

# Does the recognition of the soft signs by caregivers improve communication with health professionals?

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## What we wanted to know

### Background

RESTORE2<sup>TM</sup>Mini is an early warning tool used to identify "soft signs" of early and acute deterioration. It was adapted for those living with learning disabilities from RESTORE2<sup>TM</sup> which was designed for use in care/nursing homes.

Training for carers to support the use of the tool was carried out by trainers hosted by NHS England and NHS Improvement. It was delivered by the Clinical Lead for Learning Disability for NHS West Yorkshire Integrated Care Board in Leeds, Leeds Learning Disability Health Facilitation Team. Many people with learning disabilities run the risk of being unable to communicate their needs and symptoms. Carers act as ongoing advocates for them but face challenges in receiving timely help.

### Purpose of this Qualitative Study

To explore the usefulness and the value of training carers (of people living with learning disabilities) in RESTORE2<sup>TM</sup>Mini and how the training would assist identifying "soft signs" at early stages of acute deterioration.

Training in pulse oximetry was included to assist with identifying COVID-19 symptoms.

### Aims and Objectives

1. To understand whether the RESTORE2<sup>TM</sup>Mini training resulted in carers developing the ability to identify soft signs, thereby facilitating the early objective detection of deterioration.
2. To understand whether training in RESTORE2<sup>TM</sup>Mini improved the carers ability to communicate the acute care needs of those with learning disabilities to other health professionals.
3. To understand the impact of RESTORE2<sup>TM</sup>Mini training on clinical decision-making

"Care staff, I think, always feel a little bit like the poor relation compared to NHS staff when actually, they're really skilled staff and I think it did give them the confidence to be able to approach the GP and talk at a bit more like they knew what they were talking about" (Manager, care facility).

## What we Did

### Recruitment and Data Collection

Purposive and convenience sampling was used. All those involved in caring for people with learning disabilities who completed RESTORE2<sup>TM</sup>Mini training were invited to participate. The 10 participants were paid carers, unpaid home carers, registered nurses, and managers of facilities for people with learning disabilities.

### Data Collection

Two focus groups and four 1:1 semi-structured, in-depth interviews were completed. Data was collected between December 2021 to July 2022. Interviews were conducted after participants had opportunity to implement the RESTORE2<sup>TM</sup>Mini in their practice. Due to COVID-19 restrictions, all interviews were conducted online using Microsoft Teams. Written informed consent was obtained from all participants. Ethics approval was granted by Northumbria University Ethics Committee.

### Analysis

Data was transcribed verbatim. Thematic analysis was conducted using NVivo using the constant comparative approach.

## What we found

### Stereotypes of Carers

Health professionals made stereotypical assumptions about carers, regardless of them being paid, unpaid or home carers. The assumed biases regarding carers, appeared to shape their attitude to the carers' insights.

### Difficulty Accessing Health Professionals

Many carers struggled to get quick access to health professionals due to their assessments being disregarded.

Gatekeeping established during the COVID-19 pandemic increased the potential for health inequalities for those with learning disabilities. Carers believed that the use of RESTORE2<sup>TM</sup>Mini together with pulse oximetry secured quicker responses.

### Soft signs detection is undervalued

"Soft signs" may be disregarded and underappreciated by health professionals. They feel the signs are subjective and they often incorrectly attribute the signs as being due to the learning disability.

Carers are able to establish the baselines of those for whom they care for and use those baselines to measure against any changes. This is undoubtedly unique to those who spend the most time with the person with learning disabilities, which is usually the carer. This useful insight must not be ignored.

### Training in RESTORE2<sup>TM</sup>Mini was valuable

This study clearly shows that tools such as RESTORE2<sup>TM</sup>Mini provide carers with confidence in terminology in order to communicate the care needs of those for whom they care. Training also allow carers to maintain high quality care, advocate and voice the unmet needs of those with learning disabilities that they care for.

This opens the door for those with learning disability to be part of decision-making.

## Why is this important

- Restore2Mini<sup>TM</sup> is a useful adjunct to existing systems of assessment and referral for individuals with learning disability in all care contexts.
- This study, taken in conjunction with other similar reviews suggests that, in health sectors where staff do not have the clinical skills required for routine vital signs monitoring, the necessary equipment for vital signs monitoring or in individuals who cannot tolerate the interventions, Restore2Mini<sup>TM</sup> improves the confidence of caregivers. In the caregivers' opinion this leads to better and more timely sharing of clinical information.
- The fact that Restore2Mini<sup>TM</sup> uses holistic observation and requires no clinical skill or equipment is an advantage in care contexts. It is particularly suitable for family caregivers and for the caregivers of cared for individuals where there is continuity of carer. It is probably not suitable where the caregiver has little experience of the person with learning disabilities, as the advantage of Restore2Mini<sup>TM</sup> is that it capitalises on personal knowledge of the individual.
- Staff reported significant difficulty in attending Restore2Mini<sup>TM</sup> training events, even though these were online. Though an online teaching and assessment package for Restore2Mini<sup>TM</sup> would remove the barriers to training due to staff shortage and funding, this study and earlier studies suggest that a major part of the benefit of training is the opportunity that the sessions give for reflection and the sharing of experience.
- Adoption of Restore2Mini<sup>TM</sup> within a facility should be accompanied by appropriate amalgamation of new and existing paperwork

## Research Themes

### Carers' ability to communicate objective observations

### The use and value of Restore2Mini within a carers' role in context of their work

### Barriers to providing high quality care during the COVID-19 pandemic

### Barriers to training in RESTORE2Mini

- Carers have a unique ability to understand and manage people with learning disabilities
- Lack of understanding by other health professionals of carers' advocacy role

- Increased carers' confidence and reduced stereotypical assumptions about carers
- Provided a shared terminology
- Improved relationships with health professionals

- Limitations to access due to stringent gatekeeping during the Covid-19 pandemic
- Use of pulse oximetry results to get access to services

- Carers' needs in relation to decision-making power
- Work culture
- Staff shortage

"I can only talk for the service I managed, but staff certainly were more confident when talking to this particular customer's GP and requesting for them to come out and do home visits and they felt they had, something sort of concrete really that they could say, look his oxygen levels are poor or we've gone through these soft signs. So yeah, I think staff definitely felt a bit like they are [listened to]" (Manager, care facility).

"You know they they're not a nurse, but actually they can just see that something is not right. And that's as good as anything, really" (Senior registered nurse, care facility).

"I think anything that you know improves the access to health for the people that we support can only be a good thing, really. And it gives staff the confidence to engage with health professionals, in my opinion, I think it's of great value" (Manager, care facility)

"I think it's that we feel more listened to, because we've got that factual evidence. We feel as though somebody is actually taking in what we're saying because they believe us. Sometimes we feel our opinion doesn't really count for anything even though we're the people that know that person the best." (Manager, care facility).