for becomes suddenly ill may affect how they communicate the important information they are trying to convey to health professionals. Furthermore, the energy, time, and other resources available to them to drive the escalation process may be compromised by higher levels of underlying stress associated with many carers' lives, or new situations or illnesses, or even carers own ill health.

Table 4 summarises contributing factors identified in this study related to impediments to escalating carer concerns, related to carers emotions and stress levels.

Factor	Barrier	Contributing factors	Barrier effect or mechanism
Carers' emotions and stress levels	Fear	• Loss of control • Not knowing what is happening or fear about how quickly it could deteriorate • Fear for life of person they care about • Fear of consequences of getting it wrong	• Information offered by carer can be repetitive but not informative • Emotion conveys urgency but risks health professional discounting important information
	Anxiety and stress	• Complexity of carers lives, exacerbated if they have multiple, complex caring responsibilities • Having to continually battle and comply with onerous bureaucratic requirements for every aspect of care and treatment for person (or people) they care for	• GP or secondary care appointments are difficult to schedule to fit in with carers lives and responsibilities, which can result in delays to escalating concerns and getting timely help • Resources eg time and energy, that carers have available to drive escalation effort is unavailable when needed

TABLE 4 IMPEDIMENTS TO ESCALATING CONCERNS RELATED TO CARERS' EMOTIONS AND STRESS LEVELS

2.1.2.1 Effect on effective information flow of the fear and anxiety that carers experience

Carers of all types recognise that trying to escalate their concerns when the person they care for starts to become suddenly ill, can be a stressful and anxious time. This can mean that their ability to gather their thoughts, marshal important information and communicate effectively can be affected. One carer (who is also a qualified former health professional) described the effect that emotions have and that it is because one's emotions are so involved in caring that this happens:

> "I think it's keeping the emotion out of it. When you work with someone that closely... I mean, I work with a very small group of people where you love them in the end. They're like family to you. And I know that's not terribly professional, but you do. I mean... and I just think! Your tiger-bear mummy comes out, and not the professional nurse. I think it makes me look like a hysterical woman rather than a professional carer. I find it very difficult, because I do hysterical woman much better than I do professional carer". (Learning disability health professional).

Health professionals commented that the effect that emotions, such as fear or anxiety, had on carers efforts to escalate their concerns was that a lot of information was repeated, or that a lot of information clinicians did not need to know could be included.

However, health professionals recognised that emotion was an important part of the information being conveyed, because the emotion helps to convey the urgency of the situation:

> *"The emotional element! I think that's right. So, they've got information. It's the… It's the emotion you need to take out. But you need a bit of emotion because you need to tell them that you're worried. You know what I mean?" (Health professional, Nurse practitioner, Care home Support Team)*

In summary, the effects of fear and anxiety are that information offered by carer can be affected by becoming repetitive but not necessarily informative. Furthermore, whilst emotion does help to convey urgency, some carers feel that this risks health professionals discounting the information they are trying to convey.

2.1.2.2 Effect of additional life stresses related to caring on carers effectiveness in conveying key information

Family carers talked about how the day-to-day complexity of caring responsibilities, in combination with their other working and parenting responsibilities, could cause difficulties in being able to access GP or secondary care appointments but that this was not always understood. The effect of lack of flexibility or understanding by people within the health system could mean delays in getting appointments that the carers could actually manage to attend. One carer, who had multiple caring roles for her parents, partner, and sons, described how, for many families she knew in similar positions, receptionists misunderstood carers' needs for greater flexibility with appointments as 'queue-jumping'.

As one family carer who is also a health professional commented, being a carer of someone with a learning disability often means having to fight for everything, even things they are entitled to:

> *"It's about empowering people, isn't it? And so many of the carers don't feel empowered. And I think that's partly because everything you have to do, when you have a young person or an older person with a disability – it's a battle. You know, just filling out forms for what they're supposed to have and… Nothing is a given. And it shouldn't be made that difficult.*

> *I struggle. Even… obviously, I'm fairly well educated – but filling out some of the forms! They're not forms! They're books! So, there's always that feeling from a carer's perspective that it's hard work. So, it would be nice if we could make this part of caring for a person with a disability not hard work. Because everything else is, you know. It's horrible!" (Parent carer and health professional).*

This means that ongoing stress levels of carers may be higher than for other people with potential knock-on effects on carers resources of time and energy, needed to drive through escalating their concerns to get timely help.

Even carers who are experienced and used to dealing with the complexity of care can find that new situations can disrupt their normal ability to communicate their concerns and get timely help. New situations might include people they care for becoming seriously ill for the first time, encountering a new unknown illness or becoming ill themselves, as described by one family carer whose multiple caring responsibilities did not diminish when she herself became ill with Covid-19:

2.1.3 Carers' previous experiences

Carers reported both positive and negative previous experiences of trying to escalate their concerns. For example, many carers reported excellent relationships with their GPs, how their GP knew the person/people they cared for well, and trusted the carer. This meant that if carers said they were concerned that was sufficient grounds for the GP to ask what was needed or act. However, many carers reported negative experiences, with some emphasising this was often when concerns were escalated to services within the secondary care system. Table 5 summarises how carers previous experiences can act as a barrier to escalating concerns.

Factor	Barrier	Contributing factors	Barrier effect or mechanism
Carers previous experiences	Carer knowledge or concerns overlooked or dismissed	• Carers worry about adding to busy health professionals' workload • Health professionals are not familiar with the idiosyncratic presentation of deterioration cues in people with a learning disability • Carers are made to feel stupid or belittled by health professionals • Health professionals persistently ignore information offered by carer • Carers cannot persuade people within the organisation they work for to escalate concerns to health professionals	• Carer hesitates to escalate until concerns have become more urgent or more symptoms become apparent • Carer is unable to persuade health professional to listen or accept important information
	Previous serious or fatal outcomes	• Carers and/or people with a learning disability may hesitate to expose themselves to traumatic experiences again	• Carer hesitates to escalate until concerns have become more urgent • People with a learning disability become more fearful of health professionals and less compliant with health care procedures

TABLE 5 CARERS' PREVIOUS EXPERIENCE AS A BARRIER TO RAISING CONCERNS

2.1.3.1 Carers' knowledge or concerns overlooked

It was a common experience for carers in this study to have their concerns dismissed and it is clear this could have a negative effect on carers confidence in escalating concerns.

One carer, a former health professional themselves, commented that, in their experience, carers that have bad experiences in the past, and felt belittled were less likely to stand up for what they wanted and persist.

> *"Because just from the interaction with people that we had… Especially when we went into the breakout groups – you can almost tell from the people in the groups, the wills and the wont's. The people that are quite happy to stand up for themselves, and those that aren't. And it is about confidence, really, in what they're doing. Again, I would say the majority of people that don't, are the people that have had bad experiences and been shot down in the past. And feel that they have been belittled. So, they don't actually do it again". (Shared Lives carer, former health professional,)*

The cumulative effect of having one's concerns dismissed over and over was reported to lead to hesitancy in escalating concerns in future, waiting for more definite or additional symptoms to emerge.

Carers are often aware of the workload health professionals carry and sometimes this makes them hold off escalating their concerns until they have become more urgent, or they try escalating via alternative routes, which does not always result in timely help.

For some carers, trying to explain how their cumulative experience of an individual, and their knowledge of what specific behaviours mean for that individual in terms of physical health deterioration, was hampered by the unusual presentation of illness in people with a learning disability. This meant carers had difficulties persuading health professionals to accept important information they were trying to convey.

> *"I'm just thinking, there's one gentleman, about whom I used to have a regular conversation with a GP. This man was severely... multiply learning disabled, autistic, and physically disabled. And... ... I don't know how he'd lived that long. He was in his, like, late 60s, and I just don't know how he got there. He used to have regular chest infections towards the end. He used to have swallowing problems and things. 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. You try phoning a GP and saying, "This man... Listen to this man shouting. This man is going to have a chest infection by tomorrow". And the GP going, "He can't possibly have a chest infection and shout like that!". And every time he had a chest infection the next day. 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!"" (Learning disability health professional).*

For young, inexperienced, or less confident carers, who may be less sure about spotting deterioration, or when to escalate their concerns, these negative experiences can contribute to their expectations and attitudes to future experiences and how they are likely to be treated.

> *"I can remember one when I was first a support worker. So, I'm like 23, 24... And I was really, really new and green. And... I had a gentleman... And I think I took him to the doctors on the Friday for medication review. And he had epilepsy. And I knew nothing at this point. And the doctor said, "Oh, he's on the wrong medicine". And she cut a load of*

> *his epilepsy drugs there and then. And... You know, I'm 23 - the doctor has told me to do this. I've written it down. I'm doing it. There's a letter to prove it. I go back... He comes down to his mum's for the weekend, comes back looking absolutely dreadful. He's been seizing the whole time. And I called the doctor - and they said, "No, no - he's just getting used to his medicine changing". And I called again, and I think I called an ambulance the next morning, and he went into hospital. And he was really, really ill. He really should not have had those meds dropped. And certainly not that quickly. And that's the first time I remember getting really angry that I could see something was wrong, and I was treated like I was stupid. And actually the person was put in danger". (Learning disability health professional).*

Even experienced carers reported that sometimes despite their persistent efforts trying to escalate important information, they had to stop trying and let health professionals experience first-hand the consequences of failing to listen.

> *"Yeah, there are times like that. And, you know, being in this sector for some time, I find it just easier just to stop talking. And, you know, if you want to talk to this person, and you're not going to listen to the advice that we've given, then you're going to have to find out. Because, you know… It's not a case of me being facetious or anything like that. It's I can give you as much information as possible. Do not talk to this person from this side. You need to take your sentences a lot slower, very basic… But if you're not going to listen, then we'll evidence clearly why I'm telling you this in the first place. So, there are times that I will just stop talking. And there have been times when staff have been in hospital and I've said, then take a step back. The person supported is in hospital, they are the main carers at the moment. Take a step back. Let them see what they want to try to do. You know… And not to the point that it becomes a safeguarding concern. But, you know, to the point that the person supported shows what they're not happy with using their own forms of communication. And then they perhaps will see". (Team leader, care provider organisation).*

For care support workers, negative escalation experiences can also occur within the organisation they are working for.

> *"When I was a support worker, there was one of the ladies that I grew to know really well. So, you know her mannerisms and her expressions on her face and things like that. And I knew she wasn't well. So, I said to the senior at the time, I don't think this lady is very well. And she, sort of, like, poo-pooed it. So, I went above her, really, and I just phoned the doctor. So, when she... when the doctor came out, he admitted her to hospital. And she started having seizures and things. I went to look after her in hospital, and she started having seizures. And I thought, this lady doesn't have seizures. So, I just quietly went over, and it was quite early in the morning, about seven o'clock, and I said to the nurse, the lady is having seizures. And I said, she never has them, so... Everything was, oh my God. They were running everywhere. There were people running everywhere. And I was like, oh my God, what's happening? And she got really, really sick after that. So, they were giving her lumbar punctures, because they didn't know what was wrong with her. And then, when we look back with... They were taking her off some kind of... And I can't remember the medication. And it was some PRN medication that she was having daily, but she also had it... But when she started her medication for PRN, she... It was only for five days. And I think it's been like an overdose, if you like. . Because she always had it. And that was like the withdrawal kind of thing, coming off the medication. And then I moved on to other places. But she's since died - but she wasn't the same person after that". (Care home manager, care provider organisation).*

Even experienced care support workers could experience difficulties escalating their concerns within their organisation, despite the length of time they had been working with an individual and their expert knowledge of the person they care for. For example, experienced care support workers undergoing training in an EWS tool who had experienced this, provided feedback during their training session that on-call managers needed be trained as well.

In summary, the effect of carers' prior experiences of having their expert knowledge or concerns overlooked is that they may hesitate to escalate until concerns have become more urgent or more symptoms become apparent. These experiences may also affect their confidence and willingness to advocate.

2.1.3.2 Previous serious or fatal outcomes

Whilst the consequences for carers of negative experiences can create a barrier to future escalation, the consequence for people with a learning disability can be severe, or even fatal.

> *"One young gentleman who had autism, and the family did not… the family had said if you put him on that particular anticonvulsive, it causes him to… whatever happens. And the doctor was like, yeah, yeah – whatever! And they put him on the anticonvulsive, and he deteriorated significantly and then died". (Learning & development role, care provider organisation).*

One learning disability health professional working in a care provider organisation described the persistence and lengths they went to (and difficulties they faced) trying to escalate their concerns, although they felt they were ultimately unable to get timely help.

> *"So, we had another gentleman where his appetite was reduced – he didn't completely stop eating and drinking, but his appetite was reduced. He was a lot more lethargic. He was spending more time in bed. He wasn't wanting to engage in the things that normally were his favourite types of activities. You know, he just… just seemed not quite right. And, again, this was a gentleman who was not compliant with the assessment. In particular, a blood test, which would've been the initial thing to say – let's just do a blood test for everything. Let's check liver function – you know, all the basic things – and see whether something is going on. He wouldn't comply with that, and again we were going round and round the houses as to whether that was in his best interest, etc. To the extent that then it was decided in a multi-disciplinary best interest meeting that a diagnosis of potential depression could be made in the absence of those physical health kind of things being ruled out. And that we would start him on treatment for that and see what happened. So, that happened for three to six months. Fast forward quite a lot – deterioration continues, starts to lose weight as well. Eventually admitted to hospital because he became acutely unwell. And whilst in hospital was diagnosed with a cancer that was now not treatable.". (Learning disability health professional, care provider organisation).*

For people with a learning disability, having these negative experiences not only causes unnecessary trauma at the time but may also contribute to the build-up of anxiety and fear related to future health care interventions. For both carers and the person with a learning disability, facing the prospect of repeat traumatic outcomes such as the one described below adds to the difficulties carers face in escalating their concerns and trying to get timely help.

> *"There was a young man who was autistic, and had... Oppositional disorder. And he needed a cannula. And he said, okay, but you can't stick it down. I don't like the sticky tape on my skin. And the doctor ignored him and stuck it down. And he was understandably*

> *very upset. And because he was a young man of colour, of course the police were called and... Security guard all piled on top of him. And if you're autistic and you're already nervous and afraid, and you're probably a bit... You've demonstrated that you're touch-sensitive, by the fact you don't want to have the... You're not going to react well to having four security guards sat on top of you. So, they had to shut down the ward for a day. To calm this young man down. And what actually happened in the end was the person who was in charge of the experience of autistic and learning-disabled patients came and said things like, "Well, if you don't want to take one, you'll have to hold it down". And he went, "Well, screw that..." And it was like... This was a situation that could've been avoided. And when we had training [for health professionals about the needs of people with learning disabilities and autism in hospital, provided by the care provider organisation the interviewee works for] the next day, the doctor who had decided to stick down these things said, "I don't need this". And got up and walked out". (Manager, care provider organisation).*

In summary then, the effect of prior serious or fatal outcomes when carers have had negative experiences of trying to escalate their concerns may mean that carers and/or people with a learning disability become mistrustful of health professionals willingness to listen to them and provide appropriate help. People with a learning disability become more fearful of health professionals and less compliant with health care procedures if they have experienced negative experiences, especially where these could have been avoided by working with carers and listening to their advice and expert knowledge.

2.1.4 Carers working or caring environment

Carers identified aspects of their working or caring environment that could act as a barrier to escalating their concerns and getting timely help. Table 6 summarises five aspects.

Table 6 Impediments reported by carers

Factor	Impediment	Contributing Factors	Barrier mechanism
Carers working or caring environment	Staff turnover	High turnover of care workforce related to low pay, zero hours contracts	Carers do not have the time needed to get know the people they care for well and understand the range of normality for each individual and the significance and meaning of changes in normality
	Workload	• Staffing levels • Complexity of care • Bureaucratic burden • Number of hours available to provide care support	Carers have limited time available to escalate concerns
	Organisational procedures in care provider organisations	On-call senior staff do not have same level of knowledge about 'normality' and soft signs as carers	Carer concerns are overlooked or dismissed
	Lone working	Lack of colleagues to discuss concerns	Carers delay escalating concerns until they feel more certain

2.1.4.1 Staff turnover

Staff turnover and the high proportion of staff from agencies, was raised as an issue affecting quality of care by some of the health professionals involved in this study.

> *"Now, a district nurse going in to give insulin, and they can find somebody absolutely, you know, critically ill from an infection, and nobody has recognised that in the care home. So, I understand district nurses' passion and the safeguarding element of say why? Why? Why? Why wasn't this recognised? But I also see the bigger picture, Because it's the transient staff. It's the pressures of the workload. You know, like, we spoke about the complexity of the patients compared to 10, 15 years ago has totally gone up. So, I get it. So, I think that's sort of where this comes from". (Health professional, Nurse practitioner, Care home Support Team)*

Indeed, having time to get to know people and knowing them well was mentioned by many carers in this study as part of what constituted their expert knowledge. Clearly every time new carers become involved in the care of an individual or join a care provider team, that process has to start again. However, it seems that for many care provider staff involved in this study that there is a culture of supporting new carers to do this with the back-up of the experienced staff members.

In care settings where the care is provided on a one-to-one basis, picking up the expert knowledge about individuals is facilitated by the amount of time carers spend with each person, as well as being able to work with experienced staff and pick up knowledge from them on the job.

> *"…we've still got some really good, experienced staff, which they will shadow them anyway. So… And they're really good at pointing these things out to the new staff. So, they will pick things up relatively quickly. And a lot of the guys, they are one-to-one. So, you do get to work with them for quite a bit of time during the day. So, you do start picking up on things quite quickly". (Senior support worker, care provider staff)*

Nevertheless, there is turnover of staff, meaning that as staff become trained up, they can leave and the training has to start again.

> *"It's difficult because a lot of the staff who were here when we did the training, have moved on. And gone to other jobs. So, it's more the new guys coming. So, I will have to go through the training again with those." (Senior support worker, care provider staff)*

In comparable situations, family carers did raise the issue of having to constantly repeat the same information about things like the needs of the individual, interpreting the significance of behaviours and changes.

2.1.4.2 Workload

Several different types of carers mentioned workload as an issue that affected being able to get timely help. For example, one Shared Lives carer described how the hours of care they were being paid for was often dwarfed by the actual time it took to deliver a given aspect of care.

For other carers, one of the issues they faced was that health professionals did not always understand the type or level of care and support their care service provided. Thus, carers sometimes escalated their concerns to paramedics because there was nobody available to take the person to A&E and sit with them for however long it took to be seen.

In summary then, workload factors such as staffing levels, complexity of care, bureaucratic burden, number of hours carers are paid to provide support can have an effect on the time that carers have available to escalate their concerns.

2.1.4.3 Organisational procedures in care organisations

For carers working for care providers, there are organisational procedures that they have to follow to escalate concerns. Usually in care provider organisations, this will mean notifying a nominated on-call manager or senior member of staff.

> *"We have to inform the Senior support worker or Manager on duty who will in turn inform the registered manager/ service manager on call. Staff who work with service users know the process/ protocols to follow when they have concerns about service users' health, which again would be in the service users' support plan. A senior or manager is on site in the day and over-night, we have an on-call system for support and advise. All useful numbers are made accessible to staff teams". (Paid carer)*

However, sometimes carers felt that the barrier to escalating their concerns about an individual was the response from this internal staff member, despite them not having the expert knowledge of the individual that the support worker had.

> *"So, there are our managers that take on on-call. And it came up that they were like, I think it would be really useful with them. So, then, like, a support worker feeling empowered to tell a manager… Not necessarily their manager or their team leader, but a manager that's working the on-call at that time. " I'm the expert in this person, and this is the situation. This is what I think needs to happen". You know, and that could be… You know, PRN medication. Paracetamol. Like, you know, these… But all that needs to go through a manager. That's our policies and stuff like that. But it's just kind of like… The support worker said, you know, I've known this person for nine years, and I've been supporting them for nine years, and an on-call manager turned around and told me they're like… you know, that they didn't agree with what my decision was". (Paid carer)*

One carer described how they felt the need to circumvent this internal senior member of staff, who had dismissed their concerns.

In summary, in some situations the barrier for carers to escalate their concerns can be within the organisation they work for, if the senior staff member or on-call manager overrides their concerns.

2.1.4.4 Lone working

One issue identified by some of the carers in this study was that for care staff who are lone working, such as carers on 'waking nights' who work onsite overnight ready to respond immediately to care needs, the lack of colleagues to talk over concerns with could make it harder for them to feel confident when to escalate concerns.

> *"One of the chaps on the training last night, he works nights. Waking nights. And he said that he spends, like, time flapping if somebody is not well because there's nobody to, like, riff off. Because on-call isn't likely to answer straightaway. I mean, they should be, but you know... It is the middle of the night. The team leader wouldn't be available. But it's not often another waking night staff that knows them, that you can call on. So, there was... I think there was... What came across to me was that he felt really unsure to ring 111. And I sort of... I sort of reiterated to him, like, 111 is there for you. Like, you're not a nuisance caller. If you're on shift and you're worried about somebody's health in the middle of the night, you're not these nuisance callers that they're referring to on the programmes or in*

> *the adverts or whatever. You're the person that they want to be speaking to". (Manager, care provider organisation).*

In summary then, for paid carers who are lone working (which may also be comparable to the situation for family carers), not being able to informally talk through concerns can mean carers feel hesitant to escalate concerns.

2.1.5 Health professional related

Some of the impediments to escalating concerns that carers experience relate to the health professionals that carers interacted with. Table 7 identifies six aspects.

Health professional related		
Ability and willingness of health professionals to 'hear' and listen to information	- Information about someone's symptoms or needs is different to information they are used to hearing - Health professionals feel they understand what they need to know about people with a learning disability	- Health professionals do not information carers are tellin - Key information relevant to treatment of someone with decision-making by health p
Ability and willingness of health professionals to adjust in their communication, appropriate to the needs of the individual with a learning disability	- Lack of awareness or understanding about learning disabilities - Wide range of learning disabilities and how this affects individuals differently - Workload and time pressures on health care professionals	- Key information relevant to treatment of someone with decision-making by health p - People with a learning disal and/or participation in thei access to information adap
Ability and willingness of health professionals to adjust in their care and treatment, appropriate to the needs of the individual with a learning disability	- Lack of awareness or understanding about learning disabilities - Wide range of learning disabilities and how this affects individuals differently - Workload and time pressures on health care professionals	- People with a learning disal which could mitigated or m
Lack of knowledge and/or understanding of the differences in 'normality'	- Lack of training and awareness about learning disability - Organisational cultures and processes that do not allow for variations to 'normality'	- Health professionals do not und information carers are telling th - Key information relevant to the someone with a learning disabi by health professionals
Expert status of health professionals	- Socio-cultural internal and external expectations and pressures about knowledge health professionals 'should' have - Power relations of health professionals to patients and carers	- Health professionals do not und information carers are telling th - Key information relevant to the someone with a learning disabi by health professionals
Workload	- Time pressures - Numbers of patients - Bureaucratic workload	- Health professionals do not hav different to the information the - Health professionals do not hav care and treatment appropriate - Key information relevant to the someone with a learning disabi by health professionals
Carers perceptions of how they are valued by health professionals	- Assumptions by health professionals about the skills and knowledge of carers for people with a learning disability	- Key information relevant to the someone with a learning disabi by health professionals

Table 7 Impediments to escalating carers' concerns related to actions of health professionals

2.1.5.1 Ability and willingness of health professionals to 'hear' and listen to information

Several carers in this study described occasions when they tried to pass on key information, essential for the appropriate care and treatment of the individual but were either dismissed by health professionals or the information was ignored. Added to social status effects discussed earlier, there seems to be an inability or lack of willingness among some health professionals to ‘listen’ or 'hear' information that is different to information they may be expecting to hear or are used to hearing about other patients.

> *“Saying the person I support is squeaking high… a high-pitched squeak – it’s quite difficult for someone else to understand what that really means (Learning & development role, care provider organisation, previously care support manager).*

For one carer, who used to be a health professional themselves, it feels like an inability or unwillingness by 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… And that is very difficult to do. Because they’re working to their own agenda. You know, usually, the person that you’re caring for. You tend to know their needs far better than anybody that’s… But, again, come up with that defence of the… Usually with healthcare professionals – sadly, it has to be said – “ I know better than you because I’m a trained healthcare practitioner” (Shared Lives carer, former health professional)*

However, health professionals varied as to how whether they would listen to or accept this type of information.

> *“I think they understood why we were concerned. I’m not sure how much value they placed in the data that we were providing. And I think that varies from… from professional to professional. I’ve had consultants… you know, I’ve had some consultant neurologists, who just want a list of the seizures written on a piece of paper, and won’t look at the data we’ve got that shows that, actually, he’s more likely to have it at 4pm, because… you know, all those kinds of things. But then I’ve also had consultants who’ve said, wow, this is amazing – but it would be really useful if I could see this, this and this. So, actually, some have been really good, because they’ve helped us develop our reports to actually show what the consultants want to see. So, it varies a lot”. (Learning disability health professional, care provider organisation).*

One health professional reflected on the clinical training they had received and how they were trained in a specific approach so that it becomes deeply ingrained. For this health professional, it felt like a completely new and different language, consisting not just of different words, but a whole new way of communicating.

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’ that this takes additional energy and mental effort to process and incorporate this information into their decision-making process.

> *“It’s about that giving the information that’s relevant, as opposed to giving the information that I think they need. I’ve been there in the past, because I’ve listened when… I mean, I was very fortunate, because I was a community children’s nurse. So, I’ve been in somebody’s home when they’re trying to tell you what they think you want to know, as opposed to what you need to know.” (Shared Lives carer, former health professional)*

However, it seems that the ability and willingness of other health professionals varied on an individual basis.

In summary, then presenting information to health professionals in ways they are used to processing information may help carers trying to convey important information, relevant to the appropriate care and treatment of someone with a learning disability that they care for.

2.1.5.2 Ability and willingness of health professionals to make adjustments to their communication, appropriate to the needs of the individual with a learning disability

A related issue reported by carers in this study, was that some health professionals were unable, or unwilling, to adjust their communication appropriately to meet the needs of an individual with a learning disability. One family carer described the impact this can have for both carers and the people they care for.

> *"It's been tough because you've struggled more than I have, because I'm quite vocal. But you've struggled with understanding what GPs have said to you. You've found it really hard, understanding when they've said you need to have this done. You found it really difficult to understand. I had to come with [name] … When you had your cervical thing, didn't you? […] I had to go with [name] to have a smear test with her. Because they hadn't worked with people with learning disabilities. I had to go in there, which probably made [name] feel uncomfortable, having her husband in there with her. Trying to… These nurses do these things without even offering you any support". (Learning & development role, care provider organisation, family carer, expert by experience).*

One learning disability health professional reflected on an incident that had consumed considerable time and effort by several health professionals to resolve. A lady with a learning disability had declined treatment because the speed and presentation of contextual information had not been adapted for her needs. Once that was provided, she was able to decide and, in this case, opt for treatment. The interviewee felt that contributory factors to this situation were the speed at which doctors must think was different, as well as the way that doctors think and that the key was trying to find the right trigger word or phrase.

> *"Sometimes with doctors I think they have to think so quickly that they don't… I don't know what it is. I had one yesterday where a lady had been discharged and declined some treatment. And we were trying to figure out whether she had capacity and had made an unwise decision, or she didn't want… Or she didn't understand it and she panicked and said, no. And it took about ten emails between a couple of nurses, a GP and the consultant to work out that all we wanted to do was go along and ask her slowly and quietly with the right information, and she wanted it… I think… I think doctors are taught to think in a different way to everyone else. And sometimes you have a conversation and you're sitting there thinking, I need to find the right key word to get the right reference card out of his brain". (Learning disability health professional).*

Other carers described incidents where health professionals did not or could not understand that the way they were communicating with someone with a learning disability was creating a problem and that they were missing out on key information, important for the care and treatment of the individual.

> *"She was asked to go for a learning disability check… An annual learning disability check, which she went for. In that learning disability check, she was seen by a chap who is a paramedic practitioner. The paramedic practitioner, really, I would say, had no… no experience of how to talk to people properly. Like, how to understand how autistic people work. He was very, very offish with her. I felt like I didn't want to be there while he was questioning her. He was very dismissive over things. Because it then came out also that [Name] revealed after every time she had intercourse (she also suffered by polycystic ovary*

> *syndrome). Every time she had intercourse with her boyfriend, she bleeds heavily. But when we had the learning disability check, she didn't mention any of this to the paramedic practitioner, because she didn't feel comfortable with him, because she didn't know him. She didn't have a relationship with him". (Shared Lives carer).*

For some carers, there was an issue related to talking to health professionals about the person with a learning disability, or talking about their needs, while the person was there, especially of the disability was not obvious. For example, one parent carer described how talking about a problem in front of their high-functioning autism spectrum disorder child was a delicate balance of providing the health professional with key information and not upsetting their child.

> *"It's sometimes the other challenge with a higher functioning… I hate using that word, but it's the word that's used. Sometimes my biggest problem was trying to communicate my son had a problem without upsetting him. Because he would go, "Why do they need to know? You know, I'm not… I'm not thick or…" Because that's how it's looked at for him. So, some of it was like… I sometimes wished I could have a silent conversation. ". (Parent carer)*

One trainer and experienced carer summed up their reflections on the apparent inability or unwillingness for health professionals to learn how to communicate and look after people with a learning disability.

> *"…if they can teach people at Disney how to look after people with learning disabilities and autism and relate to them, they can teach medical professionals how to do it!" (Learning & development role, care provider organisation).*

In summary, health professionals risk missing out on key information they need to help their decision-making about appropriate diagnosis, care and treatment of people with a learning disability. Asking carers, ***"What do I need to know?"*** rather than making assumptions, is one way that health professionals could improve diagnosis, and treatment for people with a learning disability.

2.1.5.3 Ability and willingness of health professionals to make appropriate adjustments to care and treatment of the individual with a learning disability

Other carers in this study talked about situations they had experienced where health professionals could not, or would not, make appropriate adjustments to their care or treatment of people with a learning disability. One carer recalled an incident where someone she supported ended up in hospital for weeks. Despite having good verbal communication, it became apparent that the hospital staff were not communicating with him directly, waiting until carers came in to have any care related conversations. Although the person received the medical care he needed, the lack of emotional support and care that other people without a learning disability expected to receive from hospital staff, was completely lacking. For someone who already experienced mental health issues and a learning disability, this led to weeks of being in hospital in a fearful state.

> *"I used to support somebody who had lived in a long-stay hospital. And then they moved into their own home. I provided support to them. And they had bipolar, as well as a learning disability. And they had a bit of a fear of the police as part of their condition. They didn't share a lot about how their health stuff was going on, really. And they were also a smoker. And they a serious chest infection. And they had to quit smoking as part of that. So, you know, they weren't able to breathe, and it suddenly kind of deteriorated quite quickly. It probably had gone on a bit longer than we knew because the person had quite small amounts of support. So, people would go in and support… He could make his own meals and things, so… you weren't always… It was around medication support. He definitely had*

> *support around medication. But it could go a couple of days where you would only see him a couple of times a day during medication. But on this occasion, people went into the flat to see him and he was struggling to breathe. His colour had changed. He wasn't smoking – which he was always smoking when he went in his flat, so it kind of showed that he wasn't well. And so, we had to call an ambulance. Because his breathing was so severe. Which he was quite anxious about. And he had to go to hospital. We had to persuade him to go. So, when the ambulance came, he didn't want to go in it. He was quite distressed about it. But, yeah, the ambulance could see by his colour, his breathing was just… It was very fast, but very shallow. And he just wasn't getting oxygen. So, normally, straight to hospital – but it took half an hour to get him to get in the ambulance, because it started some of his anxieties around uniforms.*
>
> *I don't think they'd ever met anybody on that ward – not everybody, but a lot of them – hadn't met someone with the label of learning disability. And I think they assumed he wouldn't understand. So, any conversations that they wanted to have when staff were there… And, of course, with some people, that's absolutely reasonable, where there's somebody to support them, but… It was all the time. If, when you went onto the ward, you never saw anybody communicating with him." (Learning & development role, care provider organisation, previously care support manager).*

This example illustrates how people with a learning disability can experience fear and anxiety which could be better managed, if health professionals adjust their care and treatment appropriately to meet the needs of individuals with a learning disability. Whilst it may not be possible for health professionals to understand what they need to do to make these, they could find this out by asking carers for advice such as by asking, **"What do I need to know?"** and **"What is this person normally like?"**.

2.1.5.4 Lack of knowledge, understanding and training for health professionals about learning disabilities

An Learning Disability health professional observed that much of the difficulty around communicating with and adjusting care and treatment appropriately probably arises from lack of knowledge, experience and training about learning disabilities. Reflecting on their own training and knowledge of current training, it may be there is insufficient training for health professionals to be able to make reasonable adjustments for people with a learning disability.

> *"I think it's just borne out of lack of experience and lack of training. And a general ignorance around the facts. It's not… It's not that they're being dismissive, necessarily. Or being deliberately obstructive or unpleasant or uncaring. Certainly, when I was at medical school, which is a very long time ago now, we had no training in learning disability. None. I don't remember even if… You know, I learnt about the genetics of conditions, but I don't remember learning anything about how to look after somebody from a medical perspective with a learning disability. It was very much about syndromes, and this is what that person would have. And that's what that person would have. But the actual care, and how you make reasonable adjustments to be able to care – there was nothing. I think it's changing a little bit now." (Parent carer and health professional).*

However, the resistance to training encountered by one carer who regularly runs learning disability awareness training for health professionals, does suggest there can be quite active rejection of the need for any kind of training or adjustment.

> *"I think our project has tried to train doctors, but they're really not interested. And even F1s and F2s (*a grade of medical trainee*), who are slightly more interested, were still, like,*

> *on their phone or... kind of, one ear open. Or, let's just get through this training session, kind of thing. And even when there has been a crisis, and doctors have been involved, and I've been called in to deliver some training with them. They've gone, "Oh, I don't need this. This is irrelevant to me". And then, kind of, walked out". (Manager, care provider organisation).*

Sometimes, health professionals have to learn through experience (and despite the best efforts of carers and other health professionals to advise and support them).

> *"This is just the way the doctors think. And the same guy, actually... The one that I was telling you about - the one that had the urine infection and things. He had some stitches. He fell over... He was epileptic and he fell into his sink and he bust his head open. And they had to really, really knock him out to get these two stitches. And they had to come out. So, we tried to do it at home unsuccessfully. We tried to do it, kind of, in their own... And we said, we're going to have to take him to hospital, sedate him, and then... Take the stitches out then. And we had it all arranged with the doctor in the morning. He was absolutely fine with it. He understood... the GP explained it. But by the time it got to the afternoon, the shift had changed. By the time he got there. And the doctor was like, this is a waste of my time. I don't see why I have to do this. And he said, this young man needs to stop expecting special treatment, kind of thing. 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 then he was in the middle of listing his qualifications when he got a right hook! And luckily, the guy wasn't removed from the hospital. And we managed to sedate him, and we managed to get the stitches out. But... It's very telling that a few years later... The doctor didn't recognise me, but I recognised him. I came in with somebody else. And he walked up to me and he said hello to the person I was with. And he said to me, "What do I need to know"? And it was like... "You don't remember me, but I remember you." I didn't say anything to him. Like, obviously I don't want him to put two and two together right now. Just let me get this woman home before we do anything like that. But he did learn a big lesson that day. It's that, you know, we know what we're doing. And we know who we're supporting. (Manager, care provider organisation).*

Whilst incidents like this provide evidence that that health professionals can learn through experience, it means that people with a learning disability are experiencing avoidable pain, trauma, distress, worse health outcomes and even death.

Several carers in this study had experienced occasions where health professionals lacked knowledge about how 'normality' can be so variable and idiosyncratic in people with a learning disability. Carers described encountering narrow-minded approaches to following procedures and slotting people and situations into 'normal' boxes.

> *"My… [name] went for a blood test. Well, he did… He went for a pre-operative assessment for an in-growing toenail. We were there for two hours before he was even seen. So, you can imagine his level of anxiety is already rising. And then we finally got seen – and after we'd been seen, they sent us round to see the pre-assessment nurse, who then said he needs a full blood count done. And I just turned around to him and I said, "Why does he need a full blood count done? We've been sat here for now on three hours. He's had nothing to eat, nothing to drink. His level of anxiety is going through the roof. And now you're telling me we've got to go and sit in the blood department for a full blood count that isn't required for a local anaesthetic." And she's like, "No, just in case you need a general." They're not going to do a general, because he would have to come back. And she wouldn't… Just couldn't see it. To the extent that she then went and got her manager, who perceived my actions to be hostile, because I wouldn't permit him to have a full blood count because it*

> *wasn't necessary. Because she couldn't see it from my perspective. And she certainly couldn't see it from [name]'s perspective. So… And I think that narrow-mindedness is where the problems lie. So, it's just an example where people need to be more aware when they're dealing with people that don't fit neatly into boxes. And, let's face it, these young people don't fit into boxes at all!". (Shared Lives carer, former health professional)*

As several carers in this study commented, training for carers to spot deterioration and escalate concerns earlier may only address half of the problem and that what is also needed is a change of attitude and culture amongst health professionals. Carers' reflected on several experiences where people with a learning disability become more ill when they are admitted to hospital.

> *"One of the people that we support during COVID… So, during hectic, hectic lockdown – the first lockdown – she moved into the service so that she wouldn't be exposing the family or the people we support. So, she moved into the service. Somebody got unwell, and ended up in hospital. Not with COVID, but she did end up in hospital. And profound autism, and wouldn't eat in the hospital. It got to day three of not eating, The family phoned the manager from our service and said, look… "What do we do? Because they won't let us in. Can you talk to them?" So, she phoned them and she said, look, "You have to let me in because that person will not eat without someone who understands her and her signs. She will die, if you don't let me in to help and feed her." And they umm-ed and ahh-ed and they thought about it. And how we could pressure… And she got to go. And she went in and she fed this person for a couple of days, until she recovered – got her and the staff used to each other, so she trusted the staff to feed her – and then she could go back to the service and look after everybody else. So, I feel like it's all well and good, only… It's great to train the carers. It's great. Fantastic first step. But a lot of the time that people get ill-er in hospital… Or ill-er under doctors is because the family are not listened to. And the notes are not taken". (Learning & development role, care provider organisation).*

> *"Despite the fact that all the residents have hospital communication passports, and the fact that we always make sure that the residents go over with really up-to-date information, it's been… It's been particularly difficult since COVID because I can't allow my staff to support residents on hospital admissions. And that's made it very complicated because we're relying on the hospital to then contact us. But, pre-COVID, I would always make sure to go over, and I would, kind of, stamp my feet until I spoke to the doctors and told them that, you know, "You have got to make reasonable adjustments for S, because she just… She will not fall within your normal parameters. And that may influence the course of treatment that you decide on." Now, as it happens, S is currently in hospital. She went in with low oxygen saturations, but her oxygen stats had improved within 24 hours. And, by rights, she should've been discharged at that point. However, we're not, three and a half weeks later, and S is not discharged. And she's been quite medicalised over there. (Learning disability health professional, care home manager, care provider organisation)*

Several carers commented during training sessions for EWS tools and during interviews that whilst training in EWS tools for carers was very welcome, this needed to be paired with training for NHS staff.

> *"And one other thing that's just popped into my head, as well, that we did talk about yesterday – was kind of like how this is a nice, kind of like… And I realise that this hasn't probably happened in the way that they'd planned to. But, like, obviously the NHS had promised, you know, learning disability awareness training to NHS staff. All hospital staff. And, you know, fair enough, a pandemic happened. So, again, it put like… I think it still needs to be the priority that it was a year ago. Because it fits nicely with the other side of this. And how I sold it to our staff yesterday was that it's the other half of the… You know,*

> *of the… I don't know, like, coconut? You know? But, like, it's us doing our bit, and they're going to do their bit. But I can see, you know, if like that… I can see that relationship breaking down if NHS staff – specifically, like, GPs and the hospital staff – don't begin to improve. Because it's been a tough year for us. You know, the DNACPRs… Kind of like, people… You know, capacity issues that are being considered. You know, like… It's just been a tricky year for our relationship with health staff. (Manager, care provider organisation).*

The key thing that health professionals need to grasp, according to a carer who has extensive experience in training medical staff in learning disability awareness, is that what they are used to thinking of as 'normality' may not be how normality presents for someone with a learning disability.

> *"This is not normal presentation for this person. And it... You cannot... I mean, this is... I've trained hundreds of medical staff now and what I always tell them is what you think is normal may not be normal for that person. And that's the question that you've got to ask - what is this person like normally? Is this what you usually see? And every... Every good experience I've ever had with a medical professional has started with that question". (Manager, care provider organisation).*

In summary then, one of the most important things that any health professional can do to improve the care and treatment of people with a learning disability after asking the carer "*What do I need to know?*", is "*What is this person like normally*?"

2.1.5.5 Expert status of health professionals

Some participants in this study reflected on why it was so difficult to get some health professionals to listen to them or make appropriate adjustments to their communication and care for people with a learning disability. Some felt that the status of health professionals as 'experts', the education and training they had received and the confidence they needed to be able to do their job, could all combine to breed a certain 'arrogance' in some health professionals.

> *"We have to breed arrogance into doctors, otherwise they wouldn't be able to do the job that they do. So, they have to have that complete faith in their own decision-making ability. And I don't think that they think they have anything to learn from people with learning disabilities. I mean, I did a training course at... I think it was [hospital name], with a group of mixed medical professionals. So, there was physiotherapists, doctors... All of them. And one of the doctors complained that having people with learning disabilities there made the course take longer, and that was a waste of their time". (Manager, care provider organisation).*

Health professionals can find themselves in a difficult position of responding to the need from carers and parents to be an expert, to have knowledge and answers, and yet admit to a lack of knowledge at the same time.

> *"Well, again, it's something that I've experienced from, again… From both sides. And I saw a… I understand and I know the difficulty in relinquishing in the relation… Previously, when I was community nursing, it's the fact that we had… I was dealing with children with oncological conditions. And the parents wanted you to be an expert. They want… They needed you to be an expert. They needed to be able to trust and say everything that you've said – because they were seeking that reassurance because of the nature of what you were dealing with". (Shared Lives carer, former health professional)*

A reluctance to admit to not knowing something can be so strong for some health professionals that they feel the need to cover up.

> *"And every so often you get a locum that thinks that they're really flash. Like, I remember supporting somebody who was deaf and had a learning disability, and I was talking and signing when I was asking them questions. And the doctor was so intimidated by this, he pretended to sign. And the person I was with was going... He was saying to me in BSL(British Sign Language), what the eff is he talking about? (Manager, care provider organisation).*

However, this can cause great distress to carers and the people they care for as this carer recalled when their daughter was kept in hospital for a whole weekend because of a lack of understanding by one health professional of the differences in presentation following a seizure. The carer recalled how this doctor would not listen to them about how their daughters condition meant she presented differently and nor were they listened to when they asked for appropriate adjustments by having a single room.

> *"It's harder in hospital for them to believe you or… I don't want to say to believe you, but for you to cut across what you're trying to say. When she was very young she used to have a lot of fits – especially if she was ill with something else. Then she'd have a fit. But one time the school sent her by ambulance to hospital, and I had to go there to meet them. Because she took a long time to come out of the fit. The only reason that the A&E doctor kept her in because of the response on her foot (*Babinski Response*). Apparently your toes curl one way or another. Don't ask me… But they did what they shouldn't have done, her toes. So, they said, we'll keep her in for observation. And it was really hard – because it was a weekend and her normal specialist wasn't around. And this doctor would not listen to a word I was saying. He just wouldn't have it. And we had to wait until the Monday when her specialist turned up, and he basically came over and put his arms around me and he said, I'm here now – I'm taking over. And it's like, but why couldn't they understand that? You know, she doesn't present like a normal, everyday, you know… 5- or 6-year-old. She was pointing… Right, if she wanted something, she couldn't put her arm out straight for a cup of tea or whatever. She would be putting it up to the ceiling. I mean, her whole vision thing had gone, what was it, 45 degrees out? And I think they thought she was messing with them. And it's like, no, seriously, she doesn't do this. And then I said, can we have a private room because… You know, a single room, because she won't understand that the other children are ill and if she's… When she starts feeling better, you don't want her on a main ward […] So, of course, literally she woke up one morning, felt better because of the antiseizure medication they'd given her, and she ran amuck through the ward. And it's like… I did explain that we needed somewhere quiet, because this is normal [name]. Normal [name] is a… yeah, like a steamroller. You know, normally. But because they'd only seen her, literally, just like lying down and doing nothing. And, yeah, they couldn't…"(Family carer).*

Another carer recalled an incident which had left her feeling deeply distressed and resentful when an allied health professional (speech therapist) took up a position and not only refused to change it but actively overturned the actions of other professionals the carer had asked to help. Whilst it is not unusual for experts to have different opinions and recommendations, the effect of these actions were to deny a person with a learning disability access to communication tools which the carer felt transformed the quality of her life and aided her development for a two year period.

> *"Because I said my daughter is non-verbal. And we felt that she needed some kind of communication tool, understandably. And we bought her an electronic communication aid. Which cost a lot of money. That was £2,000. And because... Because the speech therapist at her school, just didn't listen... Well, this is in terms of listening. Didn't listen to me at all. Didn't believe that our daughter was capable of communicating with using a communication aid. And just completely shut the door, didn't want to know. So, that's why*

we bought her one. We bought her one. I set it all up. And I'm not... I'm not a speech and language therapist. I'm not a communication expert. But, you know, I did the best I could to programme it especially for her. And she did have - especially going through her teenage years - she did have a lot of behaviour issues. Because of her communication difficulties. So, she... She would get quite, sort of, like... Challenging behaviours. You know, quite severe challenging behaviour. And this communication aid - the poor thing - it would... She would... When she was feeling frustrated, she could... And agitated - she would just pick it up, and bang it on a hard surface. So that it sprung apart. And then bits of the innards, like the solder, came off. And I don't know how many countless times I had to send it back to the supplier or the manufacturer to get re-soldered and sent back. But this was her communicating. You know, she was communicating her frustration. Her agitation and everything. And it didn't mean that she wasn't capable of using a communication aid. It didn't mean that. And this woman just said, oh, she… She's just playing about with it. She can't use it. She just… She just dismissed her. She dismissed her possibilities, basically […] So, actually, she had to go… She had family issues and she had to go over to [place name]. And she was over in [place name] for a month. And while she was away, I contacted a private speech therapist. And we paid for a private speech therapy assessment. And this lady… She's an expert – in speech therapy. She's an expert in communication equipment. So, she recommended that what we did was we borrowed some from suppliers. So, I borrowed three communication aids. And I programmed them all – set them all up. It just took ages and ages and ages. Set them all up for my daughter to try. And also videoed – and the speech therapist said video her, you know, what she's using it. So, I taught her a few things. I videoed her. And then she wrote a report – the speech therapist wrote a report – and she said she was going to submit it to our county council for funding. And she said could I…? Would it be okay to submit it along with the video recording? So, I said, yeah, that's absolutely fine. Straightaway, the funding for a communication aid was approved by the county council. And they said, you know, how fantastic it was. You know, how clever she was, because she was able to communicate some basic things using this communication aid. And when this cow came back from [place name], I had to tell her that this is what I'd done. And she rang the county council and she put a block on the funding. And she actually… you know, she said, no, she can't use it. She'll just play around with it. You know, she's not capable of using it properly. And this was just unbelievable. That the professional – someone who is supposed to be supporting young people to develop their communication, was actually actively and viciously… you know, trying to stop her… Her communication development. It was unbelievable. So… I thought, I'm not having this. And I… I just arranged a meeting with her every single week. I arranged to go and see her. And he got onboard. Like, the first time I went in there was six of them against me. There was… she got the headteacher, the deputy headteacher, the speech and language, the speech and language assistant and the classroom assistant. All sorts of… They were all against… They were all there. And then there was me. And they were all saying, oh, she can't… You know, it's like cup half empty. She can't do it, she can't do it, she can't do it. And I kept saying she can do it, she can do it, she can do it. Give her a chance. And, eventually, she just gave up because she was fed up of seeing me. And she said, well, I still think it's the wrong thing. But I'm going to say to the county that they can release the funding. And it's made the biggest difference to her life. Having this communication tool […] It went over two years. Two years. This woman… you know, I've never thought I hate someone, but I do hate… Well, I hate her behaviour. I hate the way she actively stood in the way of my daughter's development. And it's kind of… You know, communication is the most important think, in a way […] I know, she just… Well, she just said… She was just cup half empty. She was just… I think it was just… I think it was just pure laziness. Can't be bothered, can't be bothered, can't be bothered. Focus on those people who are more able, because they're easier. You know, work with the easier ones. And the more difficult…

> *Because it is… It is a challenge. It's not… It's not easy, teaching, you know, my daughter to communicate and make progress with her communication aid. It's not easy. It takes work. I have to… I keep programming it… You know, reprogramming it with up-to-date vocabulary and I have to show her where it is. But, you know, she can communicate basically in a way that she couldn't before. You know, she can communicate, I think, to her level of understanding now. Which she couldn't before. Which is why she was so frustrated. So, that's the worst experience I've ever, ever, ever had with a professional. Who claims to be a professional". (Family carer)*

> *"You've got to think, well, you know, in terms of development – what are they capable of. Not… not just look… You know, you can tell a book by its cover. You know, just because of her outward behaviour – is one thing… But, I mean, it's brought her out of herself. It's made so much difference to her life. You know, it's made the world of difference. Really – she was kind of really locked inside herself. And she's much more outward – much more sociable now and… You know, as I say, she's not brilliant at communicating. She can only communicate to a certain level, but it's opened her up. It's just opened up her world". (Family carer)*

One former health professional reflected that the process of admitting a lack of knowledge and needing to ask carers to share their knowledge or accepting this knowledge, involved a loss of power for some health professionals.

> *"But the expert can't transition into the parent role, because actually it's seen like… I think it's conceding power. And, again, I suppose, with my background as a community practitioner – one of the first things you learn is the moment you walk into somebody else's household, as opposed to being on a ward, that balance of power is changed completely. Because you're not in any power. Because you're a guest in the person's home, for one. You know, the front door can be shown to you very proactively, should you come close. And I think a lot of people – a lot of practitioners that I've come across aren't able to accept that transference of power. And I hate the term power, because it's sounds so… But I think it is just the transference of power that you're acknowledging the expertise of the carer. And I think they find that they can't actually do that to themselves. (Shared Lives carer, former health professional)*

Another health professional also acknowledged that being able to admit to getting things wrong could be difficult and feel quite threatening to clinicians, particularly because of unrealistic internal and external expectations and pressure to get things right all the time.

> *"Clinicians get it wrong. And I think all of us should be able to hold our hands up and admit to that. But some don't. I think some… some clinicians find that quite threatening. Because… Partly because they feel that that shouldn't happen. You know, we should all be doing a brilliant job all the time. But I think we are human, and we do get it wrong. And if we can work with carers so that we don't get it wrong for people with learning disability… That's the key message. It's not about… You know, try not to be dismissive. It is really hard when you're busy and you… You know, you can see your tasks on your screen getting more and more, and someone else is knocking on your door because they want to ask you about something. And it often is a reflection of our stress levels, how we react to certain requests. If you request it in a certain manner, then it makes us think, oh yeah, right… I'll prioritise that. You know, it is difficult to manage your workload sometimes". (Parent carer and health professional).*

One carer recalled a situation where the actions of the health professionals involved in the incident nearly resulted in serious damage, until she managed to intervene.

> *"I think people with medical qualifications - I think they feel a bit of a hierarchy against people who work in care that don't. And, I mean, like, I've been in several situations where people... I've had to kind of... I'm thinking of one specific situation where I had somebody who was a wheelchair user in hospital, and it was a dental procedure that they had to go through. And they were hoisting them. And I said, "I'll do it." And they went, "Oh, no, no - we've got to do it. It's our insurance. You know, blah-blah-blah." And I was like, "Look, she... She had a sling on - she was wearing a sling." And they went, "Oh no, we've got to use our sling." And I said, "Well, this sling fits." And they went, "No, no, no..". So, they... Like, literally, this poor woman - who I'd kept in a sling, just to make it easier when she got into hospital, had the sling taken out, and then put another sling in. And they were hoisting her on... They were about... You know, her arm wasn't in the sling. And I said, "Well look... " And they said "We've told you already that we're doing this." And I was, like, "No, but you're really about to break her arm". And she had osteoporosis. I said, "She's got osteoporosis, and you're about to break her arm." And they just put her arm in a sling and went, oh... And it was just like, why do you feel that I don't know what I'm talking about, just because I'm not a nurse? And you haven't actually asked if I'm a nurse or not - but I'm not. But... It's like... Yeah, I remember saying, I know this person. I'm the expert in this person. Not you". (Manager, care provider organisation).*

In summary, sometimes the status of health professionals as 'experts' can be a real barrier for carers trying to convey key information, relevant to the appropriate care and treatment of the person they care for. Being able to admit to a lack of knowledge can be so difficult for some health professionals that their actions become obstructive and damaging, as well as distressing and frustrating for carers and people with a learning disablity.

2.1.5.6 Workload

Carers and health professionals involved in this study both recognised that the workload of health professionals can be part of the reason that carer concerns or expert knowledge are sometimes dismissed or overlooked. The time pressures on staff, numbers of patients they need to see and bureaucratic workload can mean there is very limited time available for health professionals to spend with each patient, and to adapt the way they work to allow extra time for additional information or to adjust their normal communication style.

> *"…if a consultant is walking in, you've only probably got those for five or… Five or six minutes, at most. And they want to do a mass collection of information and data. And make a decision, and then they're on to the next person. So, it does get quite difficult. But then that's… I think that's an issue with, kind of… recruitment, I guess, within the NHS. And having more time to spend with people. Especially with people with learning disabilities and autism. It's not a quick in-and-out consultation. It can get incredibly difficult." (Team leader, care provider organisation).*

Carers can hesitate to escalate their concerns, worrying about 'bothering' the doctor, who they know has a heavy workload.

> *"I've certainly been, like, hesitant about phoning a GP. I've certainly had that. There's definitely that they kind of get… I think they're just so over-worked, they kind of like… I need to deal with that, I don't need to deal with that. So, for some others it feels a bit dismissive. With some GPs. Some of them are superb and lovely and wonderful and wouldn't do that to you. But you do get them that are literally – they're trying to do so much so that they're literally like, okay, that's an emergency, I'll deal with that. That doesn't sound very important, I don't have to worry about it". (Learning disability health professional).*

Health professionals themselves recognised that sometimes workload pressures impacted on their capacity to listen to carers and incorporate their expert knowledge into their decision-making.

> *"Yeah, I think that's a very unique skill set – carers. And they're uniquely placed to be able to pick up the soft signs. And we, as clinicians, should not dismiss that. I think it does get dismissed. And I think that… you know, that further disadvantages people with learning disability. And it happens all the time. Not always, because the clinician is intending to be dismissive. But they're really busy. They're thinking about six million other things. And you… I've done it myself. You know, I've gone out on a visit feeling really… Not necessarily for a person with learning disability – feeling a bit grumpy. I've had a really bad morning. I've got 50 million things to do and another visit because someone says they've got a chesty cough – urgh… And you go in, and the person needs an ambulance. You can see straightaway". (Parent carer and health professional).*

However, carers felt that the needs of people with a learning disability do not, and cannot necessarily, fit within 'norms' and that this should not be a problem for people with a learning disablity, rather it is for the NHS to resolve as a systemic issue. The simple solution to some of these problems is for health professionals to ask, and listen to, what the carers have to say.

> *"Participant: hospitals can be really, really difficult. I think I could probably... I could probably to tell you more of the... I struggle to remember good experiences. And I don't whether that's just the mists of time. But I think it's better now. There's more awareness now. We're working hard. And I think a lot of Trusts now have realised that they do need learning disability nurses. And they work really, really hard. But they're not there all the time. And I think it's the tired F1 at four o'clock in the morning who hasn't got time for this, hasn't got time to spend four hours trying to build up a relationship with someone before they can stick them with a needle.*

> *Interviewer: whereas, actually, the solution to that is to listen.*

> *Participant: To what the support worker is saying, yeah. It's that simple, really, isn't it? (Manager, care provider organisation).*

In summary then, carers and health professionals themselves are aware the workload of health professionals can be heavy and can impact their capacity to hear what carers are telling them, adjust their communication style, care and treatment so that it is appropriate for individual needs. However, there is one simple action that all health professionals could take to resolve this by asking carers at the start, "*What do I need to know?"*, as well as asking *"What is this person normally like?".*

2.1.5.7 Carers' perceptions of how they are valued by health professionals

Several carers in this study described difficult experiences and encounters with health professionals. When asked why they thought such events had unfolded as they did, some of their responses identified perceptions that carers felt health professionals held about their value and skills.

> *"I think it's assumed that it's not a specialist job. And it really is. It really is. And people work so hard to build up relationships with the people that they're supporting. And they really know them so well. And they're saying to them, look, please, you know... And I think there becomes a thing with medical nurses where they're kind of, like, well, a care assistant or a support worker is somebody who didn't have the brains to be a nurse". (Learning & development role, care provider organisation, previously care support manager).*

Carers report feeling that health professionals look down on them and feel that clinical observation measurements taken by carers cannot be trusted, reinforcing carers perception that health professionals do not recognise the professional skills and abilities of carers. This may impact on the successful implementation of EWS tools that ask carers to take clinical observation measurements, if carers feel that health professionals do not take their concerns and data seriously.

> *"As long as they're on the same wavelength as you. Like I said, with the paramedic it was brilliant. Like with the emergency service call from the ambulance service. They understood when we said, this is what's happened. But I do feel… I'm not sure whether it is a correct feeling, but I do feel sometimes that some of the higher professionals – like GPs and hospital doctors and that – tend to think, oh well, yes, they've taken those readings, but we need to take some proper ones. So, I'm not sure whether they take us seriously as professionals. Taking these readings. Yeah, you're taking those readings – but can we trust them? (Senior support worker, care provider staff)*

Carers can feel that health professionals lack of understanding about learning disabilities and carers' role and skills mean that they regard carers attempts to get appropriate adjustments in care, diagnosis or treatment as queue jumping.

> *"I think she thought we were trying to skip the queue. And I think she thought that we thought that we should get special treatment because he had a disability. And we were being bolshy support workers. And, you know, trying to... We didn't want to be there. You know, and I think there was a little bit of that. But I think there's a little bit of arrogance as well, I think. I think people with medical qualifications - I think they feel a bit of a hierarchy against people who work in care that don't". (Manager, care provider organisation).*

One participant mentioned the socio-cultural gulf between doctors and carers as possibly contributing to a lack of understanding of the context and impact of a learning disability for some doctors.

> *"To get to being a doctor, you probably haven't been around a lot of vulnerable people. You know, you've probably had a quite nice family and a good education, and you've been able to cope with everything. You probably haven't had that interrupted by huge amounts of illness. You've gone to university; you've met all the other people who were just like you. And then suddenly you're dealing with everybody with dementia and learning disabilities. And severe mental illness. And deprived… I mean,[town name] has some of the 10% poorest people in Europe. So, you come across some extreme deprivation. So, people who've never had a homecooked meal from scratch, because they live on Pot Noodle and chips. And I would think for a lot of doctors, that's mind-blowing. And to put a person's health into the context of that is quite hard". (Learning disability health professional).*

In summary, carers can perceive that health professionals do not value their skills and knowledge. For carers, this may erode their willingness to keep trying to escalate their concerns or convey important information relevant to the diagnosis, care and treatment of people with a learning disability.

2.1.5.8 Health professional related summary

In summary, there are aspects of the way that health professionals behave and process information that can impact on carers efforts to escalate concerns or convey important information. This information can be very significant for enabling health professionals to make appropriate adjustments for diagnosis, care and treatment appropriate to the needs of individuals with a learning disability. Carers also feel that health professionals need training to correct a lack of knowledge and awareness about learning disabilities. As one carer commented:

> *"if they can teach people at Disney how to look after people with learning disabilities and autism and relate to them, they can teach medical professionals how to do it". (Learning & development role, care provider organisation, 25021530).*

A simple way for health professionals to manage these issues is to ask carers ***"What do I need to know?"*** and "***What is this person like normally?".***

2.1.6 Health care system structural or procedural issues

Some of the impediments to escalating concerns that carers experience are related to structural or procedural issues related to the health care system. Table 8 identifies nine aspects, in both primary and secondary care systems

Context	Issue	Contributing factors	Barrier effect or mechanism
Primary care	People are not registered as having a learning disability	- People do not know that this can be done or that it can help with access to additional health care - People are not formally diagnosed as having a learning disability - Socio-cultural values around being labelled as having a learning disability	- People with a learning disability are not flagged in primary or secondary care system - GPs and GP receptionists are not alerted that a person with a learning disability is involved unless carers make this clear - People with a learning disability do not have access to additional health care measures eg annual health check, learning disability nurses in hospital
	GP receptionist gatekeepers	- Lack of training for GP receptionists - Lack of awareness about learning disabilities among GP receptionists	- Carers are unable to get appropriate appointments for people with a learning disability eg double appointments, same GP each time - Carers are unable to get receptionists to allow them to speak directly to GPs to provide relevant information - Carers can be labelled as overanxious or pushy which may affect their ability to escalate concerns in future
	GPs triaging and appointment systems	- Triaging and appointment allocation systems mean that carers cannot access named GP or GP who knows person with a learning disability - Increase in phone consultations and difficulty in getting house calls or face to face to appointments	- GP may not have knowledge or understanding about the baseline normality for an individual nor the significance of changes from baseline that have triggered carer concerns - GPs may miss important information needed for appropriate diagnosis if face-to-face consultations cannot be provided
	Hospital passport not read or too complex	- Lengthy comprehensive document - Not read or accessed by each health professional encountered in chain of care because is so lengthy (where is document kept?) - Carers need to complete different versions for each setting	- Key information relevant to the appropriate care, diagnosis and treatment of someone with a learning disability is not incorporated into decision-making by health professionals - Carers learn to mistrust ability or willingness of health professionals to access and incorporate key information related to appropriate care, diagnosis and treatment of person with a learning disability
	111 algorithm approach	- 111 call handlers follow algorithm which does not allow for variations needed for people with a learning disability	- Key information relevant to the appropriate care, diagnosis and treatment of someone with a learning disability is not incorporated into decision-making by health professionals - Carers learn to mistrust ability or willingness of health professionals to access and incorporate key information related to appropriate care, diagnosis and treatment of person with a learning disability - Carers avoid using 111 because they usually end up being referred to ambulance service anyway or they feel 111 is unable to help them
	Paramedics	- Lack of experience/knowledge about learning disability - Lack of understanding about type of support that carers provide - Policy issues related to consent and capacity	- Paramedics make assumptions about people with a learning disability which may lead to clinical errors eg not recognising unconsciousness - Paramedics do not understand that carers may not be able to take people with a learning disability to A&E

Context	Issue	Contributing factors	Barrier effect or mechanism
			• Paramedics are not clear about regulatory and practice guidelines where people with a learning disability are non-compliant with ambulance transport
	Secondary care	• Access to healthcare when people with a learning disability are non-compliant • Lack of prioritisation for people with a learning disability in A&E • Lack of appropriate adjustment of pathway through hospital care and treatment	• Delays to diagnosis and treatment result in worse outcomes • Delays in patient pathway through hospital diagnosis, care and treatment are unnecessarily stressful or distressing for people with a learning disability
	Secondary care	• Lack of experience/knowledge about learning disability • Lack of learning disability nurses or champions • Lack of learning disability label in patient record	• People with a learning disability become more ill as a result of being in hospital • Diagnosis, care and treatment in hospital exposes people with a learning disability to unnecessary stress and distress
	Consent and/or next-of-kin issues affecting information flow	• Families of people with a learning disability who are receiving respite care prefer to take people home rather than have them admitted to hospital • Capacity to consent issues are not understood by hospital staff • Carers' input can be excluded from clinical decision-making • Carers may not be able to get important information related to ongoing care back from hospital	• Delays to diagnosis and treatment • Diagnosis, care and treatment in hospital exposes people with a learning disability to unnecessary stress and distress • Key information relevant to the appropriate care, diagnosis and treatment of someone with a learning disability is not incorporated into decision-making by health professionals

Table 8 Impediments to escalating concerns related to health care structural and procedural issues

2.1.6.1 Primary care

A significant problem that carers and their organisations experience is negotiating organisational and procedural issues to secure proper access to health professionals in primary care – even in emergency situations. Systems are organised in ways that are efficient for the service and that meet the needs of most users. There is a significant problem that these ways of working do not meet the needs of people with learning disabilities.

2.1.6.1.1 People are not registered as having a learning disability

People with a learning disability should be registered as such with their GP, thus flagging their record to show their status whenever accessed. This simplifies encounters with GP services for the carers. Many persons with learning disability are not however registered as such. Lack of registration complicates all issues by repeatedly raising the discussion of whether the individual has LD.

Several carers commented after taking part in training sessions for an EWS tool how they had not heard about annual health checks for people with a learning disability, which may suggest that the person they care for is not registered with their GP as having a learning disability. This can mean missed opportunities for discussing and capturing baseline normality with the GP which in turn could facilitate escalating carer concerns when people start to become ill and getting timely help.

One team leader in a care provider organisation explained how establishing the fact that the call related to a vulnerable adult with a learning disability very early on in their escalation calls, helped them to trigger the kind of response they needed.

> *"We're very lucky with our first responders around this area. We always make sure that… I've drilled it into my staff teams and the managers, ...that before you start talking about consciousness or anything like that, you must make it very clear that they're a vulnerable adult with a learning disability. Because I feel that you get a very different response then.". (Team leader, care provider organisation).*

Another care manager working for a care provider, caring for people who had been institutionalised for very long periods for a specific physical condition, commented that many of them also had learning disabilities, not least by virtue of their long institutionalisation, but few of them had an official learning disability diagnosis and that this meant that they were unable to access the help of Learning Disability nurses when in hospital.

Health professionals commented how if people were registered with their GPs as having a learning disability, this flag could help GPs with their prioritisation and decision-making process. For example, this health professional used the learning disability flag as a trigger to always phone people in care or with a learning disability to ask for further information.

> *"it's often around requests for home visits. And I suppose, from a purely GP perspective, we are really time limited. I know people hear this all the time, and they get fed up of hearing it, and we get fed up of saying it. We have to make sure we are using our time appropriately and only doing the home visits when we need to be doing the home visits. There's less reluctance, if you like – and I don't mean that in a negative way, to… To see people if they're willing to come up to surgery. But we know that that's not possible for everybody. So, you often find yourself in the middle of a really, really, busy stressful day – you've seen 20 patients already that morning, and there's five visits each and you've only got an hour before you've got to get back and have a meeting… You know, there's that sort of… That level of pressure. So, when people request visits, often it will go through the*

> *receptionists, and they'll just take a one-liner. You know, "not well" or something. Because they're not medical. They're not trained to take a medical history. And we're just thinking, "Oh God. How am I going to fit that in?" And should I ring the person to triage? To make sure that it is an appropriate request for a visit. Or is there something that I can just do over the phone? And that's not because we want to fob people off. Sometimes we can just deal with it very easily over the phone. And I've always had a willingness to ring people. Particularly if it's somebody in a care – whether they're Learning Disability or elderly – or somebody I know to have a learning disability… I'll ring first. To check that they don't need anything as an emergency. Because some people do sit tight and wait for you, and you get there and they need an ambulance and it could've been dealt with ages ago. " (Parent carer and health professional).*

One parent carer felt that the learning disability flag could act as an automatic trigger for GP receptionists and GPs that meant that everybody recognised the need for a different approach, so that carers were able to escalate their concerns more effectively.

One experienced health professional commented that ideally carer concerns about adults who have a learning disability should automatically trigger the same response in clinicians that mothers (parents) concerns about a baby elicits i.e., this automatically means the person needs to be seen.

However, some people and communities have sensitivities around being labelled as having a learning disability. One parent carer, with extensive experience of contact with other SEND and learning disability parent carers (through a parent carer forum) talked about how they sometimes had to use alternative wording to get around these issues.

In summary, although being flagged on primary and secondary care systems as having a learning disability could help carers escalate concerns, convey important information and provide access to important additional health care resources, this system is neither universally adopted, nor used to full benefit within the health care system. For health professionals, a learning disability flag should automatically trigger realisation that carer's concerns need a different response, and that they need to be ready to ask carers for further information such as "What do I need to know?" and What is this person like normally?".

5.1.8.1.1 GP receptionist gatekeepers, and GP triaging and appointment systems

GP receptionists were mentioned by both family carers and care support workers as a barrier for them to escalate their concerns.

Carers in care provider organisations commented on the difference they experienced between hospitals and GP surgeries, particularly with reference to 'front line admin'. Diagnostic overshadowing interfered with the management of the present situation:

> *"Most (of) the time health professionals have been understanding and listen to staff especially of those service users who are non-verbal or limited communication – hospitals have been helpful, understanding particularly when there is an Learning Disability liaison nurse/contact on site to help manage appointments and treatment and plan with the support team – GP surgeries have been the least understanding to date, time seems to be a barrier as most our guys require longer app(ointment) time and patience – front line admin at GP surgeries have had the least understanding and acceptance of staff trying to access appointments to meet the needs of those we support – it can appear that the Learning Disability overshadows an illness – they hear Learning Disability and don't see past it – this is the most frustrating barrier". (Senior support worker, care provider staff).*

Carers identified a lack of training and awareness about learning disabilities as a problem.

> *"The amount of doctor's receptionists that I've actually had to ask what medical qualifications they've got… Pales into insignificance. Because they don't receive anything. They are supposed to receive training. Because when… Shall we say, we've had experience of more than one formal complaint about the GP receptionist in the times that both personally and professionally in my medical career… And we are reassured by the practice managers, when the letter has come back, that they have received training. But when I actually had it out face-to-face with a GP, who quite categorically said they don't get any training – so be nice to them, because they don't get any training. And I almost turned around to him at that point and said they shouldn't be the first point of contact. They haven't got the skill set to be the first point of contact. If it's an administrative thing – and almost when you get your telephone triage system when you're phoning in, it should give the choice of do you want an administrative discussion? Or have you got an emergency? In which case we need to put you through to somebody like the practice nurse or whoever, who's capable of triaging that call. I think that's where it should be, really. As opposed to…" (Shared Lives carer, former health professional).*

Carers identified issues such as a lack of understanding about appropriate adjustments needed for people with a learning disability, such as longer appointments, to allow time for people who need it to settle and be able to talk about what the issue is.

Several carers commented that what they often needed was to talk to the GP and that they would make this clear to the receptionist, but still struggled to get past receptionists.

> *"We have a very good relationship with our GP surgery. That we've built up over many years. Which is a big advantage. But with new doctors, and 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.*
>
> *I think the problem is we have concerns. Concerns that we'd like to speak to the GP about. And it's whether or not that's classed as an emergency. Whether or not that is a reason to have an appointment with a GP. Often a receptionist will ask why you need to see the GP – and you'll say it's private. Or they'll say we need more information, or you'll have to wait three weeks for an appointment. When, really, we need a conversation with the GP to see if there's anything we can do to stop it escalating further into a problem". (Care provider manager).*

Experienced family carers reported having learnt to insist on speaking to the doctor but were concerned this could result in them being labelled as a 'pushy parent'.

> *"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... Now, maybe they have a checklist. I'm not blaming them, per se. But 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". But I shouldn't... Because I don't want to be labelled a pushy parent. But I know my child. And a lot of our members would say the same". (Parent carer)*

Family carers have had negative experiences because of insisting on speaking to the doctor, so being labelled as a pushy parent has consequences for carers.

> *"…because, as I say, parents are so scared of being labelled. I know of parents that have been written to by receptionists to say, "Oh, you're too pushy. If you do this again you will be…". And it's not because they've been rude, it's just because they want to see a doctor.*

> *Or someone has gone, "Oh, you've got to tell the receptionist" – and they're like, "No, I don't! I want to speak to the doctor. I know, something has happened and you're not a doctor!"" (Parent carer).*

GP receptionists generally do try to capture information to help GPs triage calls.

> *"The know to escalate, obviously, things like chest pain, very short of breath. You know, so if they heard those things, or if they heard, you know, I'm very concerned about somebody, they would highlight that on the… On our phone list, in our practice, anyway. You know, they would put a note on saying, you know, carer very worried or sounds very breathless, or person very concerned or whatever. So that we could then triage that sooner". (Health professional).*

However, as another health professional noted, the knowledge level of GP receptionists can be variable, and that training is mostly restricted to the process aspects of answering phone calls.

> *"And some receptionists I've met over the years are absolutely brilliant. They should probably have gone into nurse training because they just get it. Others, you know, may have been working in Morrison's one week and then joined us. They've got no training at all. And they don't get training to… They get training on how to deal with the phone calls and which person to send it to. Or, you know, making appointments. But they're not trained in what to listen out for, yeah". (Parent carer and health professional).*

One carer who works for a care provider has good experience of providing learning disability awareness training to a wide range of medical staff commented on their frustration at trying to provide training for GP receptionists.

> *"Who are GP's receptionists is one of the very good questions that I wanted to ask in my life. Yes, it can be… And I have literally been down to the CCG and said, I will train up every single one of your GP receptionists, and nothing ever happens. Nothing ever happens. And, yes, they are very much gatekeepers. And I think that something needs to be done with them. What, I don't know". (Manager, care provider organisation).*

There are GP appointment management systems available in some areas which some carers have found are a good way to circumvent the GP receptionist gatekeeper issues. However, for carers caring for multiple people, and using their own personal devices to access the system, data protection issues can quickly cause issues.

> *"But also accessing, kind of, a GP surgery can be quite a task at some points. The administration – the receptionists – have become almost this frontline of defence for the doctors. And, you know, it's brilliant when they say, you know, "Just go through! Ask my GP and pop it all down there". But we're… You know, we're restricted in some ways. But I'm fortunate – so the managers that I manage, we have our own… Laptops are all, kind of, mine-casted. And have all of the defences for GDPR [data protection]and stuff. My staff can't do that. So, you know, when the staff team say, "Well, I can't go and ask my GP, because then I would have to use my own personal mobile phone, and I'm not allowed to do that because my company says I can't". So, sometimes it's the… It is the understanding from the GPs where, actually, it's not average Joe in public that you're dealing with. And we're restricted. We're so restricted when it comes to GDPR and data protection". (Team leader, care provider organisation).*

In summary then, GP receptionists can act as a barrier for carers trying to escalate their concerns and there is a lack of awareness and/or training about learning disabilities which contributes to this.

Carers who experienced issues with trying to escalate their concerns to GPs mentioned that the introduction of systems where any GP within the practice may be allocated to the consultation, can cause problems. This was generally related to the fact that GPs did not understand baseline normality for the individual and therefore the basis for carer concerns.

> *"It's difficult, because unless that person has been seen for that issue a number of times, they do not know what that service user is in their normal state. If they're well and healthy. And then when you get multiple different GPs seeing them, or just… They don't understand the difference from what they are in their normal state to what they are when they're unwell". (Senior support worker, care provider staff)*

For some carers, they had agreed that future appointments would always be with the same, named GP. However, although this was agreed between the carer and GP, she struggled to make this happen within the practice systems.

> *"However, having said that, when we were sitting in front of the GP – when we did eventually get the golden appointment – he was excellent with her. Absolutely excellent with her. He understood my concerns. He listened to what I said. And he said that from now on he would always see [name]. But then, how do you make an appointment with him? You can't email him, because you email the practice manager. You can't speak to him, because you can't ring him. So, then you've got to get through this… Every time I rang the doctors surgery there wasn't… Not one time that it took me less than 18 minutes to get through to speak – and I know all of this, because I've had to report it all back to my manager. It took 18 minutes for me to get through to actually speak to a human being who would either then make me an appointment, or tell me all the appointments had gone and to call back in the afternoon. But the doctor himself was excellent, yeah". (Shared Lives carer).*

The issue for this carer is the amount of time it takes to achieve these things when the amount of care support carers are paid for does not cover the time it takes or they have time constraints because of responsibilities to other people they are caring for.

Furthermore, the introduction of phone-based triage systems and the switch to phone consultations ushered in during Covid-19 could lead to difficulties in getting the problem correctly diagnosed.

> *"Like… [name] who was a young lady who was living in the other house… When she moved in… she has autistic traits. When she first moved in – I don't know if it's the stress of moving into the house or what it was, but she's partially deaf and, as a consequence, wears hearing aids. She has an awful lot of health issues regarding ear infections. Which then… because of the way the doctors' system is nowadays, you don't have one specific GP – you phone up and you get triaged. And because of that, this young lady doesn't have a very good… Or didn't have a very good relationship with her own personal GP. So, what would happen is she would get an ear infection, someone would phone up on her behalf and say she's got an ear infection – whoever the doctor was that was on-call that particular day would prescribe antibiotics over the telephone without seeing her. And then… Come to find [name] didn't have an ear infection at all. She had a fungal infection in her ear, which antibiotics would never sort out. They would then trigger – because of overuse of antibiotics – a urine infection, which would then trigger kidney pain, upper urinary tract pain, thrush…". (Shared Lives carer).*

Covid-19 had exacerbated this problem for many carers, who found GPs were very reluctant to come out to see people but that this could compromise diagnosis and treatment e.g., using phones to capture images of rashes was not always appropriate.

> *"And especially, you know, through the pandemic, we've had video calls on our phones. I don't think that's substantial. And I quite struggle with that. You know, can you just flip the camera and show me the person's foot? Well, I can – but is that…? You know, is that satisfactory when we're talking about diagnosing something. (Team leader, care provider organisation).*

In summary, for some carers not being able to see the same GP, with whom they had built up a good relationship and who had good knowledge of the specifics of the person with a learning disability, was a barrier to escalating concerns and getting timely help.

2.1.6.2 Secondary care

The same sort of complications due to standard procedures complicate encounters with secondary care.

5.1.6.2.1 Hospital passport not read or too complex

Several carers raised issues about hospital passports being a great idea in theory but that in practice, they were not read by health professionals.

> *"And I think passports and stuff like that are brilliant. But the problem that I've encountered time after time – and this is from a carer point of view, not… is they don't get read! They don't even get looked at. And I've heard the same old excuse from healthcare practitioners – is the fact that, "Oh, I've read it, but can you just give it to me? I need it in full detail". "No, you've not read it, you just want me to give a synopsis-sized version." And, you know, it's so transparent. And that's where I can hear parents' frustration". (Shared Lives carer, former health professional)*

Given that the point of the hospital passport is to provide health professionals in secondary care with all the contextual information they needed, carers were understandably frustrated at both having to constantly repeat information to every new staff member and the fact that it did not achieve the adjustments to diagnosis, care and treatment appropriate to individuals need.

> *"Each individual we support has a hospital passport and goes in with a hospital passport. But that's not often looked at. It's got all our information in, it's got all our numbers in. It's got information about the individual, and they don't look at it. And so, you know, there is this document there, that is there to support the hospital. It's not being used. Which is of concern." (Care provider manager).*

> *"And also hospital passports are invaluable as well. If we can actually get medical staff to look at them. And that can be a challenge in itself." (Manager, care provider organisation).*

Even during the period when Covid-19 has meant carers cannot always accompany people with a learning disability into hospital, health professionals in hospitals seemed not to read or make use of the information in the hospital passport, leading to compromised care.

> *"We had a gentleman go into hospital right in the very first week of lockdown last year, and he had cellulitis. And yeah, he's… he's able. But, for me, I took him through and I had a carrier… You know, like, just a bag with all his hospital passport, his COVID passport. His medication, everything. All the hospital passports and everything, yeah. And she said, right, that's okay. I only went to the door and she said, "Right, you'll have to leave him". Well, I was distraught. I was like, "I can't leave him. He's got learning disabilities and he's part of my family", do you know what I mean? So, I had to leave him and walk out. But I said, everything is in that bag. His hospital passport. His… Everything was in there. And I don't think I got off the car park and they were ringing here – were ringing work – to say, "What*

> *medication is he on? What does he do…? What does he…?" And I was, like, "Well, just read!!". I know they haven't got time. And it was a really bad time. He was discharged without a test. That was in the very beginning. He came home… The ambulance brought him back. He came home with a plaster on his foot. His medications were all wrong. There was more… Had he not been getting his meds? But they said they'd been using it off the ward. But there was a safeguarding issue raised because the nurse I spoke to said, "Well, I don't even know what the plaster is for. She said," We haven't put it on." Well, somebody had. Because his legs had swollen up that much and they'd, sort of, like starting going black, he'd got, like, blisters or… Yeah, and his skin had… He'd all broken out. But we don't know how long this plaster… He was in a week, and we don't know how long this plaster had been on for. It was awful". (Care home manager, care provider organisation).*

Carers are aware that the workload of health professionals may preclude them having time to read and process the information in a hospital passport, or quickly find the relevant information they need in the moment.

> *"But, you know, we have some documents like hospital passports and communication passports that we use. But equally, these are very difficult for nurses and doctors to sit down and read. You know, you're handing them, like, I don't know, a sort of five- or six-page document. It might not sound a lot, but actually, if you're a nurse on a ward, you may not have that time". (Team leader, care provider organisation).*

> *"Even though I'm aware of health passports and one-page reports. You know, all of the documentation. But it's just… It has made me realise that, talking to other people… That you can have all those documents, but if it's an emergency, they don't get read. People haven't got time to read them. And then that's when assumptions are made". (Parent carer).*

For carers, completing hospital passports can take considerable time and effort, especially where carers need to complete one for each setting.

> *"Hospital passports, I'll be very honest, have not gone down very well with our parent-carers. Because they're quite complex. You need about four to five, because if your child is in this setting or… If grandma is looking after them, it's aunt and uncle… It's always down to you to update it. And they're quite long-winded". (Parent carer)*

For carers it feels pointless when they are escalating concerns, and providing as much relevant information as possible if this is not read. One senior care support worker reflected how using an EWS tools that involved taking and providing basic clinical observation data had been successful in escalating their concerns with paramedics but that it seemed to have little impact in a hospital setting.

In summary then, hospital passports not being read by health professionals in hospitals acts a barrier to effective escalation of carer concerns and conveying key information both because this impacts on getting timely and appropriate help but also because it erodes carers motivation to provide this information.

5.1.6.2.2 111 algorithmic approach

For some carers, the relative inflexibility of the algorithmic approach used by 111 meant that they had stopped ringing 111 and just went straight to using 999. Some of the things that 111 call handlers ask carers to do, do not take into account learning disability, such as difficulties in taking a temperature or feeling somebody's forehead. Likewise, sometimes carers need to make calls to 111 in a room separate to where the person with a learning disability is located and have trouble explaining to 111 why this is so and getting them to take account of these types of differences.

> *"We've kind of stopped calling… Well, for one of our guys who is… He's been in and out of hospital a lot over the last couple of years – we've actually stopped ringing 111. Because we found it pretty long-winded and frustrating. Because obviously they've got a list of things to go through. And also the paramedics have just… You know, they've always told us, you know… If you're that concerned that you need to call 111 for, you know, this particular person, just call 999. They can be there within a few minutes and… Because what normally happens is we spend ages on the phone to 111, who usually end up… Because they don't know our guys and we're always saying we don't know because of their, you know, lack of verbal communication or lack of capacity. It's much easier just to go straight to 999. Get a paramedic there, who can assess them face-to-face, because it's… Some of the things they ask us to do over at 111 are… Difficult. And it's difficult to get across to somebody on the phone. You know, they've had a busy day. They get frustrated on the phone and, you know, it can get a bit combative. So, 111 is not something… We would only use for something very mild that we… Say, if it was out of hours for the GP or out of hours for the pharmacist, and we knew it wasn't a medical emergency or, you know, we weren't that concerned". (Manager, care provider organisation)*

The carers are using the paramedic ambulance service as a proxy emergency department to get some sort of acute healthcare assessment of their patient.

In summary, for some carers 111 is not an effective route to escalate their concerns because of the inflexibility of algorithmic approach that 111 call handlers have to take and which does not seem able to take account of differences in 'normality' for people with a learning disability.

5.1.6.2.3 Ambulance service/paramedics and policy issues

Care workers in care provider organisations were mostly very positive about their experiences with paramedics, with an occasional reference to the fact that paramedics did not always understand that carers do not necessarily provide round-the-clock care.

> *"I think we've learnt… Through conversations that we've had with them – with the paramedics – normally they're very, very good. Very good. And a lot of the time they come out and say, oh, we've been here before for this gentleman. You know, and they've… Paramedics are 99 times brilliant. But it's also the paramedics have an understanding of our service as well as that. So, you know, we are funded by social services for a few hours a week. We don't have the resources to take somebody to A&E and sit there with them all day". (Care provider manager).*

However, carers did identify two issues that could sometimes act as a barrier to escalating their concerns and getting timely help through escalation via the ambulance service. Firstly, that paramedics could have a lack of learning disability awareness which led to them sometimes making assumptions.

> *"We called an ambulance. Well, it wasn't me, but it was a case that I investigated as part of my role within our organisation. And somebody was unresponsive. And they called an ambulance for her. And the ambulance people arrived. And they were in the room, and they were doing all the bits and pieces. And one of the staff members said, what's going on? And they were like, oh, she's fine, isn't she? You know, she's just non-verbal. And it was like, no, she's verbal. She talks. But they'd assumed that she was non-verbal, and that's why they weren't getting a response from her. And then, when the staff member*

> *actually said, no, we called the ambulance because she unconscious. Like, she's not waking up. And you've just come in and assumed that because she didn't say hello back to you, and because she's got a learning disability, that she can't talk. And then they kind of had an "Oh-shit!" moment... Pardon my language. But an oh-shit moment. Got their shit together, and took her out. And she ended up dying. She had sepsis. But because of that assumption, it was a half an hour delay before she got to hospital.*

Interviewer: Why do you think they didn't say, is she normally verbal?

> *Participant: Because they came in as medical professionals and made an assumption. And that was it. They didn't ask for... they didn't ask the question. And, you know, we're told, like, when the ambulance people arrive, that that's when... They take over. They should know what they're doing. And... But saying here - she's not waking up. Like, she's not responding. And they just made an assumption that that's what normally happened". (Manager, care provider organisation).*

This lack of awareness about learning disabilities could also cause carers to feel that the carer-clinical boundaries were unclear.

Secondly, the policy and legislative issues around capacity to consent and managing non-compliance could cause confusion and delays to escalation and getting timely help.

> *"So, we had a gentleman who just stopped eating and drinking, basically. Obviously got quite unwell as a response of that. But this gentleman also has very high levels of anxiety. If his structure is disturbed. And he needs predictability about what is going to happen, in order to manage his anxiety. So, having people like paramedics turn up is not something that he's easily compliant with. And our issue was it was very clear something was wrong. However, on the surface of it, in terms of acute medical emergency, there weren't any signs that he was desperately unwell in the sense that he needed an admission to hospital. And, therefore, our difficulty was getting professionals and clinicians to agree what was in his best interest, in terms of if he was going to go in for some kind of assessment, to work out what was wrong, he would need some kind of restrictive practice – whether that was sedation medically, or physical restraint, or whatever it would need to be. He was going to need something in order for those tests and assessments to take place. Then the problems, then, we came across were a number of paramedics or consultants that came out had a misunderstanding about the various legislations that they could use in order to facilitate that. So, for example, it was suggested that maybe he was sectioned under the Mental Health Act. Well, this was a physical health issue, so that wasn't an appropriate use of that act. I mean, it's taken me probably, what, 30 seconds to tell you about this – but this gentleman had this for two weeks. And we had hours and hours… You know, sometimes he was… Paramedics were arriving at nine o'clock, and it wasn't until 12 midnight on the same day that we were getting an answer. Because it was going round and round and round the houses between various clinicians and professionals. So, it was… That was a particularly complex one. But it's a good example of what can happen when somebody is clearly unwell – and we need to establish why and what the cause is – but if they're not classed as a medical emergency and they won't comply with assessment and treatment, we become very unstuck very quickly". Learning disability health professional, care provider organisation).*

In summary, there can be a lack of awareness about learning disabilities amongst paramedics which can act as a barrier to carers trying to escalate their concerns through this service. Furthermore, policy and regulatory issues and confusion can result in delays to escalation of care when people are non-complaint with health care actions e.g. being transported to hospital by ambulance.

5.1.6.2.4 Procedural or policy issues

Following on from the policy issues touched on in the previous section, there are other policy or procedural issues related to escalating concerns for people with a learning disability. Adults with learning disabilities are often not compliant with healthcare procedures but the issue of their competence can be complicated.

> *"Are you aware of the case up in the North West of [Name] I can't remember her surname. A lady with Down's who basically… She ended up dying, but she wouldn't get onto the ambulance because, you know, she didn't understand it. But they basically said, "Well, we can't force her, so she needs to go home." And she subsequently died. I can't remember… There was some abdominal something going on. But there's so many cases like that, you know. And I've probably got four or five from my own experience in the last three years that I could give. One of which has ended up in the person dying, which was the gentleman who had cancer. So, to me, that's the biggest issue. Is access when somebody is not compliant". (Learning disability health professional, care provider organisation).*

Another issue related to the lack of appropriate adjustments to how people with a learning disability are managed within secondary care.

> *"I've got one at the moment – the gentleman I just talked about, actually. No diagnosis of epilepsy. He's now had five seizures with us. Paramedics called, because obviously we've got no protocol. He doesn't have any medication because he doesn't have epilepsy. On a couple of times the paramedics have decided to take him to A&E. Of course, he's not been compliant with being in A&E. So, they've sent him back home again. He's got an appointment for a neurologist in a week's time. Yesterday he had two seizures – again ended up in A&E about one o'clock. They discussed and went to and from about what sedation was necessary in order to get a scan to find out why he was having these seizures. After some sedation, eventually, at 7pm… So, having been in A&E for most of the day, a consultant decided that a CT scan wasn't going to give them what they needed. He needed an MRI scan, so sent him home again. So, this gentleman has now had five seizures with us, and we don't know why. And my question would be if he hadn't got a learning disability, what would the treatment have been so far? Because I'm damn sure he would've had a scan of some kind to find out why is this person suddenly having seizures. I think probably the decision that the consultant made may be valid, but could that have been made seven hours earlier? That's probably more of my issue, rather than the actual decision. If a CT scan is not going to give us what we want, then I agree – why put him through that and sedation. However, at this point, he'd already been sedated". (Learning disability health professional, care provider organisation).*

Asked what would prevent these types of barriers; pro-active admission to A&E, and being seen by the right person straightaway, who has considered the information given by the carer, were given as two procedural issues that could be resolved through changing hospital policies with respect to people with a learning disability. This might help to avoid situations as described above where carers and health professionals are forced to wait until the person with learning disabilities is so poorly, they lose the capacity for non-compliance.

> *"Now you're asking! Proactive admission to A&E would be a start. In terms of reasonable adjustment, and they're expecting you to come. It's a person with learning disabilities who needs x, y, z in terms of reasonable adjustments. And a priority in terms of when they will be seen. Because I don't think… Obviously, people in A&E, you're prioritised on your medical emergency. He wasn't a medical emergency. He was stable – he was just sat in A&E. So, there's one issue in terms of the priority, in terms of getting seen.*

> *And then, when you do get seen, are you seen by the right person the first time? Because, for a consultant to then come seven hours later, and actually say no, that's not going to help… You know, and maybe we could have a proactive admission, rather than, you know, reacting when he's had a seizure." (Learning disability health professional, care provider organisation).*

In summary, there are procedural issues related to non-compliance with accessing health care by people with a learning disability and how people are managed within health care systems, that act as impediments to escalating carer concerns and that may need policy changes to resolve.

5.1.6.2.5 Direct Access during Secondary care

For some carers, the biggest barrier to getting timely help was related to admission to secondary care.

> *"Our main issue is the interaction we have with hospitals once somebody is in hospital. As opposed to the paramedics and getting anybody into hospital". (Care provider manager).*

Carers of people with complex physical health and learning disabilities commented that they tried very hard to avoid hospital admission because in their experience, people just became more ill once they were admitted.

> *"Our, kind of, quality markers for ourselves are… We always try to avoid unnecessary hospital admissions. Because if any of our… If any of the residents who live here get admitted to hospital, it is pretty much guaranteed to be a prolonged admission, a delayed discharge, and generally speaking, the residents who get admitted to hospital develop complications whilst in hospital. So, we have guidelines that the nurses are able to follow to stop people having unnecessary hospital admissions". (Learning disability health professional, care home manager, care provider organisation).*

Exposure to hospital-acquired infections is one concern but lack of knowledge about normality and working with carers to understand existing care management can also contribute to this.

> *"At the time of admission, what really needs to be established is what you're going to be treating, what the acceptable parameters are, and what the discharge plan is. Because our people are more prone to getting hospital-acquired infections". (Learning disability health professional, care home manager, care provider organisation).*

Exposure to hospital-acquired infections is one concern but lack of knowledge about normality and not working with carers to understand existing care management can also contribute to this.

> *"Well, I think some of it is underlined by fear of not knowing what to do. [Name's] situation is compounded by the fact that she has had an intermittently bypassing PEG for years. Now, it's been something that we've been trying to sort out, but the nurses had evolved a practice here to the point where it was not ideal, but manageable. But in a hospital, after supporting [name], with one round of medication, the decision was made that her PEG was not viable and that has caused all sort of problems. It's just frustrating, because by rights [name] should've been back here four weeks ago. And, as such, she has been in hospital". (Learning disability health professional, care home manager, care provider organisation).*

For this carer, there was an issue arising from the lack of a partnership approach from the hospital and a medicalised approach to solving issues without considering the implications for ongoing care for that individual, specific to their needs and context. This meant that although the initial issue that prompted escalation of concerns had been resolved, the person was still in hospital several weeks later with issues that had previously been being managed.

For several carers in this study, having a learning disability nurses available in the hospital for made the escalation of concerns and getting timely help easier. The lack of a learning disability nurse was a big barrier for escalating concerns and getting timely help. The impact of this for people with a learning disability and their carers can be experiencing greater levels of fear and distress

> *"You were in hospital in [city name] and you didn't even have a learning disability nurse. There was no learning disability nurse at the hospital. It was me that came and supported you, because [name] was so frightened. She had no support at all. In fact, they were ringing me up and saying, "Hey [name]! what's happening to your wife? She's going to bed with a…", (I hope you don't mind me saying this) With her clothes on. What's going on? We're trying to get her to wear a nightshirt." And I was saying, "Well, [name] is petrified. She's scared." I mean, she's in a ward with OAPs. She's not in a ward with people in her age group. I had to leave you at about midnight, when I came with my dad to see you… I had to leave you in this emergency bed, all night long crying your eyes out, because they couldn't find a bed for you. And also, I had to go because she was being difficult. She wasn't being difficult. She was just scared out of her wits about what was going on". (Learning & development role, care provider organisation, family carer, expert by experience).*

In summary then, for many carers a significant barrier to escalating concerns, conveying important information and getting timely help arises when people that they care for are admitted to secondary care.

5.1.6.2.6 Consent and/or next-of-kin issues affecting information flow

For some carers consent or next-of-kin issues could affect the pathway for escalating concerns. For example, one care support worker described differences in escalation procedures, depending on the type of care provided.

> *"It all depends personally on whether… because we have three clients live with us permanently in a supported living environment. At the other end of the house, we have up to four guys in on an evening or weekend, for respite. So… Initially most parents prefer us to contact them first. Just because if it's quite serious, some parents have concerns about the family member going into hospital. And we've had parents in the past that would rather come and pick them up and take them home. Rather than them going into hospital. So, yeah, we would initially contact them. With the guys in supported living, we would go through their registered GP. But, again, we've… Especially through this COVID period, we've had lots of issues. GPs don't want to come out and see the guys. So, you're either communicating to them through things like photos, or videos or… And getting a proper diagnosis is quite difficult sometimes. So, we do find that frustrating at the moment. But then, obviously, we would speak to the families to let them know what's going on". (Senior support worker, care provider staff)*

For other carers, there are nuances around consent and capacity to consent that can make things difficult for carers in trying to get timely help. For example, health professionals in hospital without understanding of learning disabilities may not understand the need to consult with carers about consent for procedures or how to communicate with people.

> *"When she was 18 she had to go in and have a cyst removed from her neck. It kept reoccurring. And in that instance, I got her learning disability nurse and her psychiatrist to write notes that I actually sellotaped to the door of her room. Saying, don't listen to [name] because [name] is very polite and as… If you say to her, how are you feeling? She'll say, fine. Because that's what you're programmed to say, you know. Are you in pain? She always says no, when she's in pain, regardless of anything. And it's like… Basically, they were saying please listen to the mum, because you can't take… And because she can talk – she can say, like, yes and no and nod and things like this – you know… At some point, you go like, don't be silly – she can't give consent to that. And they took her for a scan and they asked her if she was pregnant. And I couldn't go in with her. And it was like… Me, you know… This is beyond stupid". (Family carer).*

Sometimes, there are relationship issues that make communicating with health professionals on behalf of people with a learning disability more complex and which need sensitive handling. One carer described a situation where they had a foster parent relationship with someone that it caused distress for the person being cared for if this expressed aloud.

> *"Because at that time, I was her foster carer. I was her foster mum. I can't say it in front of [name] because she doesn't want anybody... She's your daughter. And, to her, that's who she is. And you don't have to say the other words. She's always been like that. But you do, because there's certain things as a foster carer you can't sign. And when they're in hospital... you have to explain to her. They explained that, usually, that does, you know... take it to... they're usually different with you then. But on that occasion, there wasn't. And it's the different nurses, isn't it? I mean, it's not their fault, but it was quite as though... I didn't think we were listened to. The doctor did, when the doctor came. But I think the nurses thought I was just overprotective..." (Shared Lives carer, 23041230)*

For carers providing medical care for people with complex physical health conditions who also have a learning disability, being excluded from consultations about appropriate care may be procedurally correct, but can mean that important information relevant to the care and treatment of individuals is not taken into account.

> *"The complexity of the situation is compounded by the fact that [name's] mum is her court of protection deputy for welfare. So, the hospital had been consulting directly with mum, and not necessarily with us. So, I think that some decisions may have been made which weren't… which possibly I would not have agreed with. (Learning disability health professional, care home manager, care provider organisation).*

For other care support workers, one of the issues they have is getting information back from the hospital because of next-of-kin relationships.

> *"Another concern is we are not classed as next of kin. So, the hospital is reluctant to give us any information. A lot of the people we're supporting don't have families, and their next of kin is social services. So, to try and get any information from the hospital is not easy". (Care provider manager).*

In summary, for some carers capacity to consent and next-of-kin issues can present a barrier when they are trying to escalate concerns, convey important information to or get information back from hospitals

2.2 PART TWO.

The Use of EWS Tools For The Timely Recognition And Escalation Of Their Concerns About Acute Deterioration

This study identified (In Part 1) impediments that carers encounter when trying to identify deterioration in the people for whom they care, and to escalate their concerns to get timely help. Some of the carers participating in this study had received training and access to EWS tools. This section reports the impact of training and access to an EWS tool for carers and considers this in the light of the impediments identified in the previous section. Most carers in this study who had received training and/or access to an EWS tool referred to either RESTORE2 or RESTORE2Mini. As discussed in section 3 the difference between RESTORE2 and RESTORE2Mini is that the former includes taking clinical observation (using equipment such as thermometer, pulse oximeter and blood pressure monitor) to calculate a NEWS2 score, whereas the latter does not.

Five categories of themes emerged from the analysis.

Table 9 summarises the impact of access to an EWS tool being and being trained how to use it.

Factor	Enabling Mechanism(s)	Outcome
Carer knowledge and skills	• Content of training is new knowledge, or confirmation of informal knowledge • Mix of experienced and inexperienced carers in training sessions by experienced carers and sharing of their knowledge and experiences benefits both inexperienced and experienced carers through: • Acquisition of new knowledge for new or inexperienced carers • Validation and confirmation of existing skills, knowledge, and behaviour for experienced carers • Updating of experienced carers knowledge • Broadening of experienced carers knowledge through hearing about new situations, soft signs, procedures • Depth and breadth of knowledge and experiences available as a learning resource is greatly enhanced • Reinforcement for less experienced carers of the value and status of carers as experts about the person they are caring for • Carers learn about or understand the need to capture and document information about the range of normality for each individual • Carers learn about or understand the need to capture and communicate information about the nature of change(s) in normality for the individual that have triggered their concern • Carers gather and document information about the range of normality and changes in normality with illness for each individual • Carers experiences foregrounded in training sessions as learning resource for all participants • Trainer acting as a facilitator for participants to exchange experiences and knowledge, rather than instructor (facilitator mode) • Listening to other carers experiences and recognising commonalities in experiences	• Raising skill and knowledge levels for all carers • Carers' acceptance and internalisation of new knowledge and awareness, related to current and potential future experiences, is enhanced • Baseline information is available and can be shared between carers, setting and with health professionals • Key information for emergency situations has been identified and is ready to share • Changes in normality that matter for each individual can be described and shared with other carers, between settings and with health professionals • Build evidence base for rare and complex conditions • Recognise signs of illness in rare and complex conditions • Transformation of carers conception of themselves as experts • Legitimation of carers expectation to be considered as an expert • Training triggers a change in the way carers think about the care they are providing, as well as how they assess deterioration • Gateway to other training and tools or health screening • Career development and progression opportunities • Training forms part of career development and progression opportunities for care staff • Contributes to staff recruitment and retention offer in care provider organisations

Factor	Enabling Mechanism(s)	Outcome
	• Carers experiences and knowledge validated by trainer and other participants during training sessions • Listening to other carers experiences on a peer-to-peer learning basis enhances authenticity • Trainer provides useful, authoritative and relevant knowledge (instructor mode) • Mix of experienced and inexperienced carers and types of carers who get a chance to talk amongst themselves in break-out sessions • Online format facilitates mix of carer types and experiences from disparate locations creating relative level of pseudo-anonymity (people unlikely to meet again but united by their shared carer experiences), facilitating free exchange of experiences • Hearing others in training sessions talking about other training and health screening available • Acts as introduction to healthcare knowledge and skills for carers who may have excellent social care support skills but little healthcare experience	
Carers' confidence	• Carers' confidence in their own expert skills and knowledge is enhanced through validation and 'permission-giving' by peers (other carers) and trainers (representing authority) during training • For tools that are simple paper-based tools, having a piece of paper to grab provides something literally to 'hold onto' • Following simple written instructions e.g. on the piece of paper tool, rather than having to think what to do • Having relevant information already prepared, easily to hand and ready to pass on • Simple task to follow even in new and different situations eg COVID-19	• Empowering • Carers feel empowered to insist on their expert knowledge of the person they care for being heard and taken into account, to advocate for what they think the person needs and to challenge health professionals when needed • Empowers carers and people with a learning disability to ask for information • Manage emotions at time of stress, facilitating information flow • Helps carers ground themselves and regain control of their emotions and rational thought processes that are typically 'scrambled' by 'fight or flight' reaction in high stress moments • Ensures that important information is passed on even if carers cannot recall it during 'fight or flight' reaction to moment of high stress and anxiety

Factor	Enabling Mechanism(s)	Outcome
Carers own mental and physical wellbeing	• Tool and training can be used by carers to think about their own physical and mental health, baselining normality for themselves, noticing changes and using this to recognise when they may need additional support; being able to evidence need for support • Carers who are struggling with their own physical and mental health may find it harder to have time and resources needed to notice changes in the person they care for and escalate concerns to get timely help	• Carers' awareness of their own mental and physical needs • Care needed for person with learning disabilities is escalated at right point for each specific situation to ensure timely help
Communication between carers and health professionals	• Practicing and using structured communication and using the tool to identify key changes helps carers to provide focused information that health professionals need for decision making, eg 'what they see, rather than what they think the diagnosis is'; eliminating information that is waffle or repetitive because the carer is anxious or stressed	• Focused information health professionals need for decision making • Health professionals are more likely to react in a timely and appropriate way to carer concerns
	• Carers provide information to health professionals that quantifies or provides significance context to the changes that they have observed and are concerned about • Carers can provide information on why changes in normality for the individual in question matter, even if this might not seem significant in people without learning disabilities	• Quantifying or providing significance context to carer concern • Health professionals are able to prioritise their response to carer concerns appropriately • Health professionals are triggered to respond to carer concerns, even if they have no experience or knowledge with the differences in spotting deterioration for that individual
	• Using language and a communication style that health professionals recognise can help to overcome dismissal of carer concern; elicit a faster, more appropriate response; prompt health professionals to understand important aspects they may not have knowledge of eg different presentation or experiences of pain	• Language of clinically trained people • Helps carers to escalate their concerns and trigger the response they are seeking from health professionals more effectively, more quickly • Helps carers ensure health professionals listen to and take into account important information, related to the diagnosis, care and treatment
	• Carers can apply training in structured communication techniques to: • Ask for information from health professionals when people are discharged from secondary care	• Information flow back from health professionals • Ensuring key information relating to diagnosis, ongoing care and treatment of people is shared back to carers

Factor	Enabling Mechanism(s)	Outcome
	• Make the most of appointments with health professionals, specialists by planning ahead with questions, information needs etc • Develop sufficient confidence in own skills and knowledge to be able to ask health professionals to explain unclear information or terminology	
	• GP receptionists receive training in EWS tools, and particularly using structured communication approaches, so that they: • Recognise the language of soft signs used by carers • Recognise or ask for key information gps are likely to need	• GP receptionists are able to create a receptive environment for carers to escalate concerns
Communication between carers and other carers in other settings	• Multiple carers or carers in different settings have information on baseline for individual • Multiple carers or carers in different settings can be updated with current carer concerns • Multiple carers or carers in different settings can continue to monitor changes from baseline • Easier to establish appropriate point to escalate concerns if progression of symptoms can be monitored between carers and settings	• Up-to-date information flow between multiple carers and/or different settings facilitates earlier escalation of concerns and accountability for responsibility for escalating concerns

TABLE 9 IMPACT OF TRAINING AND ACCESS TO EWS TOOLS FOR CARERS.

2.2.1 On carers' knowledge and skills

The training sessions had had important effects on the carers understanding of the work. The training can be considered as having two major effects. The interviewees had described in vivid detail the isolation they feel as carers. The work patterns of many carers involve a lot of lone working, and it was clear that even in communal workplaces there is a high staff turnover. These factors affect the development of communities of practice and communities of learning for the care profession. The carers had little experience of training and this initiative:

- Demonstrated that 'authority' cared about their work and understood the problems they face
- Showed them that they were part of a community of learners and gave them opportunity to discuss work with their peers
- It provided them with the benefits of knowing how to structure observations and the language to better express their concerns about an individual
- Because of the hunger for education that they brought to the sessions they extracted added value by accumulating general knowledge about the medical aspects of care – as well as learning specifically about EWS.

Thus, in addition to the specific value of learning about EWS there is also a general coalescence of understandings about 'caring'. This latter benefit would probably have been seen with any focussed education package for front line carers.

The impact of training and access to an EWS tool was to raise skill and knowledge levels for all types of carers and both inexperienced and experienced carers, albeit in different ways. This was particularly facilitated by having a mix of carer types involved in the sessions and the mix of content delivered by both the trainer (instructor mode) and participants through sharing experiences, in a supportive learning environment fostered by the trainer (facilitator mode).

Carers learnt the value of baselining normality for the people they care for, enabling them to capture supporting information about any changes that made them concerned. EWS tools offer a useful tool to start thinking about baselining and capturing key information. Carers also learnt that for rare or complex conditions, thinking about and capturing baseline information on the range of normality for that individual and signs of illness for the individual contributed to building an evidence base for managing the individuals ongoing health. This was particularly important to support carers advocating to manage acute illness in the face of diagnostic overshadowing for people with a learning disability and reinforcing that managing acute illness is separate to managing someone's ongoing condition.

Many carers underwent a transformative process through participating in training sessions, which legitimated their knowledge as valuable and helped them to reconceptualise themselves as experts. This in turn gave them confidence to escalate concerns and advocate for the people they care for.

The content of the training sessions delivered by trainers, as well as the sharing of experiences and information, acted as a gateway to other training and tools for some carers. Carers heard about other tools and health checks eg registering as learning disabled with GP, annual health check, DisDAT, and were inspired to follow through by the experiences they heard.

For many carers, the training offered career development and progression opportunities, or was the first step on a pathway to health care related careers.

2.2.1.1 Formalising their on the job learning and tacit knowledge

Carers of all types, paid and unpaid, inexperienced and experienced, reported beneficial impacts in terms of knowledge and skills. For example, many carers identified that they had gained new knowledge from both the content of the training sessions and sharing experiences with other carers. This new knowledge could be either new knowledge that they did not have previously, or formalisation of informal knowledge and legitimisation of this as valuable information, worth capturing and sharing with others. Formalising, capturing and being able to share knowledge was a particularly important benefit of the training and access to the tool. This carer is intuitively explaining tacit knowledge (Kallio, 2020).

> *"…when you get your regular staff and you've got people who are key workers - like myself with this lady, I know her very well. I know her inside out.. But all of that information is probably in my head. And with the key workers within the care homes, their information is in their head. I've been a key worker. I know that all of the information isn't written down anyway. So, if you know somebody is unwell, you know because you know that person so well. So, what I've been saying to the care homes is that this is really, really important that we get everything out of your head and onto a document, so that we know... So that if there is agency staff there, anybody can identify whether that person is feeling unwell.". (Community Learning Disability Nurse, care provider organisation).*

The EWS training gave the carers the vocabulary to be able to make their tacit knowledge about a person's condition explicit and thus to be able to share it with others. For experienced carers, the training confirmed that what they knew and that how they applied their knowledge and skill, was valid. This was valued by them and reinforced their confidence to keep doing what they were doing. Experienced carers also commented that although the training mirrored what they already knew and did, participating in the training was still beneficial. Hearing about other people's experiences, the wide range of types of soft signs reported by other carers and the way other carers acted in different situations was informative and they felt affirmed informal ways of working they had developed for themselves.

One health professional providing support to carers in residential care homes commented that undergoing the training would have something of a transformative effect, in that it would change the way carers cared for their residents and thought about how they assessed people.

> *"And it'll have a different view when they're looking after the residents. They'll think in a different way. Because all the training I've had has made me think differently about how to assess a patient. You know, that's what education does, doesn't it? You think differently once you've had it". (Health professional, Nurse practitioner, Care home Support Team)*

2.2.1.2 Creating a new community of learning

Other carers described how they felt that attending the training, sharing other people's experiences, and acquiring new knowledge about soft signs would help prepare them for new situations, new illnesses, and new individuals:

> *"It's made me more aware of what to look out for. Other issues. Because different levels of autism, or clients, present different traits to look for. I thought it was very good. And the fact that we're trying - another carer and myself are trying to set up a day care for learning disabilities, because there's none locally. It's good, because the next client that comes through might present differently to our clients." (Shared Lives carer)*

2.2.1.3 Formalising the baseline assessment

Another key impact of the training in terms of acquiring new knowledge, was that carers realised the importance of capturing, documenting and sharing the informal knowledge in their heads about what the baseline or range of normality for each individual was.

> *"What got me thinking after that [training session] was just to record, you know, his normal... his heart rate and his oxygen level - which has been a thing, hasn't it? With the pandemic? You know, you see people in hospital with the little clip on the finger, you know, to record the oxygen level. Or how efficient your lungs are working, sort of thing, you know? And it's got me thinking, "Yeah, I need to record that for [name] on a normal day. Because maybe his level isn't normal." But then, if he was in hospital, I could say, "Yes, this is typically what will... You know, [name]'s heart rate will be"." (Parent carer)*

This included capturing key behavioural baseline information so that everyone involved in caring for someone was aware of the range of normal behaviours and means of communication, the meaning of these behaviours and communications and what changes in these might mean.

> *"I think the important thing is what we've spoken about, really. Especially for, say, new people. New people getting to know my daughter - they need to know what's normal for her. They need to get to know how she normally is, so that they can recognise when something is not normal." (Family carer)*

One health professional commented on how they had started to use one EWS tool to collect baseline information every time they took on the care for a new person:

> *"Every time I have somebody new on my caseload - or anybody. Somebody who lives on their own. I do a Restore 2 now, and I ensure that the people... The carers know their soft signs. And I escalate it to the GP. And say, "These... I've done these Restore 2 documents so that you know if somebody is deteriorating". So, that's the only way that I can do it, really. Because I don't own that person. You know, I might not be around. But as long as other people know, I think, and are aware of how to escalate it. And then the people who they escalate it to are aware as well". (Community Learning Disability Nurse, care provider organisation).*

This approach could be usefully expanded to GPs using an EWS tool to capture key baseline information at annual health checks:

> *"I think one of the GPs actually did say that doing that Restore 2 training… Doing the Restore 2 document at the annual health check would be perfect. But what we hadn't thought about was actually the nurse or the HCA doing the annual health check while a GP could fill out that Restore 2 with the carer. (Community Learning Disability Nurse, care provider organisation).*

Another health professional emphasised the importance of having this baseline information because of how much normality and illness cues could vary in people with a learning disability:

> *"I think it's good to know a baseline, because then you can make it specific for that person. And that's the point in learning disabilities – is that, you know, nobody fits into an average box, isn't it?"*
>
> *So, it's about knowing what's different. What's a change for that person, and when that change might be significant, isn't it"? (Health professional).*

An experienced carer in one care provider organisation commented that following training in RESTORE2 (an EWS tools which involves taking some basic measurements and calculating NEWS2 scores), carers were now able to capture and monitor baselines and detect changes in normality for an individual, and that this had become particularly critical since Covid-19. It had even begun to trigger a change in attitude amongst care staff to taking basic measurements and to start having simple equipment to take temperatures, blood pressure monitors and pulse oximeters readily available for ongoing monitoring, rather than waiting for people to already be ill before thinking about taking measurements. One of the key impacts of training is that it triggers a shift in approach and data gathering by carers to collect baseline information about health, as well as the data they already capture in support plans about communication and behaviour.

A Learning & Development staff member for one care provider echoed this theme that the training may trigger a change in the way carers think about their job and how they do it, how they capture and share information about the people they care for, beyond using the tool for spotting deterioration and escalating concerns.

Other interviewees also noted that baselines could change and that using EWS tools that involved taking basic measurements to monitor baselines, not only helped pick up changes due to illness but also changes in baseline normality:

> *"Yeah, it [normality for each individual] can be different. And it also can be changing. We've got another service user that spent some time in hospital and then, since he's come out of hospital, his temperature is at a higher level. And that is, sort of, a regular thing. So, by monitoring it we now know that if his temperature is at a certain level, that is fine for him now, because it has raised. So, yes, everybody has got different readings, and you can determine what their norm is. But there are occasions when their norm does change after illness and things. So, it does give us a good record of what we're looking for". (Senior support worker, care provider staff)*

2.2.1.4 Augmenting the hospital passport

The value of a short, simple tool that facilitates being able to provide a snapshot of any individual, both in terms of the important bare essentials of what they are like normally and what has changed, was noted and particularly in contrast to Hospital Passports which although detailed and thorough, were often not used by health professionals in practice:

> *"I think most importantly, it can't be waffly. It has to be… it has to get the message across. It has to be a snapshot of the person you're dealing with. That makes it easier. Well, it's not necessarily that it makes it easier. You know, it's a quick portrayal of who you are". (Shared Lives carer, former health professional)*

Crucially though, as this carer noted, having data that enabled carers and health professionals to distinguish between variations in normality that matter and normal variations for the individual that do not matter, would not only help identify when help needed to be sought but also save wasted effort following up issues that were not problematic.

2.2.1.5 Countering diagnostic overshadowing

Carers are often confronted with the problem that there is a tendency to perceive all abnormal findings as features of the underlying LD. Understanding the importance of capturing baseline physical and behavioural information and being able to evidence changes that have triggered carers concerns, may help carers advocating for timely help in the face of such diagnostic overshadowing for people with a learning disability (where all symptoms of ill health are misattributed to the person's learning disability). One carer movingly described this phenomenon.

> *"I suppose the only thing that I would add is that… My daughter's condition was classed as a life-limiting condition. And if you get a diagnosis, it seems actually you're most often told that it's a life-limiting condition. And no, raising the alarm about acute illness, being different from progression of her disease, wasn't distinguished. So, basically, we were made to feel like we were waiting… like, the world was waiting for her to die. So, why would we raise the alarm. Why would we…? You know, and every time she did get ill, we were told this was the end – she was going to die. And twice that happened, and twice she didn't die. And, actually, when she did die, she didn't get ill first. So… there's no distinction in the professional world – or at least in the acute world –between illness and the underlying condition. And I know that that's been covered a lot with diagnostic overshadowing. But a) that's never told to parents. I know about that from work, not from having a child with disabilities. And… and I think it's more than diagnostic overshadowing. It's like when you've got an expiration date, you're lucky to have any day up until that time. And so, it's just like no consideration at all is given to the fact that this child might get ill and get better again. It's always an end-of-life event. Actually, it's never an end-of-life event until it's the end of life. And I get that we always need to be prepared and ready. But that's very different to managing acute illness. So, there almost needs to be something separate around managing acute illness in a person with a progressive and degenerative condition, because it's still different. And, actually, it almost makes the managing acute illness more important. And that's what I wish I'd known as well. Because, actually, if we'd known that to prevent aspiration would be to prolong life – like then we could make that our main focus and our mission. But we didn't know that ". (Parent carer)*

Other carers reported that using RESTORE2 enabled staff to counter the tendency towards diagnostic overshadowing.

> *"It can appear that the Learning Disability overshadows an illness – they are poorly because they have an Learning Disability has been commented with people thinking that's the issue – this is the most frustrating barrier – using the Restore2 tool has given backing to staff concerns" (Senior support worker, care provider staff)*

2.2.1.6 Documenting rare conditions

Some carers deal with rare conditions or complex mixes of learning, physical and mental health disabilities about which very little is known. Attending training had triggered reflections about the value of capturing information to provide some sort of evidence base regarding life with these conditions, as these separate comments from an interview with one parent carer describe.

> *"And I think that it was this training [The RESTORE2Mini] that made me realise that all the bits of the puzzle that I just couldn't put together, and the stuff that I thought I must just have enough knowledge to understand, but I must just be too stupid to understand… This training basically made me realise, oh no, those are the bits that no-one understands. And, actually, maybe we need to go back to the beginning and think about some of the stuff that we've been talking about, and think about what is it that people know about these children, and what do they not? and, actually… How do we empower families who clearly know more than medics, to use their experience as evidence?"*

> *"But when you're dealing with people for… who nobody knows what the outcome is. And, actually, where families are making adjustments and taking risks every single day, because no two days are the same. So, we're our own evidence base. You know, we used to have*

> *to adjust [name]'s feeds… We used to have to adjust them… you know, we would… you know, I always said it was a bit like running in a hamster wheel, but it's also one step forward, two steps back. Every single day. So, you're learning constantly. And you are always in the moment, and you're always responding and reacting. And you're building, but you don't have time to record everything you're doing. So, you are building up an evidence base, but it is all in your head".*

> *"Well, that's exactly what I found. Actually, doing it [the training]. It was like… Oh my God, so I wasn't wrong! I mean, I found it totally actually really eye-opening from that respect, actually. Just to think that… I just wish I'd known that it was okay to be confident as well. Like… That it was okay to say, "No, actually, I think in this case I do know more than anyone." Because to have a training course that basically tells you most people really don't know very much about your child – so, you are the powerholder here. Because that's not what you feel. You feel like you've got… You've got armies of people around that are used to dealing with complex people all the time. My daughter's condition was really rare. Most people with these learning disabilities do have… If they've got a diagnosis, as you say, it will be a very rare condition. And I think that kind of almost makes you feel more powerless, because you're like one in ten million. And so, you're like, well, what do I know? Because what does anyone know? So, if anyone is going to know anything, it's going to be the clinicians that maybe came across another one in ten million once upon a time. But actually what this training is doing is saying, no, you're not that unique. There are loads of people that have very complex differences about them. And the people that know about them are their families. And the people that look after them, and the people that are with them every day. And, you know… And then you find that strength in numbers. Actually, you find that your problems and the things that you need support with are things like this. And other people are coming up against the same problems. And that gives… That gives you more confidence as well. So, it definitely… To be trained in… Like, to be told, no, you're right, is very encouraging". (Parent carer)*

The transformative experience this carer described, realising and accepting that they themselves are the expert on the person they care for, was an important impact of participating in the training. This process was facilitated by the way that carers experiences were foregrounded by trainers in training sessions, enabling carers to visualise how other carers advocated for the person they cared for.

> *"And I think with the training, it... and hearing other people say how their young people were. There was one lady, wasn't there, and she spoke quite a lot about her young person. And you got a picture within you of that young person, and how that young lady was dealing with her. And I think that was good. That was a good part of it". (Shared Lives carer)*

2.2.1.7 Creating a community of practice for family carers

Listening to other carers experiences and seeing trainers validate their knowledge and skill during the sessions was part of the process that legitimated carers own knowledge about people they care for as being expert knowledge that other people needed to know.

> *"And it's only being involved in RESTORE2 that I'm kind of like, oh my God, that's a soft sign. That's like [name]'s soft sign, isn't it? So, kind of like they are instincts that I think support workers pick up. But... knowing that it's a soft sign is that first added value of the training, isn't it? Of... I'm skipping to the end now - but I think that's the... you can turn around when you're a member of staff and say, like, this is really important to know". (Manager, care provider organisation).*

Carers' acceptance and internalisation of the new knowledge they acquired during training sessions was facilitated by feeling they were not being patronised and that the training was a peer-learning session.

> *"I thought it was good. I did think it was all good. Both me and my husband did sit and do it, you know. And... I did think that... It was presented well, and it was... It came across as genuine, to get... I don't know if you know what I mean? It did come across as genuine […] She wasn't talking at you, was she? It was... It felt... everybody was on the same level". (Shared Lives carer)*

> *"Absolutely, because I didn't know that. So, I mean, I have to say the training was brilliant. And it was great to speak to other people as well, in the breakout rooms". (Family carer).*

For many carers, picking up incidental or additional information apart from soft signs and structured communication had been a useful additional impact arising from participating in the training session.

> *"Yeah, it actually spurred me on to think… To look for other things to do… You know, to do around that. Yeah, definitely". (Family carer)*

For one family carer, hearing about annual health checks during the training sessions enabled them to have a discussion with other family carers about the importance of ensuring these were carried out and thinking about prevention or monitoring for other health related conditions.

> *"But my brother carries… as I say, he's not hugely overweight, but he does carry extra weight. And as with all [people with named condition] they do like to eat. And, you know, pinch the biscuits out of the cupboard and things like that. but he's pretty good like that. you… He's not… As I say, he's mild. He's in the mild… But I do worry about diabetes and cholesterol and things like that. Which is where I picked up, actually, on the… on the training about monthly… About the yearly review. And I thought, "Well, I'm sure he hasn't been for one of those. And I would've thought our doctors would've picked up on that." But after… straight after the… the course, I thought that was one thing that I really do need to check out. So, I rang my dad. And he goes, oh, "Yeah, yeah… He should do, but he hasn't had one for two years. For about two years." And I said, well, "Why not?" And he said, "Well, I've asked him – and he said no." Which was I had to say on it… So, I was very blunt, and I said, "Well, if you don't, you're not going to pick up anything like… And I said, you've got diabetes, you've got cholesterol… You know, [name] is a big lad – if you don't pick up on any possible things, he could die and it could've been…" And I thought, "I'm going to have to be blunt here". And I said… "And I'm not saying it's your fault, but we can prevent that by getting him to these medical reviews"." (Family carer).*

Likewise, being reminded about hospital passports during the training when other participants talked about them prompted one carer to start completing a hospital passport for their brother:

> *"The hospital passport things either. Now, my younger brother, he… I'm sure he did have something like that, because of all his medical needs. I mean, it was like a little book. But I never thought until that… the course, the training – that my brother is going to need that as well. So, I've already started looking at that, and started filling the one that was put on… You can change it. So, that was brilliant. And my dad and I are going to sit through… I've put some sort of notes on it. And then we're going to sit together and do it properly. Because if I'm no around and it's my dad that needs to take him to hospital, then he needs to know… He needs to have a copy. I'll have a copy that I carry with me. You know, and then hopefully, if we need that, it's all there. It's all on paper. They'll know he can't read, they'll know he can't make decisions for himself and things like that, really". (Family carer).*

Carers were also prompted to think about finding out more information about what the annual health check should cover and possibly trying to improve the quality of it, as well as learning about useful tools such as DisDAT, (the Disability Distress Assessment tool).

> *"Well, I'm going to get my notes. Because I noted down anything that I thought… I mean, obviously, I knew we were going to get the slides as well, which I got yesterday. Just to remind myself, because I am rubbish with my memory. Definitely, like I say, the SBARD… I thought that was… And I've got that written down there. Oh, and about the… With the hospital passports and things. I've got that down. And the annual health check toolkit. Because that's the one, actually… The one thing that I did… [name] does have his annual health check – although he hasn't one because of COVID this year. They did send some paper thing for me to do – all bits and pieces. But it was like, do his blood pressure and things. So, they're having a laugh… No way. I've never even taken his blood pressure. But, yeah, that… Because I don't feel that that's probably very thorough, when we go. They ask if I'm getting any help for me, as a carer. And they ask about his general health. But I thought it would be quite interesting to actually look at that and see what they should be doing. Because I never feel it's very thorough – the health check. It's just a bit… Like, a couple of questions, tick a box. And… Yeah, so that was helpful. And the… I've got here about the Distat tool". (Family carer)*

2.2.1.8 Carers see the possibility of career progression

Some health professionals felt that the training would give care support workers more job satisfaction, although this was not something mentioned specifically by care support workers interviewed for this study. However, some care provider staff talked about how training to spot deterioration and/or structured communication would be part of their career development and progression offer to care support workers. One care provider was planning to introduce a new health partner role and planned to embed training around spotting soft signs as part of this role.

> *"It's something that we hope to do and that we want to embed in. So, we've recently… And when I say recently, like, two weeks ago – introduced a new role within each of the homes, which is called a health partner. So, we already have positive behaviour support partners. And what we wanted to do is place the same emphasis that we do on behaviours of concern that we do for health as well. And also give that career progression. So, that's something that we're wanting to encourage that role to be able to do. And the idea is that the top end – the level three version of that role description – will be a nursing associate. So, that's what we're working towards. But we're right at the very beginning of that process". (Learning disability health professional, care provider organisation).*

The benefits of training in spotting signs of deterioration included gaining confidence in their knowledge and themselves and a greater understanding of the physiological meanings behind signs of illness, leading to being able to take greater initiative in deciding when observations were needed.

> *"I mean, they do do observations now, but they… they would be directed to do them depending on what we've seen, rather than people having that kind of understanding of when to do it, or why they're doing what they're doing – if that makes sense? […] I think it will give them some confidence in what they're suggesting as well – and I think if they understand what those signs mean, in a physiological sense…" (Learning disability health professional, care provider organisation).*

This care provider had developed their own bespoke EWS tool and also provided bespoke training to their staff. However, talking about the structured communication element of training in tools like

RESTORE2Mini during the interview prompted reflection about how this training might be valuable and worth including in future training.

> *"Because although that would superficially be covered in the emergency first aid training, that wouldn't really be done in detail. You're making me think now how I can… Because I'm about to deliver some training on medical appointments, because… I won't go off on a tangent too much, but… One of the problems in inequalities is actually getting the most out of an appointment when you're actually there. And making sure that staff ask the right questions, get the right information, and can relay the information that you've given to them". (Learning disability health professional, care provider organisation).*

2.2.2 On carers' confidence

Participating in training and having access to EWS tools positively impacted on carers confidence by empowering them as experts and to use their expert knowledge of the person they care for to advocate for the help they need. It gave them confidence to escalate their concerns in the first place but also to persist when needed if they did not get the response they felt they needed. It also gave carers something to focus on, literally something to physically hold on to in the case of simple paper-based tools, and information ready to just read out as they coped with the physiological effects of adrenalin in an anxious stressful moment.

2.2.2.1 Empowerment

Participating in training sessions had an empowering effect for many carers. This arose from having their own skills and knowledge validated by either the trainer or other participants and their experiences, or both. Empowerment has two elements identified by carers: challenging and questioning, as well as trusting their own skills, knowledge and judgement, as described by one carer reflecting back to earlier in their caring journey on how having this type of training would have made a difference.

This raises the point made by another family carer of the effect that greater empowerment when children are young would have had. Carers can see situations where this would have helped them follow up queries and interventions that may have helped their children's development.

> *"I think with [name] she failed her developmental goals and things. And then at about 15 months she had some major fits that she ended up in hospital with. And that was only… Oh, take her and just keep on with her. They didn't think then that there was anything wrong. She had a CT or an MRI and they just came back and said, "Oh, she's got a cyst on the brain. Your paediatrician will be in touch with you – goodbye". So, we would've had that diagnosis when she was 15 months. It wasn't until she was 18 that we actually found out she had a mutant gene. Which was [gene name]. And that's because some university was doing a gene… A genome thing? And collecting loads of information. And it was only because the psychiatrist [Name] had at the time said, "I don't think it's all down to this cyst, [name]". I wouldn't… Because I kept saying, "Okay, if she's got a cyst on this part of her brain, why is this affected and that affected, when it's not in that part of the brain". And we couldn't understand why every… Different areas were affected as well. And it turns out that she had this mutant gene that we knew nothing about. So it was… This is what I say about when you're a new mum – you wouldn't question it. You know, if somebody says this is wrong with your child, you don't question it. And it was only until another professional when she was 18 said, hang on a minute – this sort of stuff shouldn't be happening, you know. Not because of that cyst. And it was… She wasn't misdiagnosed, because she obviously did have a cyst as well, but had we had that information earlier, things might have been different. (Family carer).*

Managers of care support workers identified that they thought staff felt empowered as a result of training.

> *"I think it empowers staff. I think one of the keys to getting heard, and getting people to support the need, as we've talked about today, is the support staff advocating for that person. And I think it gives autonomy to people to say you know this person, you're the one that's going to stand up for them in this situation. And it gives people the confidence to say that you know this person best, and you know you can say, actually, this is not the best way to do this". (Manager, care provider organisation).*

> *"Yes, absolutely. Because, you know, it's a lot easier to have a conversation with somebody if you're being prompted by, you know, like that form. They could go down and have the conversation with the medical professional, and they… I think that would give them their own confidence." (Team leader, care provider organisation).*

One family carer, who was also a member of a parent carer forum, felt that more parents need to be able to access the training and that this would empower them and give them a voice.

> *"And I think it (the training] should be given more. I think we've got to give parents more… It'll empower parents. It'll give parents a voice". (Parent carer)*

2.2.2.2 Helps with carers emotions over consultations

One important aspect of giving carers confidence related to how the training and use of an EWS tool, particularly simple paper-based tools, enabled carers to manage their emotions at a time of stress, literally giving them something to hold on to and ground them in the moment.

> *"Because I sat there through a fair percentage of the training, thinking this is about preparation. This is about people needing to have that information that they require to hand. And it's almost a reflex, as opposed to, as you say, when you're in this difficult situation… Your physiology changes yourself and your thought processes change yourself – to have something that you can pick up that will just ground you in that moment, that will focus your attention. It's going to help significantly". (Shared Lives carer, former health professional)*

This helped them steady their nerves and reading out ready pre-prepared information gave them something useful to do that did not require rational thought.

> *" It's, you know, easier to do first aid or deal with a child or an adult or a person that's not related to you. But when they're close to you, you know, you're going to have that anxiety. You're going to be nervous. And to have everything just written down, there… You can either hand it to somebody while you're upset or whatever. Or you can… If you're on the phone to the ambulance service, you can just read it off. You don't have to think about it. Which I think is… It's so helpful. Because it's all there and you don't get flustered". (Family carer).*

2.2.2.3 Improving carers self-esteem

The improved confidence that the carers felt when they were supported by data from the EWS led to them having higher self-esteem. This was important not only in terms of having confidence to escalate concerns in the first place and maintaining important information flow to the health professional in the short time available but also for carers self-esteem.

> *"I think you won't feel so bloody stupid. You'll feel like… you know, doctors can be very dismissive. And sometimes you feel like you really just don't know what the hell you're talking about. And, actually, if you've got a piece of paper in front of you – and even just the words, I've looked at my RESTORE tool… which they should be aware of. And this is what I've come up with – might just give you the confidence that you're talking about something in… on the doctor's terms". (Learning disability health professional).*

2.2.3 On carers own mental and physical wellbeing

One parent carer with connections to many others through a parent carer forum group identified the value of the training and tool for carers to track their own mental and physical wellbeing and how the tool could be adapted for this.

> *"And I think this is what this will do. And this is why I think I'll tweak it slightly for carers… For parent-carers. Because they can keep track of their own health. Then some of these soft signs count to them. Because, I'm not being funny, a lot of our parent-carers have disabilities themselves now. You know, it's… It's so… This can, sort of, be almost twofold. If that makes sense? Because, you know, we do have a lot of parents that especially, you know, have anxiety and mental health problems. So, this can be used not just for someone, but almost, like, to keep them in check every… You know, I could do a workshop and say, right, let's all do one on ourselves, and we'll do one in six months. What's improved? What hasn't improved? That's what I mean – I love this SBARD. Because I can really play with that". (Parent carer)*

For many carers, who may have physical, mental or learning disabilities themselves, using the approach they learn about in training sessions and having access to a simple tool may help carers to recognise how the way they are feeling has an impact on the person they care for. Being able to capture and convey key information about their own state of health and ability to cope could be important contextual information that needs to be considered by health professionals.

> *"You know, I know carers that have taken drugs to take their own lives, because there's been no support. And that's why I want to try and tweak this SBARD… You know, and I will use the word, actually, because that's… now I've said… When I was looking at it, at first, I was thinking is it C-BARD or SBARD – whatever. But I think it's easy. And I like to give parents easy things. So, even if they could say it in their heads – not necessarily write it down – but think, oh right, I'm not normal. I'm not normal. This isn't a good day, you know. I'm not eating because I'm so stressed. And that then could impact that I'm tired. And that could impact on what I'm doing for Johnny. So, I like that SBARD. I think that SBARD tool… I would say whoever invented it, tell them from me, it's amazing". (Parent carer)*

Importantly, this parent carer felt it was part of giving carers a voice.

> *"So, this can make a parent-carer look after themselves, and that's what I like. Because they could look at that and go, do you know what? We're not having a good day. Or, yes… And just remember they're a carer. Just remember they have a voice". (Parent carer)*

2.2.4 On communication between carers and health professionals

One of the beneficial impacts of training carers to use EWS tools was that communication with health professionals improved in several ways, resulting in carers being able to escalate more effectively, trigger the response they were seeking from health professionals or the prioritisation they felt their concerns warranted. This also benefitted health professionals by providing focused information that helped them with their decision-making and prioritisation. Both carers and health professionals felt that training for GP receptionists, and particularly the principles of structured communication, was an important part of maximising the benefits of training carers.

2.2.4.1 Focusing on information health professionals need for decision-making or ensuring appropriate care

Both carers and health professionals recognised that carers were often under time pressure to escalate their concerns and that this also often occurred under stressful conditions of anxiety or fear. Inevitably, this resulted in some information being repeated or unnecessary. Practicing using the tool to identify key information and using structured communication during training sessions, or watching others do it, was a key benefit of training sessions. Practice in how to get started, what words to open with and flowing from one information to another are all key elements of what the training enables carers to practice.

> *"My husband works in a hospital as HR, not as a doctor. But we were watching... He works at [hospital name], so we watched the 24 Hours in A&E, and last night one of the junior doctors was having to explain to somebody... To a son, that his mother was really old and that she was going to die, potentially, with sepsis, and that they might have to resuscitate her. But she just couldn't get the words in the right order, and she just looked like she wanted the ground to swallow her. So, the senior doctor kind of supported her and, kind of, filled in the gaps and then explained it. And they are so confident because they've practiced. So, I feel like what we could offer is an opportunity for them to practice which words to start with. How do you flow from, you know, explaining the previous situations and the behaviours, and so on and so forth. How you flow between those. You know, do we give them a, kind of... Like a set list and then you add, you know... So, I feel like the person has been fuzzy. I feel like they haven't had, like... Their urine has not been great. Their bowel has not been great. So, just like things to say just to get you over the, kind of, nervousness in those minutes, so that the doctor has got the information. And precede it with, so, I'm going to tell you how... I'm going to tell you the way that we've been trained. To tell you all of those things, if you have any questions, please let me know at the end. But I think it's useful if I just explain all of this to you right now. And then you have all the information you need to make an informed decision about what do we do next. So, we could help them to structure things. And I think that's half the problem. Is that you... You don't know how to start. And the doctor is, like, it's all great, but I know your name and where you live - that wasn't what I needed from you". (Learning & development role, care provider organisation).*

One experienced care manager in a care provider organisation observed that carers sometimes struggled to distinguish between reporting what they saw and what they thought was happening.

> *"I think other people kind of struggle a bit to explain what they see, without trying to give their opinion of what it is. You know, I often have a sort of… I remind people that what they're telling me is almost a diagnosis, rather than telling me what the symptoms are, you know. But, yeah, I think… Yeah, obviously, you can kind of separate those two things". (Manager, care provider organisation)*

Another parent carer observed how helpful the structured communication element of the training had been in terms of realising how important it was to have key emergency information available and to communicate that effectively.

> *"I found that really useful. Even though I'm aware of health passports and one-page reports. You know, all of the documentation. But it's just… It has made me realise that, talking to other people… That you can have all those documents, but if it's an emergency,*

> *they don't get read. People haven't got time to read them. And then that's when assumptions are made. For instance, I've got a friend whose brother is a wheelchair user, and I don't know the full facts… Yeah, I think he's got cerebral palsy. But if it was an emergency for him, the hospital's instincts straightaway would be to treat him like another patient and lay him down on the bed. And that is the worst thing that they could do. Because if they did that, he's more open to, sort of, aspiration or pneumonia. You know, his posture would be affected. And a few times she hasn't been listened to. And she's had to get quite… Not angry, but quite… You know, persuasive. Well, I suppose angry, really. You know, they're not listening to her, who knows her brother best. So, yeah, I think when it's an emergency, maybe more could be done as regards… You know, how much information is needed at the beginning of that journey, or whatever the treatment might be. I mean, it's really good because this person… They're on about their passport is online, with the notes. And I think why isn't that happening everywhere. But yeah, I think in that first instance, when it is an emergency, how is that important information given from the main carer. You know, what opportunity have they got to say, well, look… My son is allergic to penicillin or… Or my brother must not be laid flat". (Parent carer)*

From a health professional's perspective, their training enables them to extract key cues they are looking out for as part of their decision-making process. If the information is already delivered in a structured way this offers a shorter, faster way to gather that information which may reduce delays in getting timely help.

> *"It's like having a language. I can remember when we went to medical school, being told that we would effectively learn a different language throughout our medical career. And that's not just about the funny words that we come up with for describing things and conditions. It's the way in which you communicate. It's having that language that… and you're right, because when you've got your training, your brain is listening for certain cues within the conversation to hang your medical hat on. It's not fair on people who haven't had the training, actually, sometimes. But I guess that's why we're trained to then ask those salient questions. And then you try and pull it together. When you're writing your notes, you pull together what's actually been said in response to your questions, to make sense of it. But it is a shortcut. If you can do that straightaway, without being asked all those other questions, it's a shortcut". (Parent carer and health professional).*

One health professional described how carers who had not been trained focused on things that were not necessarily useful to clinicians.

> *"I think sometimes people who haven't been trained focus on the things that we're not interested in. And you have to search around the subject. And I'm trying to think of a specific example. Oh, now… yeah, they might say… If someone, say, has got a catheter in or something like that, they might be very focused on the colour of the urine. And people just do that per se. You know, they'll ring up and say, my urine has changed colour. And we know that's probably down to the fact they just haven't had enough fluids. But they won't particularly pick that bit up. So, then I need to explore why they haven't had enough fluids. And try and search around that. But they don't necessarily offer that information. But that is our job – to ask the right questions to tease out the information." (Parent carer and health professional).*

For one parent carer, the training had made them aware of the need to prepare and have quantified data ready to present and leave on file and that this could also help ensure key information was not omitted.

> *"Only just, sort of, with doing a bit of preparation. Because everything we sort of do is off the cuff, really. Just to think, yeah, you ring up your GP surgery - and it might be a consultation with the hospital. I've done this of late with the neurologist when he goes for his annual review, because his fits have been so erratic. But I wouldn't have necessarily done this every year. You just go along and then just answer any questions. But now I'll go armed with, you know, the fact that he had a bad February". (Parent carer)*

The workload of health professionals has been discussed above but for carers trying to get the help they need, being able to deliver information in ways health professional recognise sometimes is the key to getting timely help or escalating up the priority list.

> *"It is really hard when you're busy and you… you know, you can see your tasks on your screen getting more and more, and someone else is knocking on your door because they want to ask you about something. And it often is a reflection of our stress levels, how we react to certain requests. If you request it in a certain manner, then it makes us think, oh yeah, right… I'll prioritise that. You know, it is difficult to manage your workload sometimes". (Parent carer and health professional).*

> *"With the guys we're supporting, obviously, not being able to tell us, it's the stuff we've got to look out for. So, we've had a few instances lately… Two or three issues, where they have been unwell. And where we've used the recording systems, taking the measurements. And obviously monitoring whether the NEWS score is increasing or not. Unfortunately, it's a bit hit and miss when we use them with GPs. Or when we use them with the emergency services. We have to call the ambulance for one guy and they never turned up for about two hours, and then I had the emergency nurse call me. And then I was able to give her the change in this guy's NEWS score, where she said, yeah, because… it was on the list, but it wasn't listed as an emergency. So, she upgraded it to an emergency because of the NEWS score we gave it. Which was really good. When the paramedics came, they were… They could look at how we've recorded, and they could see the difference. They were really impressed with that system. Obviously we've got a hospital passport in place, which gives a lot more information about the guys. So, they did say that it was one of the best handovers they'd had". (Senior support worker, care provider staff)*

2.2.4.2 By quantifying or providing significance context to carers concerns

An important aspect for health professionals that training carers helped with related to being able to provide some quantification or significance context to carers concerns.

> *"They (carers) quite often do things by the gut. And I think particularly the RESTORE2Mini is quantifying their gut. So, they think there's a problem – but they don't have a way of putting that in language. That there isn't a… Have they got a urinary tract infection? Are they behaving differently? Are they a bit warm? Are they a bit cold? Are they annoyed by what's going on around them? Do I think they're in pain? Which might just come up as a, oh, they're just not right today. Without those "um" thoughts". (Learning disability health professional).*

Some bespoke ESW tools were able to provide extensive background contextual data to quantify carer concerns.

> *"Because our system is paperless, and it's all on our IT platform – the way that we enter information is very… almost binary. Which makes it very easy to produce data on. So, for example, every single activity that is entered on a person's diary, for each step, they're required to put what that person's perceived mood is, for example. So, we have lots and lots of data about a person's perceived mood on a daily basis. So… although that is quite*

> *subjective and, you know, scientifically not brilliant reliable data, it does give you an indication. Because if somebody, 20% of the time, has been happy – and then the next month, you know, it's 40% and then it's 60… Do you know what I mean? You can look at general trends or, you know… We can also use the diaries for how much time people were spending in bed. We also record how much support they need to give… So, every step, we record. Whether it's hand-over-hand support, a verbal prompt, a physical prompt or full support. What we were able to demonstrate as well is that this person has lost independence as well. Because they're needing more support to do the same skills and activities". (Learning disability health professional, care provider organisation).*

2.2.4.3 Using language that health professionals recognise

A related aspect of focused, quantified information that clinicians want to hear relates to using the language of clinicians in order to trigger the response carers are looking for.

> *"But I think there's value in it [RESTORE2Mini being a short, single piece of paper] because it's easier to read. But there's also value in it that people… it says what medical staff need to know. And I think it talks in their language as well". (Manager, care provider organisation).*

The importance of using language that clinicians recognised was that it helped carers overcome cultural norms about discounting their expert knowledge and information, related to their status in society.

> *"But absolutely I think the confidence that… And I think if you're dealing with slightly less complex cases, the confidence in the framing that the RESTORE2Mini… The SBARD stuff – I just think is really… It's about having that framework to say… To know how to communicate the information. And… And actually to feel, I guess, a bit on a par with… With the clinicians. And say… And actually know that you can pull something out and you can have it written down. You know, you can write the SBARD… You could actually write it down and make it look like a proper clinical document. Whereas, when you're just talking, you know, it can just be you ranting at them, and it's easier to ignore certain things. But to be able to frame it in that… In a way that the clinician would be familiar with, I think, is really helpful" (Parent carer).*

2.2.4.4 Facilitating information flowback from health professionals

Having trained and observed carers practicing structured communication, one care manager identified that they thought the training could also be usefully applied to asking for information back from health professionals.

> *"I can see it improving the communication. And I can see it improving, you know, the feedback that we get as well. So, if we thought about it in how we ask for information as well, and understanding more… Because I think there is, kind of like, a… Another problem within, kind of like, interactions between health services and social care services – is that health services think that social care services know everything that they know". (Manager, care provider organisation).*

Another manager in a care provider organisation, reflected on being able to get timely help and how training and using an EWS tool in the future might help. Their experience was that they felt they could usually get timely help from emergency services but that this became problematic once people were admitted to hospital. However, using a structured communication approach in emails with the learning disability nurse in hospital could help improve this.

> *" I would say emergency responses are usually very good until we get into the hospital, and then it relies a lot on me communicating with the learning disability nurse. And it's just kind of, like, dawned on me to, kind of like, also use SBARD in those emails. Do you know what I mean? Kind of like, with the learning disability nurse and stuff. Which I don't think I do enough of. If I'm honest. (Manager, care provider organisation).*

2.2.4.5 Overcoming problems of access to GPs

Several carers observed that the training and access to an EWS tool could help overcome the difficulties many of them encountered with gaining access to GPs.

> *"GP surgeries have been the least understanding to date, time seems to be a barrier as most our guys require longer app(ointment) time and patience – front line admin at GP surgeries have had the least understanding and acceptance of staff trying to access appointments to meet the needs of those we support". (Senior support worker, care provider staff)*

Health professionals observed that training carers to use an EWS tool might help both carers h

> *"Yeah, I mean, again, I would hope that for the carers it gives them another tool and, you know… Another measurement that they can use to, kind of, reinforce their… what they're asking for. And hopefully, you know, similarly for the receptionist – it enables them to collect some more information that they can pass on to the GP. You know, I would hope that it makes the carer sound a little bit more informed". (Health professional).*

Indeed, failing to train GP support staff and administrative staff risked losing the beneficial impacts of training carers in using EWS tools, as one health professional observed thinking about a forthcoming training programme for carers:

> *"And I'm going to ring the GP and say, this is what's happening. Here's a link to the video from the RESTORE2. Please support us, and please involve your receptionist so that they know that when people ring and they say these words to you, that a) your receptionist is empowered and knows what they're talking about and b) the person who's talking to the receptionist doesn't end up thinking, well, what was the point of that because nobody knew what I was talking about. It's a two-way process, isn't it? It's all very well and good training people up, but if you don't raise awareness in the practice where they're going to be communicating, you might as well not bother. Because you're right, the receptionist will pick out the bits they think they need. And all that work into the training and that energy that carer has put into trying to get across the story adequately is lost". (Parent carer and health professional).*

This parent carer stressed the importance of providing EWS training to GP receptionists.

> *"…like making sure that receptionists get the training. Because we've done raising awareness training, but we've not done… and that's just about disability per se, really. And communications and reasonable adjustments through the… the person's pathway through the surgery, if you like. But I think it would be really useful to start thinking about the SBARD kind of stuff…". (Parent carer and health professional).*

2.2.5 On communication between carers and carers in other settings

Carers observed after participating in training sessions for an EWS tool, that the approach could be useful for situations where people with a learning disability move between settings or more than one carer is involved in their care.

EWS tools offer a beneficial mechanism for multiple carers involved in any one individuals' chain of care to share baseline information and changes of concern. The benefits arise in several ways. Firstly, training and access to a tool can act as a conversation starter for multiple carers e.g. different family members, to discuss, develop and agree baseline information. This may also offer an opportunity for talking through different approaches and perspectives on care and health care options. Capturing information on changes of concern may also help in situations where the main carer is unable to accompany someone in an emergency eg becomes ill themselves, and other family carers need to take over. In situations where there are multiple carers and/or different settings, training and access to an EWS tool provides a mechanism to

- provide a record of actions taken by each carer, so that subsequent carers are clear what actions they may need to follow up
- identify the point at which concerns need to be escalated and provide an audit trail of this
- reduce delays in escalating concerns because people are moving between carers and settings

2.2.5.1 Provides a focus for sharing information within teams of carers working in different settings

A carer, reflecting on how the training might help in the future, identified that being able to share both baseline information and information on any changes giving concern between carers in different settings could be really helpful.

"They were saying, like, "Who do you inform?" If you take, for example, somebody like [name] – she's at home sometimes, she goes to the day centre, sometimes she goes from the day centre straight to respite. If I had concerns in the morning, but not enough… you know, just like, oh, I don't know… I think it's a really good system is like some sort of form that you can pass on to the day centre. They can then keep an eye on whatever you're talking about. Or ask whatever. And then that gets passed on to respite. Because you often find when there's more than one carer involved, the messages don't always…". (Family carer).

Being able to monitor the progression of symptoms would mean that carers at any point in someone's movement between settings could act at a timely moment to escalate concerns. Having a summary of baseline information and ongoing changes would also enable anyone in the chain of care to provide full information to health professionals. One health professional, with previous care support experience, reflected how having had an EWS tool may have changed the outcome of an incident she recalled where someone started with a cough. Carers kept escalating their concerns but the combination of multiple carers, locum GPs, lack of shared summary information of concerns and actions meant that there were delays in the final diagnosis of breast cancer which had spread to the lungs.

"I remember sending a lady… I had a lady years ago, when I was a manager of a supported living service. She started off with a little cough. And we went to the doctor, and she was given hay fever tablets, and she still had a little cough. And the little cough got worse – her behaviour changed. She became incontinent. She didn't want to go out. She was drinking beer at eight o'clock in the morning. And the support workers kept calling in GPs. And it was kind of summertime, so we kept getting locums and the ones that are around on midnight on a Saturday. She'd been in and out of hospital with chest infections, and they kept sending her home, saying she hadn't got a chest infection. And so that was… It started in the May. I think the beginning of… I think it was July – I rang the hospital, and she'd been admitted. And I said I am not willing to have this lady back in her flat, supported by my staff, until I know what is wrong with her. And when they… and they hadn't investigated – because

> *someone else had said chest infection, it hadn't been investigated any further. She had stage four breast cancer that had gone into her lungs. And, I mean, there was… I mean, she washed herself. There was no other way of us… You know, we weren't going to, sort of, feel her breasts or anything. And no-one had actually… Because she had gone into, like, [hospital name] emergency with chest infection – oh, she hasn't got one. Well, she can go home… And yet my staff had been saying this has been going on for ages. And I do wonder if something like RESTORE2 and that clear recording might have prevented that ". (Learning disability health professional).*

Equally importantly, it also means that not only might people with a learning disability receive timely help and avoid acute ill health, but it may also mean they do not miss out on activities 'just in case' because carers are concerned things might worsen.

One carer, who was part of the family for a person with a learning disability, but not the main carer, attended the training to start preparing for a time when they would become the main carer.

> *"I joined the training for my brother – my older brother, [name]. And, so, he's nearly 49. My… my mam died nine months before my younger brother. So, she… It's coming up to her ninth year, being without her. And my dad… He's getting on a bit. He refuses to put my brother into any sort of respite care, because that's the pact that my mum and dad had. They would always want to look after the children themselves, and things like that. My dad isn't in the best of health either. Luckily, they're literally minutes round the corner, so… And I've just been, sort of, taking on more of a role. I mean, I've always been there as the little sister. But I've noticing a lot more, as he's getting older, he's… He carried a lot of weight. And there's just, sort of, little things that are… My dad doesn't recognise, but I probably would. And I just wanted to be able to go on the course, get some ideas of what I would be looking at, and that sort of thing…". (Family carer).*

As a direct result of attending the training, this carer became aware of a number of helpful health screening or information tools e.g. annual health review, hospital passport. The impact of the training for this carer was that it opened a conversation between themselves and the registered main carer about establishing baseline and key information. Furthermore, attending the training provided a means for this carer to open a conversation with the main carer about some potential health issues they were concerned about such as diabetes and cholesterol. Having heard about the potential value of annual health checks during the training course, the carer was prompted to have a conversation with the main carer and ask what was happening about annual health checks. The main carer had asked the person with a learning disability if they wanted an annual health check, who had said no, so no further action was taken.

Another important outcome from training and access to the EWS tool was that it provided this carer with the opportunity to have a conversation with the main carer and discuss perhaps taking a more pro-active approach to monitoring changes and thinking about what soft signs might mean.

> *"I think it's so important for my dad to notice things as well. Because he does tend to go round… And I'm not being unkind to my dad, but he… you know, he's a bit blinkered sometimes. " (Family carer).*

A change in approach like this, from dealing with the symptom to thinking about underlying causes and what else might be going on, is a key part of escalating concerns early enough to get timely help.

Training one member of the carers caring for an individual has a multiplier effect, driving up the knowledge, skill and care levels for all carers.

2.2.5.2 The EWS tool would smooth out problems when people with Learning Disability move between settings and carers

Lead carers could use the tool to discuss changes in the provision of care with new carers and services. A parent carer, reflecting about the impact of EWS training and access to the tool, was researching options for her daughter with severe learning difficulties to move into her own home, with round-the-clock support, and felt that the tool offered them a way to capture and share key information with new carers who did not know the person.

Similarly, in situations where there was a high turnover of staff or lots of agency staff being used, as happened during Covid-19, care support workers did not necessarily have time to get to know people well. Thus, using an EWS tool to capture baseline information and changes in normality would provide them with at least some information.

Carers commented that often there was extensive baseline information already available in people's files but that precisely because it was so thorough, it was not always possible for every carer involved in a chain of care to read or access the information. The advantage of EWS tools that captured key information in short accessible ways was that all carers in the chain of care might be more likely and able to absorb summary key information.

2.2.5.3 The EWS record provides a channel of information and an audit trail for review

Some carers also observed that capturing information on changes from normality and actions taken using an EWS tool could be a useful part of the documentary or audit trail of actions taken and agreed.

> *"I think I would certainly feel more confident having that SBARD tool in front of my with a few scribbled notes on it. And it's also… I think if you're a care worker, you can leave that as your record of what was said as well. Because you're spending your life writing notes, ticking boxes, saying you've done stuff. The bureaucracy is necessary but enormous". (Learning disability health professional).*

Capturing information on changes from baseline which may cause concern, actions taken and agreed was also identified as one way of increasing accountability in a chain of multiple carers and settings by one carer. Being able to track developments, actions and outcomes can be a valuable resource for reflection and learning to prevent future adverse events.

> *"But I also think it's a double-edged thing that if the next person you've handed that to hasn't done what they should have, then you can wipe the floor with them because you know you did… Do you know what I mean? You pass that information on. So, if it had to be acted on, and then it wasn't… you've got grounds for concern". (Family carer).*

2.3 Facilitators and impediments to the implementation of programmes training and providing carers with access to an EWS tool

This study was conducted alongside the roll-out of access to, and training in how to use, an EWS tool for 5,000 carers across England. The training programme was funded by NHS England & NHS Improvement, using a super-trainer model for delivery. Phase 1 consisted of trainers being trained to deliver the training. These trainers are referred to as ‘super-trainers’ and the training for Phase 1 was delivered by Wessex AHSN. Phase 2 consisted of these super-trainers delivering training to a further 50 care support workers or family carers. The aim was to train a total of 5,000 carers, although this target was exceeded. Participants were recruited from both Phase 1 and Phase 2, as many of the super-trainers were carers themselves. Wessex AHSN carried out their own evaluation of training delivery and impact but this study offered a further opportunity to identify, in addition to the opinions of those involved in the care of Learning Disability regarding the use of EWS, factors that might operate as impediments and facilitators to the implementation of a national training programme providing access to EWS tools for carers.

Table 9 summarises 21 enabling mechanisms, identified from interviews with carers after training and access to an EWS tool. These enabling mechanisms are organised into three themes related to the content or format of the tool, the format of the training sessions or other contextual factors.

2.3.1 Content and Format of the tools

2.3.1.1 Cutting-edge and research based

One care manager in a care provider organisation commented that being able to point out to the staff being trained that the tool was 'cutting-edge' and research-based, reinforced that the training and use of the tool was something worth doing. The organisation this care manager worked for prided themselves on their modern, innovative approach so being able to offer this tool to care workers may also contribute to making care workers feel valued for the work they do, both by offered access to the latest developments in care work but also by being able to offer high-quality care to their service users.

> *"And if that had come up in research and stuff like that as well. It has more impact for me to say, like, this is quite a useful thing for you to do. And our organisation – you know, we're quite a progressive organisation, and we do want to be modern and different". (Manager, care provider organisation).*

2.3.1.2 Paper-based simplicity

Carers interviewed for this study commented on the simple paper-based format of the tool and how this would make it more accessible and acceptable to many carers for several reasons. Firstly, because they felt that not all carers were comfortable with digital tools, and secondly, because not all carers had access to devices or internet.

> *"To me, as well, is that it's important… You've got to take all the digital-ness out of it, right? Because carers aren't comfortable, you know. They're much better than what they were, because they've had to be. Through Teams and family visits via FaceTime or whatever – they're much better. The pandemic has done that. They're still very wary of technology. So, I know that just getting it on paper is a good start". (Health professional, Nurse practitioner, Care home Support Team).*

> *"So, yeah, I mean, obviously the IT is a problem at the moment. We haven't… As I said, we have a variety of IT skills from they literally cannot open a computer… Try and do IT training is someone can't operate IT – that's a mind bender. Or they haven't got the equipment. Like, they are old school. They don't have smartphones. They don't have laptops and tablets at home. And especially in COVID – if they're living on their own and they can't get to borrow one from their next-door neighbour, because you can't see your next-door neighbour – this has provided a couple of interesting challenges". (Learning & development role, care provider organisation).*

Thirdly, another health professional involved in rolling out training in the tool observed that having a piece of paper with summary information which is easy to access and interpret would be very helpful in situations where there are a lot of staff coming in who do not know the people they are caring for well, as happened during Covid-19 when use of agency staff increased as staff had to self-isolate.

Another care manager commented that it would be much easier to justify and persuade team leaders to persuade carers in their teams to use the tool because it is just one piece of paper. Using this one piece of paper would enable them to avoid acute deterioration in the people they cared for, which in turn would help them avoid having to use far more complex and time-consuming tools that they would be expected to use (like the Anticipatory Care Calendar or ACC) if people did become ill.

For this care manager RESTORE2Mini achieved the same objective in terms providing evidence to support carer concerns as other tools but with far less paperwork and involving far fewer people and time.

> *"We've used the anticipatory care calendar in the past. Are you familiar with that tool? So, I think that's a great tool. But it's really... It's a lot of paperwork. It's just too much. So, we only implement it if somebody has come out of hospital and, maybe, has bounced in and out of hospital. And that's a decision that [care provider organisation name] makes with me, as the health lead at the time, the team leader, and the team. And we would come. And maybe the community team. Community learning disability team. We would do a team meeting where we would implement it. And so everybody would understand. But what I always used to say to people about that... When they brought that in - like, this is your justification. This is your, kind of, you know, pass Go, collect £200 thing that you can say, this justifies you. And there's a weight behind that. And I think RESTORE2(Mini) does the same thing". (Manager, care provider organisation).*

Family carers talked about how useful it would to be able to have tool readily available. That way, if someone in the family noticed a change they could quickly and easily have a quick look at the tool and refresh their minds about whether it might be a soft sign. Other family carers talked about how it could be passed on to other carers and other settings easily such as people moved to day care, respite care, or even when people started at a new setting with new carers, that it could be tucked into the transfer file. One learning disability health professional talked about being able to scribble a few notes on it but also being able to use it as a succinct way to capture and record actions taken.

> *"I think I would certainly feel more confident having that SBARD tool in front of me with a few scribbled notes on it. And it's also… I think if you're a care worker, you can leave that as your record of what was said as well. Because you're spending your life writing notes, ticking boxes, saying you've done stuff. The bureaucracy is necessary but enormous". (Learning disability health professional).*

2.3.1.3 Visual and diagrammatic tool

Carers commented that the visual and diagrammatic format of the tool made it much easier for them to understand and use.

> *"But what was very, very helpful was the diagram. And that is something I'm going to pass on to other people who care for her.*
>
> *Yeah, it's very visual. It's very visual... It's very... I'm not good at drawing. I'm quite good at writing, but I'm not very good at drawing. So, it's very... It's very clear, you know, the actual physical... The diagram. And that's a very good thing to put in a training pack, I think. I've written a support plan for her. I've been doing that. Quite a comprehensive support plan. But, actually, you know, they say a picture... A good picture can replace 1,000 words. So, I think having that diagram could be helpful." (Family carer)*

For one care manager who had experience of rolling-out training and using both RESTORE2 and RESTORE2Mini, the visual clarity of RESTORE2Mini was a distinct benefit of the latter over the former.

> *"Restore2 mini is just a clearer tool that is easier on the eye when referring to for support and using – soft signs and SBARD guiding staff". (Care manager, care provider organisation)*

2.3.1.4 Does not add to paperwork burden

Carers talked about the bureaucracy and paperwork burden involved in caring which meant that carers were very keen on anything that helped them avoid acute deterioration without adding to their paperwork burden.

> *"And even one patient who's deteriorated takes a massive part of that carer's or RN's day out. Because, getting an ambulance, getting paperwork together, telling the family what's happening… You know, they haven't got the staff that they've got in hospitals. It's massive, massive chunk of their day with one deteriorating resident". (Health professional, Nurse practitioner, Care home Support Team)*

For one care manager, it was easy to see that the carers they trained appreciated that it did not add to their paperwork.

> *"And it's like it's reducing the paperwork. It's… You don't… Kind of like, once you've finished the training, people aren't rolling their eyes at you. They kind of… It's easier to get buy-in for it. And I think they can directly see that it's empowering them. Like you said, all those great words. And it's saving them a job in the future". (Manager, care provider organisation).*

For family carers, somewhat exasperated at providing comprehensive information to new settings but then finding that it is not read, the appeal of a one-page profile of what normality in moods and expressions looked like, had great appeal.

> *"I don't think people always read... If there's lots of stuff. Because I did send… There was masses upon masses of information that I had to give to college. And they've asked me questions over this time, but I'm like, "Well, that's actually in that information that I gave you." So, I don't think people read when there's massive… They send out these big booklets for you to fill out, but do they…? But, maybe, like, a one-page profile of what… You know, what happy looks like and what sad looks like or angry or upset". (Family carer).*

2.3.1.5 Easy to see the benefits

People in this study involved in training carers commented that it was easy to see immediately how using this tool would help.

> *"And I just think it's important to get it out on paper, and then they can just make an instant impact on the calls to clinicians. I know it will". (Health professional, Nurse practitioner, Care home Support Team).*

Being able to see the benefits is also a key part of getting care provider management support to allow access to care workers to be able to be trained.

> *"I think engagement from the managers – care home managers. They need to see it as a positive. They need to see that it's going to help their staff and residents. So… I know that [care home name], because of the relationship that they've got with [GP name] and they've met me once now. And if I go and make a phone call, they say, hi, it's [name]… You know, I work alongside [GP name]. [GP name] would like me to try this training with you guys, and they'll do anything for him. Because they know he's got their back, do you know what I mean? It's about relationships. So, the GP is a stakeholder. So, you've got medical support and they're having… And the manager is on board. And then you've got somebody who is equipped and sees the true benefit of it. So, a good educator. And I think if you've got the*

> *time and the capacity to do it, I think… I think that would make it work ". (Health professional, Nurse practitioner, Care home Support Team).*

For one experienced family carer, who commented that they had deliberately held back identifying soft signs in the first part of the training because they felt they were fairly familiar with it and wanted to ensure other participants got the benefit of the training, practicing the structured communication had clearly been enjoyable and somewhat surprising, in a pleasant way.

> *"You know, I really look at the little group that I was in, [name] … She came from a medical background. And she was… She turned around and said, I wouldn't even think of looking for those sorts of signs, because I'm medical and not learning difficulties. And that was really good. And when they were saying, okay, let's go through this scenario, I tried very hard to, sort of, step back from that. Because I thought I want them to work out signs. I know some of the signs. I don't want to just feed them the answers. I want them to find it first. And, yeah, it was really good.(Family carer).*

2.3.1.6 Easy to start using straight after training

One of the key points about EWS tools like RESTORE2Mini are that they do not require equipment eg thermometers, blood pressure machines, pulse oximeters. This was mentioned as a key point by trainers and carers, in terms of generally not having access to equipment, time taken to train carers to use the equipment, using the equipment regularly enough to maintain competency, the feasibility of being able to use the equipment with some people with learning disabilities. The immediacy of being able to apply training, straight after sessions is an important aspect of what makes the tool valuable to care provider organisations.

> *"Whereas I could do the training and expect someone to walk out and spot someone behaving differently immediately with a RESTORE2Mini". (Learning disability health professional).*

Likewise, carers were able to imagine using it straight away after training.

> *"Yeah, yeah. In fact, this afternoon I'm going to… I'm attending a mental health… No, not mental health. Dementia screen for my mother, with her". (Shared Lives carer).*

2.3.1.7 Simple and fast to use

Several people in this study commented about other tools or systems they used but that which took a long time to prepare (e.g., Anticipatory Care Calendar), read through (e.g.,Hospital Passport) or keep up to date. EWS tools that are simple and fast to use mean the tool can be quickly and easily used, increasing the likelihood that the tool and approach become normalised as part of everyday care.

2.3.1.8 Potential for digital or app-based versions of EWS tool and integration with other online systems

It is worth noting that in the context of gaining managerial level support for the implementation and roll-out of training that the potential for digital or app-based versions of EWS tools staff was generally received positively. Despite managers/supervisory staff feeling that not all carers were ready or able to embrace digital yet, and notwithstanding GDPR and device security issues, the possibility of using an app was felt to be useful.

> *"But if there was an app available, those services that do have it, that would be useful. I think people were trying to be… trying to get away from paper and be more tech-based".*

> *(Learning & development role, care provider organisation, previously care support manager).*
>
> *"We are gradually looking at how we can go digital. But, unfortunately, that's not my decision. That's higher up. I would love to go digital with everything, but at the moment I don't think the digital one would benefit". (Senior support worker, care provider staff)*

For one bespoke EWS tool, carers in over ten residential service locations input data in a simple binary format (responses to questions). Data input is related to various screening tools as per NICE guidelines (nutrition, hydration, skin integrity, sleep, positioning, mobility) and the system has been designed to weight data and generate risk levels and alerts. This enables specialist learning disability clinicians to monitor remotely and advise carers on actions that need taking when pre-determined alerts are triggered and provide sophisticated background and contextual data to support any concerns.

The appeal for this sort of functionality to supervisory and managerial staff , that is, remote monitoring - even for less sophisticated data-driven systems, may help roll-out of training programmes and implementation of the approach in terms of getting started while organisational, GDPR, privacy and equipment issues catch up.

> *"Our company is looking getting rid of all the… You know, paper documentation, and going more digital. Personally, I think it's a much better way to go. Because you do have… It is stored. I mean, and I don't know whether… I don't know how, sort of, technical it is. But then you… I presume, you know, you can actually see patterns and… You know, you can do all sorts of stuff with data nowadays, can't you?*

2.3.2 Format of training

2.3.2.1 Realistic

One experienced care manager, who was widely experienced in care support work, training, engagement and outreach, commented that the realistic scenarios provided as part of the training package for practicing SBARD, facilitated the practicality of running the training session. The fact that these scenarios felt realistic to people is also likely to enhance their valuing of the training, internalisation of the content to their own situation and behaviours and ongoing application in daily caring life.

> *"Yeah, I think the practicality of how to use it in that super-training training… So, like… And the scenarios provided – I presume that they were from real-life scenarios". (Manager, care provider organisation).*

2.3.2.2 Short, resource-light training sessions

Training sessions for EWS tools that are based on soft signs only, (such as RESTORE2Mini, Stop and Watch and Significant Care) do not require special equipment, space or software. Thus, the sessions require less resources (time, equipment, appropriately trained trainers). The roll-out of RESTORE2Mini was offered online to super-trainers and all super-trainers were provided with a complete training resources pack (free downloadable tool[1], training slides, links to training videos).

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[1] Other soft sign based EWS tools eg Significant 7, Stop and Watch also offer free downloads. Is My Resident Unwell and RESTORE2 are EWS tool that require observations to be taken to calculate a NEWS2 score. Both also offer free downloads of the tool and training videos .

This meant that for super-trainers, delivering training sessions (which were planned both online and in care homes when Covid-19 restrictions relaxed), they had access to everything needed to run a training session and just needed to focus on recruitment of participants and delivery.

One experienced super-trainer with experience of another digital tool reflected that the lengthy and formal training required for that EWS tool affected capacity of the team train. For this super-trainer, the fact the training could be adapted to even shorter bursts, going out several times to care homes to reinforce and embed the training, was a major advantage.

2.3.2.3 No equipment needed or training to use equipment before tool can be used

Some care provider managers in this study had previously rolled out training in RESTORE2 before participating in super-training sessions to roll out RESTORE2Mini. For these carers, there was a distinct advantage to training sessions using EWS tools that did not require access to equipment or training carers how to use the equipment.

> *"I mean, we have struggled to roll out RESTORE2, which is why we've gone to the RESTORE2Mini, because we probably do a larger number of people safely on the RESTORE2Mini. And then add in the 2 afterwards. I think the bit we were frightened of, and the bit that causes the problem, is the equipment to get the NEWS2, and the confidence and competence in using it. And that's the bit that takes the time. Whereas I could do the training and expect someone to walk out and spot someone behaving differently immediately with a RESTOREMini". (Learning disability health professional).*

For other super-trainers, the difficulties in getting complete vital signs data for residents, in the learning disability homes they supported, meant that a tool like RESTORE2Mini was better aligned with the realities of the caring environment that they are working in.

> *"Really, you know, in LD, the likelihood of getting a full set of obs are very poor, you know? You know, you might be lucky – you might get a sats probe stuck on a finger but very rarely you get a… temperature. They're just absolutely terrified of anything going near their ears. And a blood pressure – it hurts – they're not going to let you do that, so… It's almost… For LD, it's a different ball game than it is to the bulk of my homes. And the thing is, though, we've signed a… Well, somebody signed a contract to cover Learning Disability homes. And [care home name] isn't the only one in our remit. There's a few dotted around the city. So, you almost have to be like a chameleon and adapt to the home. So, you know, whatever the tool is called, the emphasis in LD, for me, it will be the soft signs. I know those guys aren't going to be able to get a full set of obs. And that's all they've got". (Health professional, Nurse practitioner, Care home Support Team).*

2.3.2.4 Practising or watching other carer participants practising structured communication during the session

Role playing, or observing other participants roleplaying, a structured communication conversation of someone trying to escalate their concerns to a health professional e.g., GP, was an effective way for participants to understand and start putting into practice (or imagining themselves doing something similar).

> *"And then when we do the SBARD conversation, we practice it with the scenario, and then they practice with their people they still have in those kind of conversations. So, they're doing… So, you know, phoning your actual GP. And talk through as if this was really happening to them. You know, you've said these are all the soft signs and what you'd*

> *expect to see. Now tell the doctor that's what you've seen. And so we're practicing it in real life, so… In a role play, but how it would go for them really. And I think that makes a big difference too, because they've already… We've already reinforced, yeah, that's a great conversation – those things you've said are the things that you need to be saying in real life". (Learning & development role, care provider organisation, previously care support manager).*

For one family carer, participating in the role play had been a big part of the learning experience – actually trying to do it, getting it a bit wrong but understanding why, had really helped their sensemaking process.

> *"I found that really useful. Yeah, I just found the whole thing… I was just, sort of, buzzing after. Just, sort of, like, wow… There's all these things to help. But, yeah, I was… I was the only one on a group session that actually put their hand up and said, right, I'll say what I've got. And some of the things weren't in the right place. But I think if you don't speak up and say, it's not criticism – but have somebody say, well, actually, that could've been better in this place. That goes in there. And I felt better after that, knowing that I know now which bits… And on my piece of paper that I had – and I've had all the slides come through via email now – I can just write on there. Right, this goes in that section, that needs to go in that section. And, you know, it just makes more sense to me now". (Family carer).*

For one super-trainer in a care provider, early feedback from and initial training sessions they had delivered, were that practising by using the scenarios during sessions was easier than in real life. The difficulty for carers was being able to pick out the relevant information they needed in a real life situation. However, the fact that they had identified this as a problem suggests they had grasped the principle that there is important and relevant information to be picked out. As the super-trainer commented, practice and confidence may be all that these carers need to be able to put the training into practice successfully.

> *"So, the feedback from yesterday I thought was really interesting regarding this point. Because they said using the scenarios in the super training… They said, oh, it's dead easy when you've got a scenario, but you know it's not easy when you don't have the scenario written out in front of you, to pick out those elements. So, I think that they still felt that in that moment it would be really, really jumbled. I think that that's why we practice scenarios. You know, it will be easier in a training scenario than it would be in a face-to-face scenario. But I think it was, kind of, like… I think it's still difficult for them to pick out the relevant information that they needed. But I wonder if that's just practice and confidence". (Manager, care provider organisation).*

2.3.2.5 Training can be easily flexed for small or large groups

Members of the research team participated in ten super-trainer sessions and three training sessions run by a super-trainer, all of which were online and had variable participant numbers. Observations of the dynamics of different size groups in the training sessions suggest that training sessions can be flexed to accommodate larger or smaller groups, without significant loss of training impact. Using the break-out room format for short multi-group learning sessions on identifying soft signs (which was virtual in all the sessions the research team participated in) contributed to creating a more intimate, personalised 'emotionally safe learning' space where participants seemed to feel free to exchange and talk about experiences. One super-trainer commented that in the environment they would be delivering the training and based on their past experience of delivering training and education, the training they would be delivering for care home staff would have to be *in situ*, in short bursts with just two or three members of staff at a time.

> *"So, I was quite enthused after watching [name] … She was amazing on the… She's lovely, isn't she? That you can adapt the education to suit yourself. So, I found it very realistic. So, I know through previous education that I've done that you've got to go to the care home. They won't let people out of the care home for formal training. It's just an impossibility – particularly at the minute. They're so short-staffed. They're all run ragged. So, when I do go out, it'll be me to them, and it'll be short bursts. So, when she mentioned you can do it in 30 minutes, and you can revisit it – I think that's the way forward for care homes. You're just catching them as much as you can. In small numbers. You can't… You know, it's just a logistical nightmare going into a care home and saying can I have six of your members of staff? You're talking twos and threes. To get them off the floor and to do it". (Health professional, Nurse practitioner, Care home Support Team).*

2.3.2.6 Supportive learning and sharing environment

The way that training sessions were structured for RESTORE2Mini was that they included training content delivered by the trainer as well as working together on a training task. However, the approach was very orientated to inviting participants to share and talk between themselves on a peer-to-peer basis, giving primacy to their experiences and knowledge. Even carers, who were experienced and trained in other aspects of supporting people with severe medical conditions, found that listening to other people and talking to people in the training sessions about soft signs in people with a learning disability was a key part of their learning experience.

> *"Yeah, because… you don't… You don't think about it with another person. Maybe the children that you live with in your house, because you're there all the time. But it's great for my job as well, because I have… All of the children that I teach have got quite severe medical conditions, degenerative conditions. And I've had, you know, quite a lot of training in all areas. But then quite a lot of their signs are quite blatant. They're quite in your face – they're having a seizure. They feel really hot. And because you're working in close contact with them and quite… Quite a lot of physical contact, because they can't do things to themselves – you do feel that… You feel if they've got cold hands. You know, it's easier to pick up, I think. But, if an adult… With [Name], it is a lot more difficult. And because he's an adult, even though I'm saying to my dad it's… You know, he's not age appropriate. I think sometimes you do sort of skim over things. And, you know… And it's things like… Sometimes he might just be feeling a bit sad. You know, he might be missing my mum or… You know, our mum. Or, you know, he hasn't been out and seen his friends and things like that. Because he used to go to a club on an evening. And, you know, you think, well, sometimes perhaps he's just having a bad day. But when you listen to other people, and you talk with other people in the group – I thought that was really interesting. I was in a really good, communicative group". (Family carer).*

The use of break-out rooms further facilitated this exchange between participants. This was a key part of creating a supportive learning and sharing environment and contributed to the transformative effect of the training, whereby participants felt their knowledge and experience were validated and part of the knowledge base of spotting soft signs of acute deterioration in people with a learning disability.

> *"I think it empowers staff. I think one of the keys to getting heard, and getting people to support the need, as we've talked about today, is the support staff advocating for that person. And I think it gives autonomy to people to say you know this person, you're the one that's going to stand up for them in this situation. And it gives people the confidence to say that you know this person best, and you know you can say, actually, this is not the best way*

> *to do this. Or this is not… This is what this person needs right now. This is… You know, I know this person, and this is what they need". (Manager, care provider organisation).*

2.3.2.7 Carers do not feel patronised

The experience of learning by sharing experiences and knowledge helped to create a learning experience where carers did not feel patronised.

> *"I thought it was good. I did think it was all good. Both me and my husband did sit and do it, you know. And... I did think that... It was presented well, and it was... It came across as genuine, to get... I don't know if you know what I mean? It did come across as genuine […] She wasn't talking at you, was she? It was... It felt... everybody was on the same level". (Family carer).*

Even though some experienced carers felt the training just confirmed what they were already doing, this aspect of using and building on participants existing knowledge and experiences was a valuable part of the validation of carers expert status and knowledge.

2.3.2.8 Training easily adapted to specific contexts

Trainers talked about the value of being able to adapt the training and materials to their specific context and needs. For example, being able to deliver the training in shorter longer bursts or being able to substitute scenarios that were specific to the group of people they supported and how this helped make the training more relevant.

> *"So, we adapted the RESTORE2 training a little bit, in terms of we put… So, there's case studies in it. But we put our own case studies in that were more for our group of people......We have two scenarios that are more our group of people". (Learning & development role, care provider organisation, previously care support manager).*

Trainers are also able to adapt sessions to achieve specific training outcomes. For example, one trainer described how they encouraged participants to discuss the specific soft signs and baseline of the people they supported during the break-out sessions. If participants did not know this information, they could then set that as an action for them to go away and find those things out.

2.3.2.9 Super-training model

Trainers found that the super-training model was an effective way of cascading the training out to carers. One trainer commented on how going through the training themselves had really increased their knowledge and understanding of the tool, despite having already come across the tool before and referred to it in other training events.

> *"All I wanted to add on that, I think, really, is that I've come across the RESTORE2Mini tool before it was re-done for supported living. And had it as, like, a talking point in my health and relationships training. But because I hadn't had the super-training training, I don't think I understood it as well. And I knew it was kind of a little bit useful – the language of it was a bit… For us, as a supported living provider. But I kind of got it. But now I can – because of the super-training training, because of the RESTORE2Mini project, you know, I've definitely got a better grasp of it. And therefore they've filtered down training to our staff is improved as well. Because of my improved knowledge of it". (Manager, care provider organisation).*

One aspect of the training identified by some carers who had gone through the training was that they felt able to share the approach informally with other carers, either with other carers involved in the care of the same person or as a general change in approach to caring. In combination with the fact that the approach is simple and fast-to-use, this suggests that not everybody has to be trained in the approach for it to become embedded more widely. Indeed, one trainer described arranging to train the entire learning disability team in their area so that they could then cascade the approach out to carers they encountered.

Another carer described how they would coach another carer within their family with an adapted version of the principles, presenting it in a way that best suited their needs and abilities.
The effect of this is that the training lends itself to a useful multiplier effect, where training impacts beyond just the circle of those who participate in training sessions.

2.3.2.10 Flexible delivery mode – onsite or online

The format of training for tools like RESTORE2Mini (that do not need equipment or training to use equipment) is that it can be easily delivered on site, online or even in a mix of both modes. Some trainers identified that being able to deliver short training bursts, on-site in care homes and being able to keep going back delivering training to more people, refreshing and consolidating training was a key part of what would make the training successful for them.

> *"So, I know through previous education that I've done that you've got to go to the care home. They won't let people out of the care home for formal training. It's just an impossibility – particularly at the minute. They're so short-staffed (Health professional, Nurse practitioner, Care home Support Team).*

However, Covid-19 meant that super-training and some follow-on training sessions for carers had to be delivered online. In fact, there are several benefits associated with this. Firstly, online delivery minimises travel time for trainers and carers, meaning trainers can deliver more training sessions. For carers, being able to participate online might be the only way for them to access the training, as otherwise having to arrange alternative care for the person or people they care for to attend training could act as a barrier. For example, paid carers such as Shared Lives carers, would be expected to make their own arrangements for non-mandatory training. However, equality of access to training sessions and the specific needs of different carers may still be an issue requiring further consideration.

Another valuable aspect of online delivery of training sessions is that there were often a good mix of types of carers, with a range of experiences, and from all around the country.

The fact that participants were often from all over the country (an ice-breaking activity at the start of sessions emphasised this although this was not necessarily the aim of the activity) helped to create a sense of a broadly spread, national project, which reinforced the value of the training and tool. This mix of participants was identified by one participant as being a key part of the training experience, especially for new carers.

2.3.2.11 Care provider management support

Support from care provider organisations and care home managers and senior staff is a key 'enabler' to in to rolling out training across care providers. This support and commitment includes:

- providing care support workers time to attend the training
- creating an organisational culture that supports and reinforces the training
- supports care staff to advocate for the people the care for

One super-trainer described how this engagement and support from care home managers, together with the good working relationships that had been established in their area were a really key enabler for rolling out the training in their area, as well as training from within their own organisation to deliver the training.

> *"So, I think engagement from the managers – care home managers. They need to see it as a positive. They need to see that it's going to help their staff and residents. ....And also I've got the support of my line manager. You know, to do it". (Health professional, Nurse practitioner, Care home Support Team).*

There can be worries in care homes about relationships and perceived criticism by NHS staff, particularly related to prior experiences which may have resulted in measures being taken by NHS staff or CQC staff. Thus, there may be sensitivities in gaining access to care staff, depending on who is delivering training.

> *"So, you know, being diplomatic, a proactive manager would, you know, allow… us into the homes, basically. We're a guest in their homes, you know. It's not a given that we can be there to support them. I think there's a lot of distrust because we wear an NHS uniform. .....So, I've worked really, really hard in the homes that I've been in, so they know my worth. And they've allowed me in. And it's paid off. It really has". (Health professional, Nurse practitioner, Care home Support Team).*

Creating an organisational culture that supports carers to advocate is also key to embedding the approach within organisations. One senior staff member, reflecting about the value of the training acknowledged that it was helpful in supporting and reinforcing the culture and procedures they had already established.

The culture this senior carer had fostered and established meant that cares escalating their concerns felt empowered to advocate, to challenge and to be very clear about what they wanted to happen.

The training was valued by this senior carer as evidencing and substantiating what they were doing and was the first time they had experienced training of this kind.

> *"Not really, no. That was the first time we'd… It was almost, kind of, evidencing and substantiating what we're doing. Which is quite nice to hear, actually". (Team leader, care provider organisation).*

2.3.2.12 Covid-19 – Increased relevance and benefit of tool and training for carers

Some trainers talked about how Covid-19 had emphasised the relevance and importance for carers of learning the EWS approach to patient assessment, both in terms of using tools like RESTORE2Mini, but also the importance of always noticing things like a changed respiratory rate or a minor change in behaviour, that might suggest the need to do a formal assessment. One of the impacts of Covid-19 for carers who alread use a soft signs approach was the realisation that they did not need to be medically trained to gather data on some basic health measures. This reinforces that for some carers EWS tools which do involve using equipment to take measurements and calculating NEWS2 scores can feel like a natural progression from using a soft signs approach, like RESTORE2Mini.

> *"So, we're delivering the RESTORE training at the moment. The RESTORE2. And I've been delivering it. Part of the activities is to explain a time when you've supported somebody. And what was that like? So, wider… my view is a lot of people we support, the things that they're seeing that are different are not as obvious as their colour has changed. It's that they're now making a high-pitched squeak, instead of a low-pitched squeak, or their hand*

> *flapping has increased, or their hand flapping has decreased. So, there's a lot of things that are subtle around the way that people communicate that are not typical for the general population. And so being able to explain to a doctor that the person I support is squeaking high… A high-pitched squeak – that's quite difficult for someone else to understand, well, what that really means.... I think one of the other things that's helped with the RESTORE2, a lot of the people In the organisation, are support workers. So, they are not health assistants. So, they would know somebody's communication or their behaviour has changed, and they would know, perhaps, if someone's colour changed. But they're not used to routinely, until we started doing the training, counting breaths. So, they wouldn't have have had the language to describe breathing rate changes. So, that isn't something that would historically be taught. They don't generally have blood pressure measures. So, they wouldn't have been measuring blood pressure. They didn't used to have the oximeters. More so now, because of COVID, but only… In a lot of the services, only if they've got a concern of someone's health is already deteriorating, and then they've been supplied. So, the kind of soft skills, they are doing. But I think one of the things that has been a bit of a revelation for staff is, okay, we don't need to be medically trained to check breathing rates, to check temperatures, to do these things". (Learning & development role, care provider organisation, previously care support manager).*

A senior care staff member also emphasised the difference that Covid-19 had made in terms of the relevance of the approach and care staff realising that taking basic health measurements was not necessarily a clinical or medical demand on them, particularly if they themselves had used equipment such as pulse oximeters during the pandemic. This reinforces that EWS tools that do not use equipment or calculate NEWS2 scores and are based on soft signs can be a good initial approach for many carers, and are, indeed, already used by many carers, and that there can be a natural progression onto EWS tools that do use equipment and calculate NEWS2 scores. Covid-19 has somewhat inadvertently facilitated the acceptability of these types of approaches.

> *"The last year (beginning 2020) it (RESTORE2) has been implemented and staff teams made much more aware with training and rolling out the info etc in team meetings – Covid has made using the tool more relevant with staff realising it is not a clinical/medical demand on them – staff who have been poorly themselves or tested positive for covid, have been loaned oximeters to monitor their own oxygen levels – staff observing behaviours and picking up soft signs have been in use for a number of years before hearing of Restore2 mini as this has been the easiest indicator to someone being unwell". (Manager, care provider staff).*

It was interesting to note that carers talked about how practices had changed as a result of Covid-19 and how often they now took temperatures. Alongside this, carers were generally more aware of the use of equipment such as pulse oximeters and more inclined to think favourably about the potential benefits of their use. One senior carer, who had not received training in the use of any type of EWS, reflected that a pulse oximeter would have been an easier way to monitor pulse rate, which they would not normally do but had needed to do so for a specific period.

> *"We take temperatures, only due to COVID, twice a day. Which is fine. One of the ladies with dementia, she has got… something wrong with her heart, but she has a low pulse rate. So, they had to take pulses. With the count. And that's really hard to do, because you've got to find a pulse and then you've got to try and count. And people are trained in that, but we just had to do it for a week. You know, and that scared you, just doing the pulse. So, probably the oximeter would have been probably better and more accurate". (Care home manager, care provider organisation).*

One senior carer described the dramatic change in approach and understanding about slight changes in soft signs they had gone through as a result of Covid-19.

> *"So, we had an individual here who had COVID. So, in the first… this was in April… Yes, April last year. And this gentleman is very, kind of, low arousal anyway. And very quiet. And spends quite a lot of time in bed. Doesn't really talk. So, with regards to identifying a medical issue, or the startings of a medical issue, it's really quite difficult with him. The initial concern was there was a change in breathing. It was ever such a slight change, but it was noticed that it was in quite staccato bursts. And then would be quite drawn out. So, that was our first concern that we did have. And, you know, we always move straight to potential UTI or looking at seizure activity. If we come across any, kind of, ailments, so to speak. Just to make sure. Because normally – epilepsy, for all of its sins, is actually quite a good indicator of there being something wrong. So, when we're feeling they've got high temperatures, chest infections or UTIs, you tend to see a rise in frequency of seizures. So, that's normally one of the things that we'll start looking for. But, yes, this gentleman had quite laboured and erratic breathing. But was also very difficult to arouse. And to kind of engage with. So, this was in the first… you know, we were in the stages of reading about COVID, and not necessarily taking much time to finish the BBC News reports. So… We called up the paramedics who, you know, at that time, didn't come in in masks or anything like that. And we had the discussion about, you know, could this be COVID? And they said, "You know, has he got all of the symptoms" – which at that time was the taste. We don't know if he can or can't taste or smell. We went off the temperature, and his temperature was climbing very steadily. And no cough was present – which is what, you know, we were told initially to look out for. It's that continuous cough. So, yeah, the paramedics attended. And we got to the point that we always do with paramedics – it's, "Do you think we need to take them in?" So, you know, they came and did their obs – and their kind of saturation, blood oxygen and all of those bits and bobs and there was clearly something wrong. Whether it was a kind of UTI that he'd got which had caused these issues – because they can be quite severe if… especially if you've not got a great health starting point. UTIs can be quite notorious for making you even worse. So, yeah, that was the… the most frequent kind of one that we've come across. And in such an odd time. Had it happened now, it would be very easy – what we were, you know, looking for and going to start saying, this is what we're seeing. Do you think it…? And, you know, kickstart with the lateral flow tests and the PCR tests and stuff like that. But at that time we were still very juvenile with our understanding of COVID". (Team leader, care provider organisation).*

Covid-19 not only triggered increased familiarity and acceptance of using equipment to take some basic measurements but also demand for equipment to be able to do this.

For family carers, Covid-19 had ushered in equivalent major changes in the relevance and benefits of training in EWS tools. One parent carer described how they hoped to adapt RESTORE2Mini to help other family carers who had suddenly found themselves in an unanticipated or extended caring role and that being trained with an EWS tool like RESTORE2Mini could really help new carers, suddenly thrust into this role. The really key aspect of an EWS tool like RESTORE2Mini was the way it encouraged everybody involved in the care of a person with a learning disability to think about and summarise, '*what do I know about this person normally?*' and '*what is it that has made me concerned*?'

2.3.3 Factors that hinder the roll-out of training and of access to an EWS tool

Table 10 summarises 12 impediments identified from interviews with carers about their experiences after having received training and access to an EWS tool.

Impediments	Factor	Outcome
Carer-clinical boundary effects	• asking staff on minimum pay to carry out tasks they regard as clinical but not paying them more • active resistance to role creep for social carers to take on health-care related aspects • fear or responsibility for getting things wrong • risk of being sued	• Carers resist training or application of training and tool use in caring daily life
Language	• Some carers and care provider staff described impediments to accessing online training and using the EWS tools for non-native English speakers. Both carers and care provider staff talked about making alternative language versions of both online learning and the EWS tool available but still felt that some carers would struggle with carrying out and recording assessment observations and/or data in English	• Training and tool use may not be accessible to all carers
Relevance to specific context of carers	• Some carers and care provider staff talked about struggling with some aspects of the training, eg scenarios but also some of the examples used, where this did not relate to the conditions or level of disability experienced by the people that they supported.	• Carers may feel the training and tool is not relevant for their needs
IT related issues for digital or app-based version of EWS tools	• Carers and care provider organisation managers raised concerns about privacy and GDPR related issues needing to be resolved prior to widespread roll-out of digital or app versions – issues identified by carers include whose device (carers or person with learning disability?); who has legitimate access to person with learning disability's personal health data; care organisations procedures around using personal devices at work • Some carers commented that previous experience of using other online EWS tools might affect future willingness to engage with another tool and training. These carers described issues with other online EWS tools such as poor wi-fi connectabilty; very formal, time-consuming training resulting in limited uptake so that tool use was not widely adopted	• Some carers may be reluctant or unable to engage with digital or app-based version of EWS tools
Carer learning styles, IT skills or access to online training or online tool format	• Some care provider managers reported that many of their care support workers had dyslexia, dysphasia or other issues which could make online training or online tools difficult to access eg physical co-ordination to manoeuvre hands for e-learning; colours of training materials onscreen; density of text onscreen. IT experience and skills ranged from carers with no experience at all using computers, smart phones or tablets, through carers who could use them but had no access to either IT equipment or internet (a particular issue during Covid-19 when carers living on their own could no longer use neighbours and friend's facilities)	• Training and tool use may not be accessible to all carers
EWS tools that involve using equipment	• Carers and care provider managers talked about difficulties around accessing equipment for tools that involve calculating NEWS2 scores eg thermometers, pulse oximeters	• Training and EWS tools that involve equipment e.g., to calculate NEWS2 scores, may be more difficult to implement and have less successful take-up

Impediments	Factor	Outcome
	• Carers and care provider staff and managers talked about carers reluctance to use health-related equipment • Carers and care provider staff and managers talked about issues related to maintaining carers confidence and competence to use equipment, especially blood pressure cuffs • Some carers talked about experiences where observation data they provided from using equipment was discounted or distrusted by health professionals. Repeated experiences of health-related data being ignored or discounted by health professionals may discourage carers from providing such data in future	
Funding	• May covers only mandatory training for some carers	• Training and access to tools may not be equitably distributed
Training is not mandatory	• Experienced carers and/or carers who have to incur direct or indirect costs to attend training may not do so	• Training and access to tools may not be equitably distributed
High staff turnover	• Staff turnover in some settings can be high eg care homes, and means that care providers may need to commit to repeating training sessions regularly to ensure new staff receive training	• Widespread adoption of training and tool may not be achieved
Health professionals unaware of EWS training and tool	• Carers expressed concerns that **if** health professionals, and others, especially including GP receptionists, were unaware of the training and tool and able to recognise the language carers used eg talking about soft signs, carers efforts to use the tool would not result in any improvement in outcomes	• Carers give up trying to apply training and tool
Multiplicity of tools and schemes	• Some carers talked about confusion between all the schemes they were aware of. Likewise, carers felt that confusion can arise because different people use different schemes (care staff may provide care across different local authority areas so may have to use different EWS tools, depending on which local authority area the person they are supporting lives in). Some carers felt that if everybody used the same tool, everybody would adapt to it and it would become a uniformly recognised way of collecting and providing information	• Carers dismiss training opportunity and tool
Learning Disability label	• Some parent carers representatives talked about cultural norms for some groups about a learning disability label. This meant that learning disabilities were not spoken about or formally recognised, and training or tools labelled as learning disability would be avoided. • At the same time, carers for people with different labels eg SEND, might overlook the training or not be offered the opportunity when the issues experienced by this group of carers was very similar.	• Carers dismiss, overlook or are not aware of training and tool

TABLE 10 IMPEDIMENTS TO ROLLING OUT TRAINING AND ACCESS TO ACUTE DETERIORATION TOOL FOR CARERS.

2.3.3.1 Carer-clinical boundary effects

Some trainers described resistance to training, particularly when using EWS tools which involve using equipment and calculating NEWS2 scores.

> *"We have a bit of a resistance with, like… Particularly when we've done the RESTORE2 with the NEWS score – we're not medical, we don't do that, duh-duh-duh-duh-duh… And I think people have been a bit frightened of having that education. And I think that within this, like, suing culture there's this, sort of… Fear of holding something that's above their weight. And actually they've kind of minimum wage and you're asking them for, sort of, clinical calculations that are very simple. But you would feel awful if you got them wrong, wouldn't you?" (Learning disability health professional).*

Whilst carers working in a care provider organisation may be asked to attend training, their willingness to internalise the training and apply it in their working lives may be affected if they perceive they are being asked to take on additional responsibility without additional pay.

> *"I think there's something about, like, that's beyond my pay grade. Kind of, that I'm not… I don't want to hold that responsibility. If I'm worried, I ring a doctor and somebody else decides. And I think that's fine. You know, and I think we need to be clear that we're not asking them not to do that. It's more about gathering information so that we can make that process more helpful for everybody. Rather than I'm asking you to decide what needs to happen with this person. Because we're not asking them that". (Health professional).*

For others, there can be a feeling that there are boundaries between social care and health care are important and taking on what may be perceived as health care responsibilities blurs these lines. There can be tensions between what health professionals perceive as being appropriate care and what care workers perceive as their role and that of health professionals, as the following two quotes from a health professional and paid carer illustrate.

For example, one health professional trainer felt that social care trained staff caring for people with a learning disability who had complex needs might contribute to some of the issues reported in LeDeR reviews.

> *"So, what we've done at the beginning of the trial is sort of do a survey first to see where their confidence level lies. I think they're happy in using it in the same way that they'd use a thermometer. You know, as something they can feed back to a GP. But not as something that leads them to make a… You know, a kind of scoring system, or make a decision about when they escalate something. I think that seems to be the feeling I'm getting at the moment. Which makes sense, because a lot of our learning disability patients are more… You know, their staff are more social care trained. Which is where some of the issues arise, I think, from what we see in, like, the leader reviews and things. Is that, you know, it's often… They have complex needs, but they're being cared for by people with social care training backgrounds, rather than healthcare or nursing backgrounds". (Health professional).*

In contrast, a senior carer involved in delivering training in their organisation had not had feedback from people being trained relating to caring-clinical boundaries, but did express their own reservations. This carer explained that they were a good carer providing support for living, not a poorly skilled healthcare professional.

> *"And I think we as a social care setting are being increasingly asked to do more things. So, like, the clicky things with the finger – I'm not even sure what it's called. Is it blood oxygen? And then kind of like temperatures. And then it kind of creeps into blood pressure, maybe, or something like that. But I… I've always advocated, like, really strongly for… We can say we don't do that – we're supported living. And that, like, you know, people… I know that people misunderstand what supported living is. So, they're kind of like… And I had to explain to an Learning Disability nurse recently what supported living was, and she was adamant that they should have nurses there, in supported living schemes. And I was, like, no – they don't. And luckily for us, you know, we're in [city name]. And, like, we were one of the first areas to kind of like really implement person-centredness supported living. So, we've got, like, a really strong, kind of like, grounding in it. And I think we know our identity at [organisation name] as an organisation. We're forged in this way. So, we're really lucky to be able to push back and say, like, no – we don't do that here. But I think we're unusual". (Manager, care provider organisation).*

2.3.3.2 Language

One family carer trainer observed that many of the families to whom they planned to deliver training would need the tool translated into other languages. However, there was also a risk that without contextual interpretation, key information could be lost or misinterpreted.

> *"I will try and put this in other languages. Because I've got a lot of families that are speaking their third language. So, you know, it's becoming a bit of a problem at the moment, so… You know, I'll be honest – I'm in the middle of writing for the end of season… For how can I translate all my documents? Like, the SEND documents. Because I haven't got that facility. But that's what… It's almost like… That's why with my peer-to-peer support… You know, I will find a family that speaks English well, and if I then know there's another family that doesn't, that's when I link them together. Because it's then that they might be able to translate that and say this is what it means. Because it does get lost in translation when I'm saying something, or they're reading it wrongly". (Parent carer).*

2.3.3.3 Relevance to specific context of carers

Despite the fact that some trainers felt the tool was easy to adapt to their specific context, this was not always perceived by all carers or trainers when the example scenarios in the provided training pack did not relate to their context or particular problems.

2.3.3.4 IT related issues for digital or app-based version of EWS tools

For some carers, app-based versions of EWS tools were a welcome future development whereas for others, problems with access to digital equipment and internet or IT skills could act as a barrier.

One trainer described a previous experience with an app-based EWS tool which had struggled to succeed, related mainly to problems with wi-fi access in care homes.

> *"I knew about it, because our team was previously involved in rolling out [EWS tool name]. That's another bit of a tale. So, two members of the team… two of my colleagues… I think maybe started in 2018 – back to 2018 – part of the [scheme name], started rolling out the [EWS tool name]. But, to be fair, it didn't do very well. I hope I can speak frankly. It had a number of issues. So, a lot of it was technical problems. So, like, Wi-Fi in care homes […] So, [EWS tool name] is the NEWS part of it. So, it's the actual blood pressure monitoring, the temperature – all wired into a… you know, like a pad. Like an iPad-type of thing. And it catches all the clinical obs and… We did a bit of education about, again, recognising deteriorating patients and when to escalate care to the right professionals. Or to get them*

> *into hospital, really. So… my two colleagues, I know were doing their utmost. And they're really good, experienced educators. And… But I think they engaged carers in care homes to train them with NEWS and with the [EWS tool name] tablet and all the equipment. But I think the technical difficulties put people off. So, the Wi-Fi, because it operated on Wi-Fi to enter the data to connect to the pad". (Health professional, Nurse practitioner, Care home Support Team).*

Other trainers were very positive about using app-based version but described organisational issues, such as complying with GDPR, that needed to be resolved first and that this was an issue for senior management to deal with.

> *"At the moment, we are looking into going digital. But at the moment we're pretty much paper based. So, it would… I don't think it would… Unless everybody had it downloaded to their phone – which then you've got issues with possible GDPR breeches and stuff like that. We are gradually looking at how we can go digital. At the moment I don't think the digital one would benefit us". (Senior support worker, care provider staff).*

For some trainers, access to IT equipment/devices and differing levels of IT skills and familiarity within teams or care provider organisations was a real issue they needed to work with in order to roll-out training.

2.3.3.5 EWS tools that involve using equipment

Impediments related to EWS tools that used equipment mentioned by carers and trainers related to access to equipment, training to use equipment, reluctance to use equipment by carers and gaining compliance with some individuals and using equipment often enough to maintain confidence and competence. Several interviewees reported that there was insufficient equipment available for general use of an EWS that required clinical measurement of vital signs.

> *"I suppose it's only really being used when we think it's necessary. When somebody is poorly. And, you know, luckily, our guys aren't poorly that often. By the time we need to use it again, everybody has forgotten how to use it!" (Manager, care provider organisation).*

For one trainer, it was important that training was not presented in terms of having to use equipment and take measurements.

One solution to this aspect of the barrier might be that senior staff, already trained in areas such as medication, take on the role of using equipment, as suggested by one trainer reflecting on whether their colleagues would be comfortable taking the role of using a thermometer and pulse oximeter. However, for some carers even if they overcame these impediments and provided measurements to health professionals, there was a perception that health professionals might dismiss them anyway.

> *"As long as they're on the same wavelength as you. Like I said, with the paramedic it was brilliant. Like with the emergency service call from the ambulance service. They understood when we said, this is what's happened. But I do feel… I'm not sure whether it is a correct feeling, but I do feel sometimes that some of the higher professionals – like GPs and hospital doctors and that – tend to think, oh well, yes, they've taken those readings, but we need to take some proper ones. So, I'm not sure whether they take us seriously as professionals. Taking these readings. Yeah, you're taking those readings – but can we trust them?". (Senior support worker, care provider staff).*

2.3.3.6 Funding

The availability of funding for rolling out training programmes in EWS tools was identified as an issue by one health professional involved in a regional roll-out of training.

> *"Yeah, so I think going wider, we probably need to think about, kind of, you know, social care and things, who fund these placements… Fund these people being involved as well. Because, you know, our primary care liaison nurse are not going to be able to train every carer. You know, so… or we involve the district nursing team as well. And they're already doing some roll out in other… In, you know, other care homes. So, I think that's what they, sort of, need to look at, going forward. So, the primary care liaison nurses are happy to help and be involved. But I think if you're looking at rolling it out to, you know, the whole county, then that's going to be too much for them". (Health professional).*

Within care providers, some health professional trainers felt that the funding structure of care packages did not allow sufficient funding for non-mandatory training.

2.3.3.7 Training is not mandatory

One trainer reflected that for the experienced carers in their context, unless the training was mandatory, they did not feel they would be able to get engagement.

> *"And we had this conversation with [Name], who was on the call. From Shared Live Plus. She was an absolute diamond. And I said to her... She said, how did you feel the course went? And I went, well, where do I go from here? It's almost like go and sell windows - there you go. I told you how to sell them, told you what to say... Bye. There was no real follow up on that. There was no real literature that came through with those slides that they did. And I said to her, could you...? Try to imagine me going on to our WhatsApp group and saying, right guys, those of you that have been carers for 24 years - when I've only been a carer for, like, four... I'm now going to tell you how to look for your clients'... You know, look at your client to decide if they're okay, or if there's something presenting an issue. I said they would... Excuse my language - they would tell me to bugger off. They really would. They would... Who the hell are you? You don't know my client like I do, and it in that sense they would be dead right. Dead right. So, what I said was, I do think the only way any of us are going to get to teach any other carers is if that course is made mandatory. Voluntarily, they will not do it. But it needs to be mandatory for new carers". (Shared Lives carer).*

2.3.3.8 Staff turnover

Some trainers identified that staff turnover in some settings could be a barrier to rolling out training programmes successfully, because of staff turnover rates and having to go back and train new carers constantly.

> *"Because it's so transient in care homes – the workforce just moves on because of the low pay. And, you know, they're bank nurses a lot of the time. I mean, that's not the rule – because a lot of the homes are very good and retain their staff. But generally, I think that is a problem. You need that constant education element going into care homes…". (Health professional, Nurse practitioner, Care home Support Team).*

2.3.3.9 Health professionals unaware of EWS training and tool

Some carers and trainers identified that they felt successful rolling-out of a training programme was predicated on an assumption that health professionals at all levels had been trained and would recognise important information being passed on to them by carers who had been trained to use EWS tools.

> *"So, we're making the assumption when we do the training that we're using the language of medical people, because doctors and nurses use it, and we're assuming therefore that the receptionist… I'm not saying they haven't, but they're trained in the same kind of conversations. That they'll spot from it what's crucial about that. So, they would know that that's a scary breathing rate and it's a sign of sepsis or whatever. But, yeah, you're right, I don't know whether that actually is the case. You know, so… And I guess that's the same when you phone 999 or 111, because a lot of ours are 111. We're making the assumption that this kind of SBARD… That's how medical people speak, and the people we're speaking to also will speak that language. So, if that's not the case, then of course that's going to be a gap". (Learning & development role, care provider organisation, previously care support manager).*

This also extended to non-health professionals working in the health system, with particular reference by some to GP receptionists.

> *"I just think it depends on who is on the other end of the phone. So, if I said soft signs, would my receptionist know what I'm talking about?". (Parent carer).*

> *"My voice wasn't listened to because... Don't get me wrong, I class as... I was told he'd never finish school. He's got a first-class honours [degree] in [subject names]. He's about to do his Masters, because he had to... But his problem is, even now, I still have to go to hospital with him. Because he struggles. He says, I'm not sure what they mean. And yet he's the most intelligent person you can meet. And that's why I said about the training - don't just train doctors. You've got to train the receptionist. But in the real world you've got to get through your receptionist. As a parent, if you're in a care home, you've normally got a link to a doctor, but if you're a parent carer, you've got to... And I don't mean to say the receptionists are horrible. But if you phoned up with some of those soft signs, they would just say to you, it's not urgent. It's not urgent. Go away. Or wait until... If they've got a temperature, wait until they're not eating or... ". (Parent carer).*

One family carer, reflecting on whether the training might help them going forward, felt that it would, if professionals were trained rather than paid or unpaid carers.

> *"So, if it was training professionals – I'm not on about carers, family members and support workers – then I think, yeah, in a way, it would help me. Because if I went somewhere, they would get it and understand. But for… as a point, personally, it wouldn't in that way. Professionals, if it rolled out – and definitely any sort of TA, support workers, then, yes, it would help". (Parent carer).*

2.3.3.10 Multiplicity of tools and schemes

Some carers talked about confusion between all the schemes they were aware of as being a problematic part of rolling-out training to carers.

> *"And I know there's been several other schemes. And I think that's, again, part of the problem. Is there isn't just one scheme. And it's trying to get that uniformity, so everybody is using the same tool. And if people are using the same tool, then people become adaptive to it very quickly. Whereas when you're having to use bits of information or bits of different tools from all over the place, then it becomes very confusing". (Shared Lives carer, former health professional).*

For some carers, providing care across different local authority areas meant having to use different EWS tools, depending on which local authority area the person they are supporting lives in. Thus, these carers would need training in several different EWS tools. Some carers felt that if everybody used the same tool, everybody would adapt to it and it would become a uniformly recognised way of collecting and providing information.

2.3.3.11 Learning Disability label

One parent carer, with many connections to other parent carers through a parent carer forum described aspects of a learning disability label that could act as impediments in rolling out training programmes in EWS tools. Sometimes, the issue was related to people not wanting to be or feel labelled as having a learning disability.

Sometimes, there were cultural values around a learning disability label that might mean the training and tool would not be accessed by some carers if it was labelled as being for learning disablity.

In contrast to this perspective, this carer also felt that sometimes that a learning disability label created inequalities with respect to other types of disabilities.

2.3.4 Review of whether training and access to an EWS tool helps carers overcome impediments to spotting acute deterioration and escalating concerns

This section considers whether the impacts arising from training and access to an EWS tool and some of the relevant enabling mechanisms identified above, help to address the impediments carers face trying to spot acute deterioration and escalate their concerns to get timely help.

In summary, training and access to an EWS tool does help to address impediments carers experience when trying to spot acute deterioration in people with a learning disability and escalate their concerns. There are many impediments remaining which are not addressed by training carers and providing them with access to EWS tools, including:

- Health professionals understanding of what social care offers
- Health professionals lack of education in learning disability awareness
- Minimum pay levels of carers
- Negative attitudes to carers and lack of recognition of their expert knowledge
- Training is not mandatory for paid carers, this could address access inequalities for paid carers
- Lack of knowledge, training and awareness about learning disabilities, soft signs and differences in ‘normality’ amongst health professionals is not addressed
- Lack of ‘flagging’ mechanism in health care systems to alert GP receptionists and health care professionals to the need for appropriate adjustments
- Flagging mechanism alerting 111 to the need for appropriate adjustments
- Lack of learning disability nurses
- Procedural or policy issues in healthcare that obstruct the activities of the social care sector when accessing healthcare.

3 PART THREE DISCUSSION AND CONCLUSIONS

3.1 Overview of findings

3.1.1 EWS tools

There are two types of EWS tools in use across England for monitoring acute deterioration in people with a learning disability and escalating concerns: those that involve using equipment to take basic measurements and those that do not. RESTORE2; Is My Resident Unwell?; Whzan; and; Anticipatory Care Calendar all involve taking basic measurements and calculating a score. Tools like RESTORE2Mini, Stop and Watch, Significant 7+/Significant Care and specific situation tools e.g., Covid-19 Grab and Go form, do not involve taking basic measurements. There also bespoke tools or systems which have been adapted for use by individual care providers, which may or may not involve taking basic measurements and calculating scores. As in other healthcare settings the lack of standardisation reduces the effectiveness of the tools. In England the activities of the RCP and NHS England in promoting NEWS and NEWS2 as universal practice in acute care has resulted in a universally understood system. An agreed standardisation in the community and care sectors would be useful.

3.1.2 Soft signs of acute deterioration or illness in people with a learning disability.

There is great variability in the type and presentation of soft signs that may indicate acute deterioration in people with a learning disability. Carers were found to have a deep, yet informal, understanding of the concept from their personal experience of caring. Carers become familiar with and used to spotting these soft signs in the people they care for and are often able to interpret what they may indicate. However, it takes time and a distinct caring skill set to develop this knowledge. Furthermore, this knowledge is often informal (in carers heads) and there is value in mechanisms which facilitate carers converting this to formal knowledge. There are already mechanisms designed to do this such as hospital passports. However, carers experiences and perceptions are that these are not used by health professionals, possibly because their very comprehensiveness makes them inconvenient at the moment of need. For some carers, the effort of completing hospital passports, and having one for each setting where the person is cared for, is also a barrier. Thus, there is a need for paperwork to be in a format which not only facilitates capturing and sharing relevant aspects of carers' knowledge about soft signs for an individual, but which is easy for other carers and health professionals to understand.

To spot soft signs carers rely on another aspect of their informal knowledge: how someone with a learning disability might present. Carers often understand that physiological baselines and behavioural responses of people with a learning disability are different from the general population and that their usual status can be highly idiosyncratic, even dynamic. Carers experiences and perceptions of many health professionals' ability and/or willingness to understand this suggests that workers in the health sector do not understand Learning Disability and its effects on the individual. There is value in mechanisms which facilitate carers converting their informal knowledge about 'normality' for the people they care for to formal knowledge, in formats which trigger more active access and internalisation of this knowledge by others, including both other carers and health professionals.

This study was conducted at an early stage in the introduction of EWS in the Learning Disability community, carers did not have much (if any) experience of presenting the EWS data to health professionals, and it is not possible to draw any conclusions about the effect on communication and the perception of carers by health professionals.

In summary then, mechanisms that facilitate carers gaining knowledge and awareness about the range and variation in softs signs is likely to be valuable for many carers. All carers may face new illnesses such as Covid-19, or may encounter acute illness for the first time with the otherwise healthy people with a learning disability they care for. For new carers, or experienced carers beginning to care for new individuals, developing knowledge and awareness of soft signs and normality may take time, during which time people with a Learning Disability may become ill. In some situations, carers will often be encountering and caring for new people with a learning disability and will not have the time needed to develop this knowledge e.g., agency staff filling in vacancies. Therefore, building an evidence base on the range and type of soft signs may be a useful resource for both carers and health professionals.

3.2 Discussion

This study explored carers’ experiences of escalating concerns to other health professionals. In addition, it explored their experience of the training provided when adopting Restore2 Mini to improve the recognition of acute deterioration in people with a learning disability. In interpreting the evidence and the findings of this report it is important to remember that only the perspective of the carers is presented here. The persistent complaint of the carers is that they cannot communicate, because they cannot get access to the responsible healthcare professionals; and that when they do get a voice it is often disregarded. This is noteworthy because people with Learning Disability *do* have worse outcomes than would be expected (Louch et al., 2021), and many of their problems start with communication between professionals (Tuffrey-Wijne & Hollins, 2014).

3.2.1 The Role of Carers

This study has revealed the complexity of the role of carers. They are a heterogenous group. They have a wide variety of backgrounds and come to caring for persons with learning disability for a variety of reasons. Many are the parents or siblings of the people for whom they care. Some carers are paid, and some are unpaid, many have long relationships with individuals with LD, whereas others work through agencies and may not get to know their clients well. Whatever their background their role is to assist people with Learning Disability to maximise their potential and live rewarding lives.

When the person with Learning Disability requires the attention of healthcare services their carer acts as their supporter, interpreter, and advocate. A person with Learning Disability denied the presence of a carer who understands them loses their voice just as surely as a person dependent on sign language when no one knows how to sign. The presence of their carer is a necessary adjustment to the management of many people with LD.

Many individuals with Learning Disability can understand what is required of them, and can communicate satisfactorily for themselves, others have significant difficulties. The carer functions to give their client a voice - allowing them to participate in decision making. Problems of communication can be very deceptive for health professionals unaccustomed to dealing with LD. Some individuals appear to understand and respond in ways which seem to confirm their understanding; however, the carer will recognise that what the person is saying is perhaps a ‘stock’ response that does not mean that they have understood. Other people with Learning Disability may respond verbally with words or sounds that are meaningless to the health professional, but that the carer understands demonstrate understanding and an appropriate response.

Another specific contribution to management, that carers identify, concerns the issue of capacity. Difficulty with communication interferes with the person with LD’s behaviour about making choices about treatment. When a patient refuses to cooperate and will not allow a treatment, or get into an ambulance, health professionals may assume that this constitutes a refusal of treatment, and this will be followed by a discussion of whether the individual has capacity. This response is appropriate in the case of a patient without LD. A person with Learning Disability may be behaving in this way for several reasons. They may understand what is happening and be consenting, but fear and unfamiliarity is overwhelming their positive intention. They may not be able to understand what is required of them, because the decision is not being presented to them in a way that they can understand. In these circumstances, particularly where the patient has verbal communication, carers reported that health professionals interpret lack of cooperation as refusal of treatment, and to assume they understand and have capacity. The carer may know that some aspect of the situation: seeing a syringe, the use of protective equipment, a smell, or a sound is frightening the individual. Carers work around this situation every day in their normal work and can – if given the opportunity - often calm the situation and engineer cooperation. Repeatedly they reported incidents where they were dismissed and not allowed to participate. This sometimes resulted in long delays to treatment whilst the issue of capacity and consent to treatment was resolved in committee.

The complexity of the carer/person with Learning Disability relationship is clearly not understood by healthcare professionals. In many cases the patient with Learning Disability can only function adequately in a healthcare environment with the constant assistance of their carer. Health professionals are used to working with healthcare assistants and see the carer as filling this role. They do not recognise that the Learning Disability carer brings insights, skills and knowledge that are essential to the smooth management of care. The situation is worse for family carers who are apt to be sent to the relatives’ room and not recognised as having even the credibility of a healthcare assistant.

3.2.2 Proxy communication

Further difficulties arise when the carer is not available. When people with Learning Disability have difficulty in communicating, health professionals often perceive the problem to be due to lack of understanding, or even the capacity to understand. The carers report that this leads health professionals to rely wholly on proxy communication via the carers, ignoring the person with LD’s attempts to communicate and ceasing communication with their patient when there is no carer present. This lack of understanding by the health professional is compounded by the fact that healthcare professionals are reported in these interviews to disregard the carer’s opinions and insights because of their lack of qualifications and lack of sophisticated medical vocabulary.

These facts result in there being two communication problems. Firstly, most health professionals are very poor at communicating with persons with Learning Disability and secondly, many health professionals disregard the information and insights available from a proper partnership with the carers.

3.2.3 Carers are often denied access to more senior health professionals

Carers often require to meet with relevant health professionals: to bring a concern to the notice of the relevant team, to “interpret” for their client and to obtain formal and informal advice. This study suggests that getting access to senior healthcare professionals can be difficult and time consuming. Seeing the carer as a healthcare assistant or relative with only a lowly place in the medical hierarchy, first contact workers deny the carer any opportunity to speak with senior members of the team. This applies to GP receptionists, Emergency Department triage nurses, hospital ward staff and many others. If the patient were a child the senior staff who make therapeutic decisions would actively seek to communicate with the parents to take a history and explain treatment. In many ways the carer has a similar role to a parent, but they are frequently asked to leave. Clearly this has been worse during the COVID19 pandemic. The consequence of this denial of access is that clinical teams do not get all the relevant information about a patient and families and social care teams do not get adequate information about clinical decisions.

- **Carers need access to clinical decision makers and should not be dismissed as minor functionaries.**

3.2.4 Care and support should not be medicalised

The carers opinion was that ‘medicalising’ the lives of those with Learning Disability is undesirable. Taking the pulse, oximetry and blood pressure measurement are often frightening interventions for people with Learning Disability who also do not easily become accustomed to them with their regular use. The carers however strongly supported taking infrequent readings to establish a ‘normal’ as complex physical problems often affect the vital signs of those with LD. Carers were concerned that if they were seen as possessing ‘medical’ skills this might, paradoxically, make it more difficult for them to make referrals into the healthcare sector.

- **Carers help people with Learning Disability live their lives. They do not have clinical skills. People with Learning Disability do not need to live in a medicalised environment.**

3.2.5 Carers are Ignored by Health Professionals

It was a salutary experience to hear the accounts of how carers were sometimes treated by health professionals in acute care. These interviews revealed multiple stories of carers concerns and their opinions being disregarded by health professionals in the acute sector. No staff group was exempt including senior doctors. There were several incidents where in the opinion of the carer, the dismissive attitude to their concerns resulted in harm, even the death of a patient. The experiences of the carers revealed that health professionals who have little experience of Learning Disability expect the normal symptoms and signs of disease to be unaffected by LD. In reality, their expression can be very altered and only a person used to communicating with that person can recognise the changed behaviour. The person with Learning Disability may also respond very differently to the use of routine relatively unthreatening medical devices. A carer is accustomed to gentling and cajoling towards cooperation and understands that even a spoon can be scary. A doctor may approach the individual with a 20ml syringe and needle, and then interpret their response as though it were a considered refusal of treatment. In routine practice the issue of capacity seldom arises; a patient with Learning Disability may limit investigation and treatment in many ways, usually from fear, and once refusal has occurred the issue of capacity will delay matters and cause extra work. It would be far better to enlist the help of the carer to bring the person with Learning Disability to permit the necessary treatments and remain calm. On the evidence of the carers this is often not what happens. Carers may have more than one role: carer, parent, trained health professional (current or past) and in dealings with acute care health professionals they are relegated to whatever role is lowest in status. This is most galling for parent carers who are also health professionals but whose role in hospital is relegated to that of “relly” (a dismissive expression for a relative) by healthcare professionals. It is clear from this research that carers have important skills and experience that inform their understanding of the condition of the persons with Learning Disability who they support. The problem was not that they lacked the knowledge and skills to communicate these understandings, but that they were not listened to, and often not given the opportunity to speak. The health professionals were knowledgeable and experienced in their own specialisms but did not understand how the idiosyncrasies of people with Learning Disability could disrupt clinical investigation and treatment.

- **The role of the carer is disregarded by many health professionals who do not realise that they have a part to play by providing information on the individual, by helping the individual with their fears and as their interpreter.**
- **It is not always possible to take a full set of clinical observations with all people with a learning disability.**
- **The baseline of people with a learning disability for standard clinical observations may be different to that seen in the general population, and indeed may be highly idiosyncratic. Therefore, using scoring systems developed for the general population may not generate health information that conforms in the same way as occurs in the general population.**
- **The signs of illness or acute deterioration in people with a learning disability may be variable highly idiosyncratic and may present differently to that in the general population.**

3.2.6 The training programmes have been welcomed

Carers are a professionally neglected group in general and particularly in the field of LD. These carers bewailed the general lack of training and had seized upon the EWS teaching as a way to explore their learning beyond the immediate intention of the sessions. Even online they had seen it opening up a community of practice, as well as learning. They had avidly grasped the opportunity to change their own practice and there were many reports of how they intended to change their practice. It was striking that these new ideas were originating with the carers themselves and again emerged from their unique understandings of supporting LD. There is no data to show whether the use of an EWS improves the way health professionals perceive carers and whether communication across the care sector / health sector boundary is improved. However, the training and use of the EWS has, at this early stage, already improved the confidence of carers and raised their self-respect as professionals.

- **This training was welcomed because the carers had so little opportunity to access training.**

3.2.7 Soft signs

It was a revelation to many of the carers that what they were doing already, by recognising the significance of tiny changes in the behaviour of people with Learning Disability as being highly significant signals of potentially serious problems. This is what they had been trying to communicate to health professionals and the soft signs based EWS was legitimising their observations and calling upon the health professionals to listen. They found this exciting. As part of this study the carers were asked to describe the soft signs that they recognised on a day-to-day basis as indicating that an individual may be developing a medical problem. These findings are summarised in Appendix

- **The training was revelatory. The carers were delighted to find that the soft signs approach endorsed their existing approach to recognising potential acute illness in people with learning disability.**

3.2.8 Training for health professionals

Carers were very critical of the response they met from many ‘gatekeepers’ in the healthcare system. They were particularly critical of GP receptionists. Carers felt that even when they were armed with a Restore 2 Mini they would not be listened to. Hospital doctors expect clinical assessment data, rather than soft signs, and most GP receptionists are unaware of the concept. The message from the carers was clear: health professionals need to understand the rudiments of communicating with people who have LD, and particularly where there is coexisting autism.

- **Health professionals need to understand that the nature of Learning Disability makes normal communication difficult or impossible and that carers can show them how best to behave and communicate when dealing with such patients.**

3.2.9 The Inertia of the system

One of the striking outcomes of the interviews in this study was difficult it can be for people with Learning Disability to access healthcare. Carers know what they want and need, but the system makes difficulties. The interviews reveal carers regularly striving to communicate with doctors and other healthcare providers. Without question the system is overstretched and the healthcare workers have a difficult task prioritising their overwhelming work schedule. Healthcare is best organised for those who can speak for themselves. When people cannot and others have to speak on their behalf, issues of confidentiality and competence arise. These complicate and often obstruct care.

Gatekeepers, receptionists etc., expect those presenting on behalf of another to be able to provide basic information about the individual and the presentation. When the person becoming ill has Learning Disability this information may not be available. It may be impossible to get them to explain whether they are in pain, whether they feel nausea and so on. Their Learning Disability may lead them to deny these symptoms even when they have them and understand what is being asked.

The plea from carers is that when Learning Disability is present the healthcare professional listens to the carer and does not expect the same level of information to be available as with others. Learning Disability so complicates the presentation of illness that they should be made a special case.

All persons with Learning Disability should be registered as such with their GP. This prompts their annual review and simplifies communication when they need medical services. Lack of registration leaves the carer struggling to be allowed to act as the persons proxy and complicates their evaluation.

Carers report that much of the documentation that accompanies an individual to hospital or to a change in their place of care is too unwieldy to be useful. In particular, healthcare passports were often not read. In the interviews the carers seize on the EWS as a possible, more comprehensible alternative. The EWS is not intended for this purpose and is not suitable. Nonetheless the criticism may be valid, that the healthcare passport is too complex to be useful.

- **For persons with Learning Disability and their carers the bureaucracy of healthcare is an obstacle that leads to delay in getting appropriate care and obstructs the flow of information.**

- **The effects of Learning Disability on communication should be understood by all concerned and the role of the carer as 'interpreter' of both language and behaviour should be recognised.**

3.2.10 Using EWS should not result in sick patients being cared for in inappropriate settings

Carers in the social care sector are not trained health professionals and the settings in which they work do not have the basic necessities required for the care of sick patients. EWSs are a way of measuring the severity of illness and demonstrating that an individual needs to be transferred to a healthcare environment. There is concern that if healthcare professionals see carers presenting NEWS scores and discussing them in appropriate language, they may conclude that the caring environment in which the person with Learning Disability lives is a safe place for them to stay, at least at present. This is categorically wrong. Part of the Learning Disability training for health professionals should be to teach them that Learning Disability persons live in 'home like' accommodation or at home and that it is no more suitable for a sick patient than is anyone's house. EWS could have the perverse effect of increasing risk for persons with Learning Disability by even further delaying their arrival in hospital.

3.3 Recommendations

1. Health professionals are trained to ask carers '*What do I need to know*?' followed by '*What is this person usually like*?'
2. As many carers and health professionals as possible are trained in spotting signs of acute deterioration using soft signs and to understand the significance of changes in soft signs.
3. As many administrative and managerial staff as possible (such as GP receptionists, 111 call handlers, and on call care service managers) who exercise triage functions (whether formally or informally) when persons with learning disability access healthcare services, are trained to understand and recognise the significance of structured communication tools and early warning scores.
4. As many health professionals as possible (including those at points of access to health care systems such as GP receptionists, 111 call handlers) receive learning disability awareness training.
5. Policy and process impediments to appropriate adjustments to care, diagnosis and treatment for people with a learning disability are addressed
6. When persons with Learning Disability develop acute illness they require support by the same health professionals as anyone else. Training carers to perform simple systematic evaluation of clinical signs does not make them into healthcare professionals and their ability to undertake and calculate an EWS should not be interpreted as showing that they, and their care environment is a suitable place for patients who have the potential for rapid deterioration.
7. The importance of registering Learning Disability with GPs and hospitals is to be emphasised.

3.4 Study limitations

As a study of communication between the social care and healthcare sectors this study suffers from the disadvantage that only the carer's perceptions are presented. A full appreciation of the problems requires that we hear the voices of those acute care providers who receive the person with learning disability. It is at this transition, as with the whole population, that they become ‘patients’. They are not patients by virtue of having learning disability. It is much more difficult to identify healthcare professionals to interview about the care of patients with Learning Disability because, in general acute care settings, each practitioner has little experience of patients with learning disability.

The timing of data collection in this study occurred shortly (within one to three months) after carers had received training. Thus, their experiences and reflections did not necessarily cover the full effects of internalisation, embedding and application of the training in daily caring life.

Although information about the study was widely disseminated and participation invited from everybody who met the selection criteria, it is possible that people who volunteered to participate were those that had more positive, or more negative, experiences of the training and tool. There is scope for further studies to seek out contrasting views of people who have experienced training and access to an EWS tool.

This study focused on carers for adults with learning disabilities but the need for equivalent studies focusing on the experiences of carers for children with learning disabilities was raised by one participant.

3.5 Further research

Following up the impact of training and access to EWS tools after a period of time to allow embedding of the tool in daily culture and organisational culture (care providers) or caring approach (family carers).

There is also a need for further research into the barriers that carers meet when representing people with Learning Disability at the gateway to healthcare professionals. The lived experience of gatekeeper professionals should be explored to better understand why carers believe that they raise significant impediments to care across the healthcare/social care divide.

4 APPENDIX A Scoping review of Early Warning Scoring tools in use in England

4.1 Background

Scoring systems, based on the patient's vital signs, were initially developed in the hope that a high score would identify those patients who had subtle changes, that marked them as being at risk of sudden, severe deterioration. It was hoped that this would facilitate earlier intervention and that this would, in turn, lead to improved outcomes. The score provided a common vocabulary for the discussion of the patients' physiology. Recently the use of EWS has extended in two ways. Firstly, they provide an additional 'vital sign' that is a composite of the usual observations and this is used to indicate the patients progress when a potentially critical state is established. It is postulated that changes in this composite have greater validity and reliability in recognising patients who are beginning to deteriorate and continuing rises in the EWS reflect deterioration.

FIGURE 3 THE USES OF EARLY WARNING SCORES

- To identify a cohort of patients who are at greater risk of sudden deterioration because they have multiple small deviations from normal in their physiology as reflected by the measurement of routine vital signs.
- To track the progress of patients whose vital signs are abnormal due to them having an established acute illness.
- To provide an index of the severity of a patient's illness.
- To provide a vocabulary that can be used by health professionals when discussing the condition of patients.
- To incorporate 'soft signs' into the assessment of individuals in community, home and general practice settings.

The use of a deterioration score also helps carers who are inexperienced or less able to interpret complex physiological changes, to understand that a patient with multiple small signs of instability is at risk. In many cases the score helps the carer by providing additional information and by mandating referral to the next tier of responsibility (what health professionals call escalation).

The development of EWS and of specialised teams that respond, evaluate and treat patients with severe deterioration has taken place in the context of acute and critical care. Similar problems with recognising the onset of serious illness are encountered outside the hospital. EWS provides a common language for the discussion of a person's severity of illness and it has found application in the Emergency Department, Pre-Hospital care and to some extent in General Practice.

There is a similar problem in recognising the onset of serious illness in care environments, whether these be residential care of the elderly, residential and day care of individuals with learning difficulties, or the care of these groups in their or their family's homes. In these situations the occurrence of deterioration is rare, the carers (whether paid or unpaid) have little or no training in the use of equipment to undertake a vital-signs assessment, and there is an understandable reluctance to ‘medicalise’ the environment.

These considerations have led to the development of several simplified scoring tools. In acute care standardisation upon the NEWS2 system has occurred in England owing to the support of the Royal College of Physicians and NHS England. Outside of acute care there are a variety of tools in use and little research exists to support their validity. A recent development has been the emphasis on ‘soft signs’. These are small changes in a persons behaviour that occur in the early stages of illness. Soft signs are discussed in 3.

4.2 Review of Tools in Use

A scoping review to gain knowledge of EWS tools being used in England was undertaken (including geographical distribution, patient groups and setting type). Information on the EWS tools in use was obtained by:

- Online hand searching
- Emailing selected CCGs leads for social care provision for adults with learning disabilities or autism (a mass email to all CCGs was not possible because of the COVID-19 pandemic and pressure on CCGs at the time)
- Collecting data from care provider organisations about EWS tools they used or were of
- Collecting data from carers about other EWS tools or training they had used or were aware of
- Collecting data through professional networks

Table 11. summarises this information.

Table 11 Warning Systems being used in community settings in England Jan 2021

EWS	Type and content	Area(s) used (Jan 2021)	Settings used (Jan 2021)
RESTORE2™	- Soft signs - Establish normal baseline - Requires NEWS2 scores - Communication pathway - Paper based	21 national locations	- Care Homes - Domiciliary Care - Learning Disability.
RESTORE2 Mini for care homes and domiciliary care (Condensed version RESTORE2 Mini)	- Soft signs - Communication pathway - Paper based	National roll-out of RESTORE2Mini and variants via LeDeR, Learning Disability & Autism Programme, NHS England and NHS Improvement	- Care homes - Domiciliary
RESTORE2 Digital	- Soft signs - Requires NEWS2 scores - Communication pathway - Medical emergency prompts - Resident's summary - Normal for resident - Escalation settings - Telehealth	Currently being piloted	- Pilot in 25 care homes
Is My Resident Unwell? Launched March 2020. Also known as Is My Resident Well? (launched 2018)	- Soft signs - Requires NEWS2 scores - Communication pathway - Information about end of life, anticipatory care of Emergency Health Care plan and DNACPR - Paper based	North East & North Cumbria AHSNs Hammersmith & Fulham GP Federation	- Care Homes
Stop and Watch (launched in UK, 2019)	- Soft signs - Paper based	North Cumbria CCG	- Care Homes - Domiciliary Care - Learning Disability
NEWS/ NEWS2	- Paper based - Hard signs	Available nationally, evaluation of use in care home settings in Sunderland	Elderly care homes
Is My Resident Unwell? (launched March 2020) Also known as "Is My Resident Well?" (launched 2018)	- Soft signs - NEWS2 scores - Communication pathway - Completing person name, signature & date of completion	Northeast & North Cumbria AHSN Hammersmith & Fulham GP Federation	- Care Homes

EWS	Type and content	Area(s) used (Jan 2021)	Settings used (Jan 2021)
	• Information about end of life, anticipatory care of Emergency Health Care plan and DNACPR • Paper based		
Significant 7+	• Paper based • Communication pathway • Paper based		• Care Homes • Domiciliary Care
Significant Care (adaptation of Significant Care for informal carers)	• Soft signs • Communication pathway • Paper based	North East London Foundation Trust (north-east London Boroughs of Barking and Dagenham, Havering, Redbridge and Waltham Forest, Essex and Kent and Medway and Barnet)	• Informal carers
Whzan (Blue Box System) (launched 2013)	• Vital signs (includes pulse oximeter; blood pressure monitor, thermometer; tablet in telehealth case "BLUE BOX") • NEWS2 score • Home activity monitoring ("GUARDIAN KIT") • Remote monitoring via Whzapp	Isle of Wight, Sunderland, Mid and South Essex STP	• Care Homes • Domiciliary Care • Home carers
COVID-19 Grab and Go form	• Communication guide • Pain indicator guide • Breathing or swallowing issues • Normal medication summary • Co-morbidity information		• Learning disability
Just Ask "COULD IT BE SEPSIS"	• Soft signs	Nationally available via Sepsis Trust	• Care homes • Learning disability • General public
Anticipatory Care Calendar	• Daily surveillance health observations • Traffic light system triggers appropriate response to changes	Innovation Agency (AHSN for North West coast) Cheshire, Merseyside, Lancashire and South Cumbria	• Social care settings for people with learning disabilities, dementia, frail elderly, stroke, degenerative conditions
Bespoke EWS tools (A variety of local systems are in use. Sometimes adapted to local circumstances or particular patient groups)	• Baseline data for wide range of markers • NEWS2 scores • Escalation settings • Telehealth • Behavioural data • Care plans		

Nothing is known about the effectiveness of any EWS in improving outcomes in persons with LD. No comments can therefore be made about the relative merits of the scoring systems in use.

There are two categories of EWS: those requiring vital signs data and requiring the use of equipment, and those based on behavioural observation. As yet there is no evidence of their relative effectiveness.

There is no reason why the review and referral pathways for a person with LD, whether living at home or in care, should be any different from those for any other individual. The difference is that most people with Learning Disability cannot self-refer and need their carer to accompany them on their path for all the reasons we have discussed.

5 APPENDIX B Soft signs of acute deterioration in people with learning disabilities

‘Soft signs’ is a term arising from projects delivered by Interserve Healthcare and West Hampshire CCG, working with Wessex Patient Safety Collaborative, to identify early signs of physical deterioration in non-hospital settings such as care homes, people’s own homes (Cooper, 2020). Soft signs refer to the early signs, flags or indicators of physical deterioration that occurs when people start to become ill, as distinct from ‘Hard signs’ that can be measured, such as heart rate, blood pressure or temperature.

Interserve Healthcare, who provide healthcare to people with complex and critical medical conditions in their own homes, shared a taxonomy of soft signs developed for use by their staff (Interserve and Wessex Patient Safety Collaboration, 2017).

For the carers participating in this research, paid or unpaid, experienced, or inexperienced; sharing information on the range, type and variety of soft signs that may indicate deterioration was reported to be a useful part of the training sessions they participated in for using RESTORE2Mini. Although carers become very familiar with ‘normality’ for the person or people they care for, and able to spot and interpret subtle changes, this can take time to develop. Starting to care for the first time, caring for new people, or caring for someone when they first become ill can mean carers have little knowledge of soft signs for a new person or situation. Furthermore, several carers described how, so far, the person they cared for was generally healthy, and they had not yet experienced illness or sudden deterioration. For these carers, gaining knowledge about soft signs in advance had been an ‘*eye-opening experience’*.

Likewise, it is clear from carers experiences that health professionals, who do not have the time or opportunity to develop knowledge of ‘normality’ and the changes in ‘normality’ that matter, in relation to an individual person with learning difficulties, and may be sceptical of the changes that have triggered carers concerns. Therefore, information on the range and type of soft signs may be a useful resource for both carers and health professionals.

However, it is also worth noting that, for the carers in this study, sometimes it is combinations of changes in ‘normality’ (combinations of several soft signs) that provides key information and triggered their concerns. Thus, information on the wide range and variability in soft signs for people with a learning disability presented in Table 1 should be a useful resource for carers and health professionals.

Although pain is often an indicator of acute deterioration, it was clear from the carers in this study, that the wide range of ability to feel, locate, articulate, or verbally communicate pain for some people with learning disabilities, means that identifying whether people are in pain is itself often complex. It was also clear that many carers felt health professionals were unaware of this, and, that failure to ask carers, listen to or value carers expert knowledge of the person resulted in poorer levels of diagnosis, care, and treatment, including pain management. In summary, pain as a specific ‘soft sign’ in people with a learning disability:

- can look very different from person to person
- may not manifest, be experienced or be communicated in the same way as in the general population

Health professionals do not necessarily understand this, and carers need to be able to articulate their concerns in an effective way.

Several carers reported that challenging behaviour could be a cue that people were feeling unwell or in pain. Whilst anyone can display challenging behaviour, it has been recognised as an effective way for people with a learning disability, and particularly severe learning disabilities, to control what is going on around them, communicate, or get their needs met (McGill, 2021). Carers in this study reported noticing new challenging behaviour where none had previously been evident, a change in the type of challenging behaviour, or an increase or decrease in existing challenging behaviour. Carers become experienced in the behaviours their clients demonstrate when they are becoming unwell. The behaviours are often specific to the individual but in those that have recurring problems of being unwell, such as headaches or urinary tract infections, the same behaviours are exhibited. Some carers also talked about difficulties they had experienced persuading health care professionals of the significance of changes in challenging behaviour and how they knew this meant something serious was wrong. Furthermore, people with a learning disability, whose behaviour is regarded as challenging by health professionals, were sometimes penalised for example by having their personal records labelled as ‘difficult’ rather than constructive support such as ‘do not approach from right side’. One guiding principle of managing the challenging behaviour of persons with learning disabilities is that other people need to change the way they behave when interacting with them (McGill, 2021). Carers in this study reported experiences with some health professionals who were unaware or unwilling to do this.

In summary then, this study identified that:

- There are many different ‘soft signs’ and these can be different for every person
- When carers know what people are like normally, they can spot changes
- Sometimes carers might understand what ‘soft signs’ (changes) mean but not always
- It is useful for carers to hear about each other’s experiences in spotting soft signs
- Health professionals, particularly those specialising in acute care, may not understand and may discount the significance of soft signs

Table 12. below presents a taxonomy for soft signs of acute deterioration reported by carers participating in this study.

Table 12 Types of soft signs reported by carers

Theme	Soft sign type	Variations and examples
Behavioural	Confusion	
	Challenging behaviour -increases or decreases	Shouting Swearing Running around Throwing things Turning over furniture Chewing furniture
	Going to bed or staying in bed more than usual	
	Increased or decreased activity	Pacing – starting to pace when normally does not or sitting down when normally paces Lies down Becoming active at night Running up and down stairs Running round garden Normally lively, becomes less boisterous
	Lack of interest in normal surroundings or activities	Not wanting to watch TV Refusing to engage in activities they normally enjoy Withdrawing from company of others Spending more time in bedroom Not wanting to go out Do not respond to prompts or instructions
	Lethargy	Sleeping more than usual Lethargic at time of day normally active or energetic Not wanting to do anything Difficult to arouse
	Mood change	Normally outgoing, happy, laughing at jokes or others playing around but becomes sub Becoming snappy or stroppy Normally happy, singing, joking and chatty but becomes cross, loud, more verbally aggr aimed at self
	Quieter than usual	
	Louder than usual	Shouting – more loudly, for long periods
	Self-harming	Biting self; biting hand
	Touching part of the body	Tapping teeth with finger Tapping with feet Grabbing groin when passing urine
	Repeatedly banging leg	
	Flinching	
Communication	Facial expression	Change in facial expression while being moved or handled, rolled or limbs moved
	Hand flapping – more or less	Hands flicker more when anxious
	Sounds	Squeaking – pitch can change from normal pitch to high or low pitch Crying – especially if rarely cries Shouting Stops making sounds if non-verbal
	Losing or not using usual communication methods	Losing verbal skills One-word answers instead of normal chatty conversations
	Verbal but misleading	Say what they think you might want to hear Agrees with last item on a list or whatever carer suggests Interprets and responds very literally to questions Articulate, intelligent and have capacity but actually struggle to understand what health Response to open-ended questions eg unless asked if ears hurting, will not mention if as Mental health issues or other mean person is in denial and will not or cannot admit to p Verbal but cannot articulate pain or where pain located Fear or distrust of medical people, environments, uniforms means person unable or un symptoms Sounds so articulate to health professionals they assume person has capacity to describ symptoms (eg people with autism traits)
Physical	Breathing	
	Dribbling	Starts dribbling when does not normally dribble Dribbling changes – more or less
	Eyes	Not making eye contact Eyes do not look right - lose shininess Eye movement changes

Theme	Soft sign type	Variations and examples
	Loss of appetite – partial or completely	Not wanting meals Not wanting treats eg cakes, biscuits Reduced appetite Can be difficult to tell with people who are PEG fed Clamping lips shut to prevent being fed Pushing away food Stopping eating by people who are normally keen or enthusiastic about food can be ver and seriousness not understood by health care professionals
	Drinking less or not drinking at all	
	Seizures	Seizures start or increase Increased frequency of seizures in people with epilepsy is a good indicator of something
	Skin or face colour	Change in skin colour on face or body from normal – flushing, red, paler or grey
	Sweating	
	Temperature	Baseline temperatures can be higher or lower in people with learning disabilities and ot Importance of baselining normal range of temperatures Baseline temperature can change
	Toileting changes	Becoming incontinent when not normally so Increase or decrease in urination Increase in constipation Increase in diarrhoea
	Weight changes	Can be difficult to measure without specialist weighing equipment eg for wheelchair us
Pain	High pain threshold	If complains about pain means pain is severe Cannot locate pain or point to where pain might be Cannot understand pain
	Can be experienced differently by different people	
	Referred pain can add to difficulties detecting and locating pain	Example of someone who was less verbal and a wheelchair user but indicating pain in k referred pain from dislocated hip

6 https://wessexahsn.org.uk/img/projects/Soft%20Signs%20White%20Paper%20GC%20WPSC%20Final%201.1.pdf)

7 Appendix C The Interview discussion guide.

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