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*Tailoring the rehabilitative environment
for people with sensory overload*

JENNIFER COTTER R00016312

DR JOE MOYNIHAN

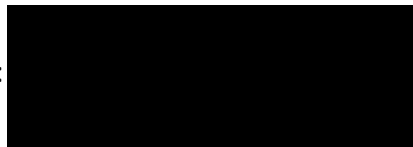
Declaration

This thesis is submitted to Munster Technological University in fulfilment of the requirement for the award of master's degree.

Submission Date:

I hereby certify that the material which is submitted in this thesis for the award of the Masters in Applied Social Sciences is entirely my own work except where otherwise accredited and that the thesis has not been submitted for an award at any other institution other than the fulfilment of the award named above

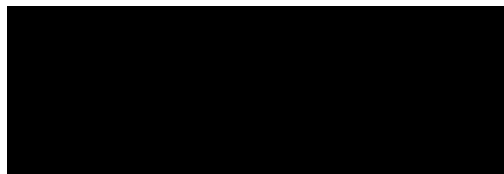
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Signature of Supervisor:



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Thank you to each person who took the time and energy to participate in this study. To the participants experiencing sensory overload post ABI, thank you for sharing your knowledge and personal experiences so generously, openly, and honestly. I will be forever grateful for your invaluable contributions.

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To Mom, Chris, and Jim thank you for always cheering me on.



Abstract

Sensory overload is a complex sensory processing disorder which can develop post Acquired Brain Injury (ABI). The condition can be extremely debilitating and people who develop it are further hampered by lack of informational resources, sensory overload is currently under researched in the Acquired Brain Injury rehabilitation sector. This qualitative study documents participants first hand experiences of sensory overload post ABI and includes insights and observations from professionals working in the Acquired Brain Injury rehabilitation sector in Ireland.

In this study, sensory overload is the focal point and a new rehabilitation tool in the form of a sensory menu is introduced. The literature review details Acquired Brain Injury and sensory overload individually, and then explains the strong linkages between them. It covers theoretical background, sensory triggers, and the current research regarding the importance of sensory informed spaces. Ten participants took part in the study. The researcher used semi

structured interviews as the main data collection method, an overview of all data collection methods including the rationale behind each method is explained. The results and discussion chapter is split up to examine three robust themes that emerged in detail: life altering consequences and loss, sensory overload triggers, education and the rehabilitation environment. The researcher discovered that sensory overload is having a profound impact on people's lives. The participants careers, hobbies and social outlets have all been lost or significantly altered. In addition to having to adapt to common triggers post Acquired Brain Injury, participants reported experiencing a new, uniquely triggering relationship with sensory information. In reference to sensory overload, the participants talked about it being a hidden consequence of Acquired Brain Injury that they find difficult to explain, and people who have never experienced it have great difficulty understanding. All professional participants acknowledged how overlooked sensory needs currently are in ABI rehabilitation environments. Sensory informed education can be the catalyst to creating sensory informed spaces and building awareness within families, friendships and communities about sensory overload and the challenges it presents.

In response to these findings, the researcher recommends that sensory menus are developed into standard practice in ABI rehabilitation services. The sensory menu is an innovative tool that has the potential to strengthen the arsenal of health care practitioners and professionals working in the ABI rehabilitation sector. Critically, the research findings provide a solid tangible reference for people with sensory overload, who reported experiencing a new and sudden, intensely challenging, relationship with sensory information post ABI. The rehabilitation environment can become a malleable tool that clearly represents and responds

to each person's sensory needs and preferences post Acquired Brain Injury. Moreover, it is envisaged that the research findings will not only inform how sensory menus can be utilised in ABI rehabilitation but how they can be developed over time into sensory portfolios and incorporated into other rehabilitative environments to enhance service provision.

Glossary of Terms

Acquired Brain Injury (ABI)	The term Acquired Brain Injury (ABI) is used to describe damage to the brain that occurs during the course of a person’s lifetime. People who have Acquired Brain Injuries were not born with a brain injury. Each person was living a life without disability, and they acquired their brain injury through a life altering illness or accident (National Rehabilitation Hospital, 2016).
Sensory Overload	Sensory processing refers to a person’s ability to register and respond to the sensory information they receive from their social and physical environment (Sinclair et al., 2017). Sensory overload is a sensory processing disorder that can occur post ABI. The effects can cause intense adverse reactions to sensory stimuli (Scotland Acquired Brain Injury Network, 2017).
Service User	Each social care sector uses different terms to describe the individuals or group of people who attend services. In this study the widely used term “service user” will be used throughout.

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Chapter 1 Introduction

1.0 Introduction

Acquired Brain Injury (ABI) is an umbrella term, it is used to describe damage to the brain that occurs during the course of a person's lifetime, through accident or illness, and the multitude of disabilities that can result (National Rehabilitation Hospital, 2016). Sensory overload is a rare, unique, and complex sensory processing disorder that people can develop post Acquired Brain Injury (Hoffman, 2019). Sensory disabilities are well documented in conditions such as autism spectrum disorder, however sensory disorders remain largely under researched in the Acquired Brain Injury field. The role of sensorial experiences in the development of therapeutic settings is said to be *"an area still ripe for additional work"* (Gorman, 2017).

Rehabilitation programmes are broadly designed and routinely aimed towards improving function. Sensory needs and experiences have historically not been the primary focus in rehabilitation settings (Shull and Damian, 2015). This study aims to bring sensory overload to the forefront in Acquired Brain Injury rehabilitation services, so that sensory needs are treated with equal importance to service users' physical and cognitive needs.

This qualitative study documented ABI rehabilitation service users' first-hand experiences and recorded people's personal accounts of developing sensory overload post Acquired Brain Injury. The study includes valuable insights and observations from professionals working in the Acquired Brain Injury sector in Ireland. In this study sensory overload is the focal point and a new rehabilitation tool in the form of a sensory menu is introduced.

Chapter 1 begins by identifying the aims and objectives of the research, followed by the background and rationale of the study.

Chapter 2 forms the literature review; it details Acquired Brain Injury and Sensory Overload individually, and then explains the strong linkages between them. The literature review covers theoretical background, sensory triggers, and the current research regarding the importance of sensory informed spaces. The inspiration for the sensory menu in the present study is explained in this chapter.

Chapter 3 contains the methodology. It begins by providing an overview of the data collection methods including the rationale behind each method. The data analysis, the qualitative nature of the research and the ethical considerations of the study are explained. The participants and the data collection methods are then described in further detail.

Chapter 4 is the results and discussion chapter. This chapter is split up to examine three robust themes in detail:

1. Life altering consequences and loss
2. Sensory overload triggers
3. Education and the rehabilitation environment.

The implications for practice and the strengths and limitations of the study are examined. The research recommendations are put forward.

Chapter 5 summarises and concludes the research study.

1.2 Aims and Objectives

The primary aim of this study is twofold.

- To highlight the first hand experiences of people living with sensory overload post Acquired Brain Injury in Ireland.
- To illustrate the importance of creating sensory informed environments in Acquired Brain Injury rehabilitation services.

1.2.1 Main Research Question

- How does sensory overload impact people post Acquired Brain Injury and how can ABI rehabilitation services in Ireland address services users sensory needs?

1.2.2 Sub Questions

- How does the ABI rehabilitative environment currently cater for people with sensory overload?
- How can the ABI rehabilitative environment be improved to enhance the service people with sensory overload receive?
- How will these new insights and adaptations benefit people with sensory overload?

1.2.3 Objectives

- Explore sensory overload and its effects with participants.
- Identify any new insights that investigating the effects of sensory processing disorders can provide for people with sensory overload and professionals working in the ABI rehabilitation sector.

- Introduce a sensory menu as a new rehabilitation tool and examine how it can be used to benefit people who are experiencing sensory overload post ABI and enhance Acquired Brain Injury rehabilitation services in Ireland.

1.3 Rationale and Background

At present, particularly in an Irish context, research into sensory overload post Acquired Brain Injury is extremely limited. The rehabilitation environment and how it is designed plays a crucial role in service user recovery outcomes. However, despite this, sensory processing conditions that amplify the person's awareness to negative and positive environmental factors remain largely unresearched (Grevan et al., 2019). There is a plethora of information on the physical and cognitive challenges that present for people post ABI, however there is a clear gap in the literature when it comes to examining the sensorial impact of Acquired Brain Injuries.

The researcher has worked in the Acquired Brain Injury rehabilitation sector for ten years as a Rehabilitation Services officer and volunteered in the rehabilitation department for two years prior to becoming a staff member. In that time, the researcher has observed how different settings evoke different emotional, physical, and sensorial responses from service users. The energy of rehabilitative spaces appears to be fluid. In an activity room for example, the energy can depend on factors such as how the furniture is set up, the presence or absence of music and the level of natural day light available. In the community, service users can become agitated in crowds or loud settings. In contrast, the energy of the group seems to be elevated by activities that include nature such as parks, gardens, and trips to the beach.

The most up to date research concludes that Acquired Brain Injury rehabilitation services need to adapt and be tailored for each individual in order to respond to each person's evolving needs and wants (Wells, 2018). This is particularly relevant for people experiencing sensory overload, as their experiences are often so individualised. Professionals working in the ABI rehabilitation sector highlight that sensory overload can compound the loneliness and

depression initially caused by an ABI, as the very nature of the condition can prevent people from attending peer support groups. By exploring the lived experiences of people with sensory overload and introducing a sensory menu as a rehabilitation tool, the study aims to give participants the opportunity to record their sensory experiences and needs in a new and visual way. The burden will no longer fall on the individual to adapt to rehabilitation settings ill equipped to serve their sensory needs. The rehabilitation environment can become a malleable tool that clearly represents and responds to each person's sensory needs and preferences.

1.4 Chapter Conclusion

This introductory chapter explained the background to the research topic being explored in this study. It included the aims of objectives of the study and laid out the rationale for the research undertaken. The next chapter will examine the literature review.



Chapter 2. Literature Review

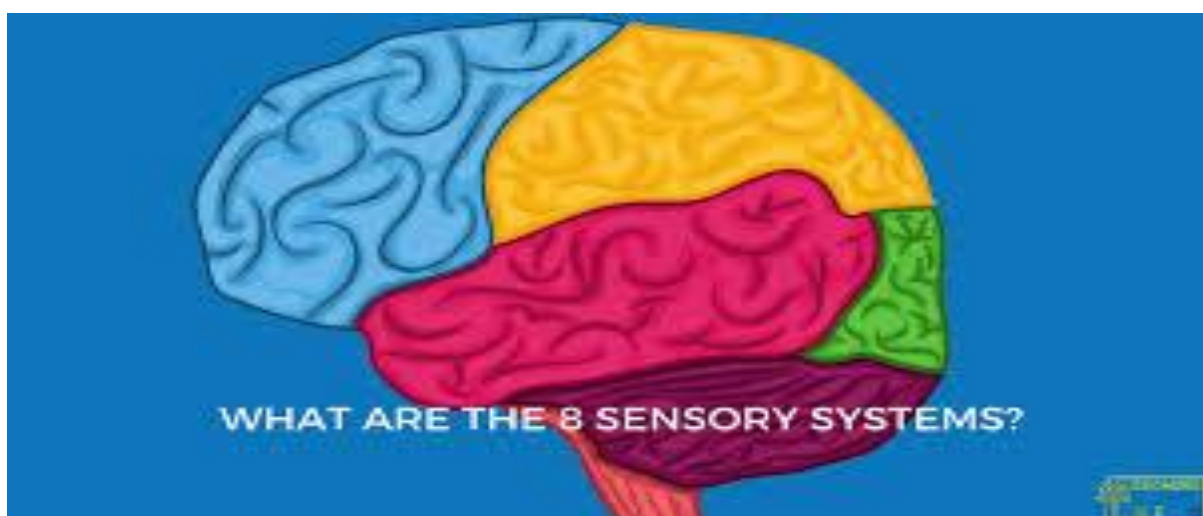
2.0 Introduction

This chapter will begin with a short introduction to sensory overload and Acquired Brain Injury, before outlining how sensory overload and Acquired Brain Injury are interlinked. The theoretical background of the study will be addressed, and sensory triggers will be explored. The chapter will conclude by discussing tailored, sensory friendly environments and the benefits of creating sensory informed settings in in the Acquired Brain Injury sector.

2.1 Sensory Overload

Unsurprisingly a key characteristic inherently linked to every species' survival is this ability to acclimatise to the surrounding atmosphere. As humans, environmental sensitivity is crucial for successful adaptation to the various settings we navigate on a daily basis. Remarkably, each individuals' sensitivity and responsivity are different, even to the same environmental encounters and conditions (Pluess, 2015).

Sensory processing refers to a person's ability to register and respond to the sensory information they receive from their social and physical environment. Sensory overload is a sensory processing disorder that interferes with a person's ability to receive information from their environment. This can heighten sensitivity greatly and dull responsivity significantly, consequently a person's emotional and behavioural regulation, as well as their motor functions, can be severely impacted (Sinclair et al., 2017). The debilitating physical effects of sensory overload can create enormous and complex daily challenges for the person. This is in addition to the emotional distress sensory overload can cause for the individual and their family/social unit. The result is substantial social and environmental challenges in the home and in the community (Tavassoli et al., 2019).



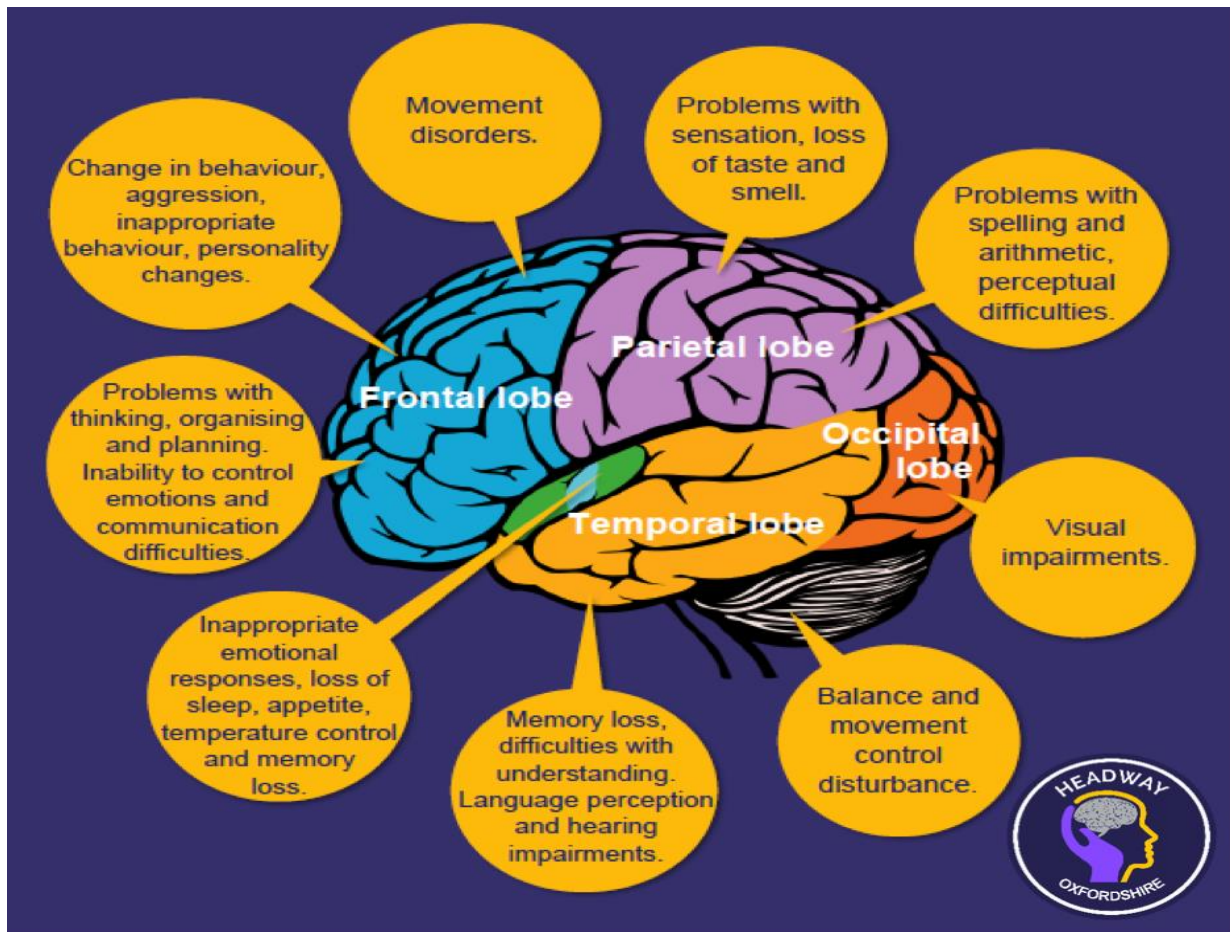
Notably, eight sensory systems are referred to in the literature when discussing sensory overload. The standard five: sight, sound, smell, touch, taste, and three others - the sense of movement through space, the sense of muscles and joints and the sense of internal organs. It is said that sensory overload regularly causes individuals to feel bombarded, the person experiences sensory input *“too easily, too intensely, or for too long”* (Collins and Miller, 2012). As a result, the person may panic, become extremely nauseous and anxious, they may lose their attention and concentration skills and withdraw from activities out of fear. The person may experience a physical break down due to their body’s intense response to sensory stimuli (IBID).

2.2 Acquired Brain Injury

As outlined in the introductory chapter, Acquired brain injury is an umbrella term. It is used to describe damage to the to the brain that occurs through accident, or sudden illness and the multitude of disabilities that can result. Acquired Brain Injuries can be caused in a myriad of ways, for example by a road traffic accident, a stroke, an injury sustained in a fall, a brain haemorrhage, brain tumours, or an infection such as meningitis (National Rehabilitation Hospital 2016³). Acquired Brain Injuries can be classed in two ways. They can be described as open or closed injuries, or to use the more frequently used medical terms, traumatic or non-traumatic (Giustini, et al., 2013). ABI is classed as traumatic or non-traumatic in direct reference to the origin of the injury (Mitchell, 2021). Simply put, this means that an injury was caused by impact, for example through a fall, or it was caused by internal factors such as a stroke.

Fundamentally each Acquired Brain Injury is different, depending on which part of the brain is affected and the severity of the injury. The effects of an Acquired Brain Injury can be

expansive and extensive, they include cognitive, physical, emotional, behavioural, communicative and the focal point of this study, sensory challenges (Headway Ireland, 2021).



(Shelley, n.d.)

It is estimated that 69 million people sustain an Acquired Brain Injury globally each year (Dewan et al., 2018). Irish statistics approximate that 100,000 people between the ages of 16-65 years are currently living with an Acquired Brain Injury across the country, and this number is estimated to be increasing by 20,000 people every year (Acquired Brain Injury Ireland, 2019). Acquired Brain Injury is one of the leading causes of disability and death in adults worldwide (Meijering et al., 2019). As the statistics suggest, there is an important present, and ever increasing need to cater for this target group in rehabilitation settings.

After the acute hospital stage and rehabilitation therapies, many Acquired Brain Injury survivors still face serious physical and cognitive conditions when they try to return to their former pre injury lives. In addition to lasting physical impairments such as loss of motor functions, there are often less apparent complex disabilities associated with cognition, emotional processing, and sensory perception (Meijering et al., 2019). There are a wide range of services in Ireland geared towards physical therapies, in addition specialised rehabilitation settings are designed to deliver cognitive therapies post ABI. There is very limited research on sensory disabilities post ABI and subsequently Acquire Brain Injury rehabilitation settings are not currently designed or equipped to respond to sensory needs.

2.3 Sensory Overload Post Acquired Brain Injury

Following an Acquired Brain Injury, a person's sensory processing skills may be impaired, consequently the person may become overwhelmed or distressed by common stimuli. The stimulus may be external, for example fluorescent lighting, or internal, for example fatigue. This condition can be described as hypersensitivity, over stimulation or sensory overload (Scotland Acquired Brain Injury Network, 2017). For the purpose of this study the term sensory overload is used throughout as this is the term participants identified with.

When the brain is damaged, the frontal lobes and linked brain structures may no longer effectively manage emotional responses. Consequently, a person can have difficulty controlling their emotions. This is known as emotional lability, people presenting with emotional lability may shift quickly from one strong emotion to another. Emotional responses can be misplaced, for example, the person may laugh in a situation even though they report feeling sad. Following an ABI, the person may experience a wide range of emotions such as disbelief, anger, regret, guilt, and grief. The person may also have to negotiate enormous

changes in their lives for example acquired disability, severe fatigue and exiting the employment sector.

Emotional reactions are influenced by the person's physical and social environment. For example, if a person visits an unfamiliar or particularly busy setting, their stress levels may increase. This can evoke an emotional response and affects how the person feels and acts. Many different factors can cause emotional responses, these are commonly known as triggers. These triggers will vary from person to person. Environmental triggers following an ABI commonly include noise, light, new situations, crowds, and unexpected changes to routine (Headway Ireland, 2021). In addition to emotional lability, sustaining an Acquired Brain Injury can cause depression, irritability, and anxiety disorders (Levin & Diaz-Arrastia, 2015). The evidence suggests that these conditions can present long term for many ABI survivors (Scholten et al., 2016).

Cognitive functioning is understandably one of the most common areas of difficulty experienced by ABI survivors, processing and attention deficits are especially frequent. Due to a negatively altered attention span, it can be challenging for the person to tune out stimuli. Prior to the person's Acquired Brain Injury common stimuli would have routinely faded into the background, for example the conversations of other people in a restaurant. Post ABI, background stimuli can become amplified and overpowering, consequently it can dominate the person's focus. This may result in the person being unable to converse and unable to attend to tasks. This can spark frustration and feelings of distress (Scotland Acquired Brain Injury Network, 2017).

Moreover, injury to the frontal lobes of the brain can reduce a person's ability to recognise negative emotions such as sadness and anger in other people so it can impact on how a person

relates to their family members and their peers. (Hadjam, 2015). Sustaining an ABI can result in a sudden, permanent disability that the survivor and their family must adapt to, with no warning or opportunity to prepare for (Patel et al., 2016).

Overall, the person may feel less in control of their lives. These comprehensive sensory, physical, cognitive and character changes can cause intense stress and emotional turmoil for the person themselves, and for their family/friends (Tavassoli et al., 2019). ABI survivors highlight that it is incredibly difficult for their family, friends, clinicians, and social network to fully appreciate what it is like to have an Acquired Brain Injury. One ABI survivor equates having an ABI to living on a different universe, describing it on his online platform as a place *“where sound, light, smells, gravity, thought and more are all amplified, thicker, stickier, harder, and otherwise completely different than you experience on earth”* (Jones, 2019).

Undeniably the effects of sensory overload can be all encompassing, interfering with the person's:

- Quality of life and overall wellbeing.
- Social life, community integration and previously enjoyed pastimes.
- Educational and occupational performances.
- Access to rehabilitation and ability to participate in rehabilitative therapies.
- Cognitive functioning and physical mobility.
- Home environment by limiting the person's ability to live independently or alternatively settle back into the family home or a residential care setting

(Scotland Acquired Brain Injury Network, 2017).



2.4 Theoretical Background

By examining the origins of research into the role environmental factors play in therapeutic settings we can see how modern concepts developed. Tolman (1948) first introduced the theory of emotional mapping to the world. It is a process that was once primarily used for geological studies. The idea is grounded within geo participation, which uses spatial analysis to get people involved in their communities (Tolman, 1948) (Panek, 2016). In 1992 Wilbert Gesler conceptualised the idea of therapeutic landscapes to explore how and why certain settings create therapeutic environments (Gesler, 1992) (Bell et al., 2018). The theory of therapeutic landscapes is acknowledged as one of the primary geographical contributions to the study of health and wellbeing (Williams, 2016). In 2001 researchers highlighted that our experiences in therapeutic settings are not solely based on our visual experiences but

informed by other sensory activities too, namely sound, touch, taste, and smell (Holloway and Hubbard 2001). It has been discovered that each person's sensory experiences play a key role in their levels of engagement in therapeutic spaces (Milligan et al., 2004).

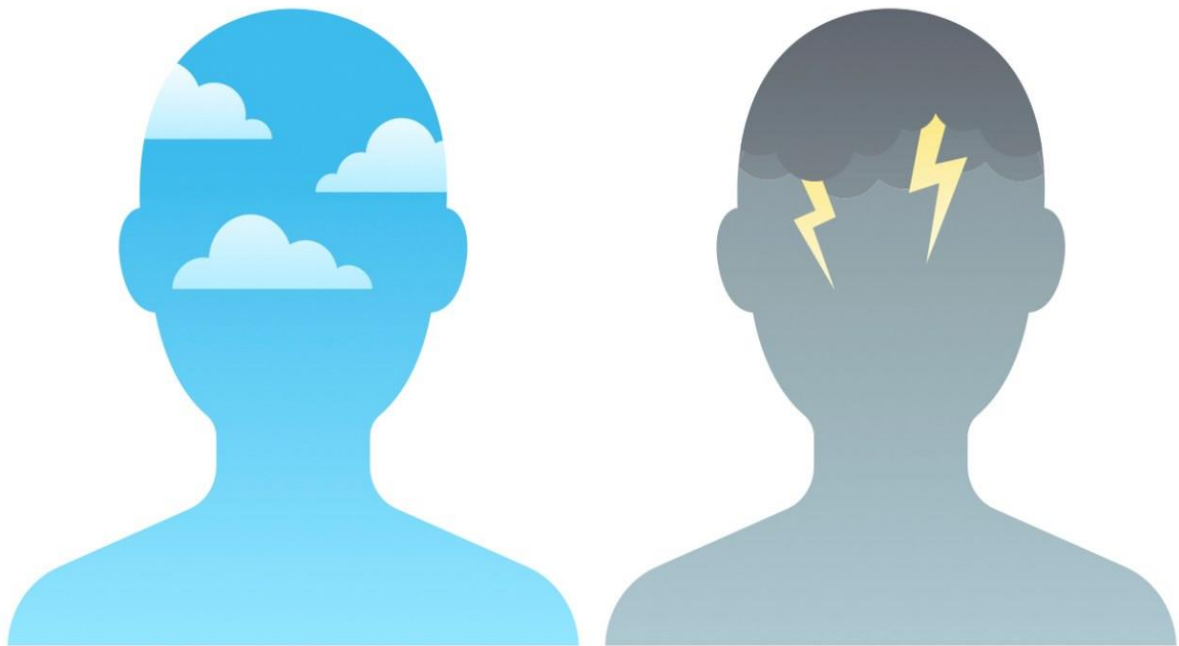
Over time these concepts have evolved and lead to further research into the role of place in health and wellbeing. In 2009 Nold mapped people's experiences as they walked through San Francisco city and then interpreted the data to show how people continuously interact with their environment. For example, highlighting where people felt most stimulated and where they felt most calm. Nold (2009) suggests that the data is rich with observations, he suggests it not only shows communal patterns, but also documents how each individual responds differently to the same environmental stimuli. He points out that some people's experiences were influenced by their memories, while others were influenced by the present moment (Nold, 2009).

Research acknowledges that spatial dynamics and public health are intrinsically linked. (Stadler et al., 2013). Notably, when considering built structures, it is not necessarily the modernity of a building that promotes service user wellbeing, it is the design of the setting that is paramount. The design that responds to the needs and supports the requirements of the service user will provide a better therapeutic and healing environment overall. It has been demonstrated that hospital environments are closely linked to patients' recovery. It is put forward in the literature that ergonomically designed hospitals greatly enhance the safety and well-being of patients and staff, this is achieved by carefully considering features such as lighting, ventilation, and the impact of noise. Researchers have discovered that some patients respond greatly to having a hospital room with a view, leading to shorter recovery times. The

colours of health care settings are also reported to have a bearing on patients and staff. Additional features that were proven to promote patient satisfaction included hospitals which were designed in a way that respected the person's privacy, provided spacious and aesthetically deigned rooms, supplied access to Wi-Fi and visitor friendly areas. It concludes that the physical environment is of the utmost importance in healthcare delivery and patient outcomes (Fadda, 2019). These findings reinforce the importance of carefully designing Acquired Brain Injury rehabilitation centres.

By considering the role of design, researchers emphasise the importance of consciously creating therapeutic settings. The positioning of windows, the choice of furniture shapes, lighting, the form and function of the space, and the types of textiles used, must all be carefully selected. Researchers emphasise the ways in which these elements can enhance the reassuring and comforting qualities of the therapeutic environment or in contrast, how they can be triggering. For example, textiles with a complex pattern may trigger disorientation (Chrysikou, 2014). It is said that therapy sessions are influenced by environmental factors inside and outside of the physical space, as well as by the participants and facilitators engaged in the session (McKinny and Honig, 2017). Some scholars suggest that there is a spectrality to spaces which can trigger past trauma if not carefully considered. It is acknowledged that the therapeutic environment can be supportive to the rehabilitative process, or it can be at odds against it. Notably, therapeutic settings can act as catalysts for change and encourage positive encounters with peers. However, if the sensory experiences of the setting are not carefully curated, the narrative of the rehabilitation space can become negatively charged and connected to sensory triggers (Liddicoat, 2019).

These findings highlight how crucial it is for Acquired Brain Injury rehabilitation settings to consider the sensory experiences of each person. Every person that attends ABI rehabilitation services have experienced a life altering injury and they have spent significant time in acute hospital care. It is paramount that the settings people are attending to rehabilitate post ABI are tailored in a trigger conscious manner and in tune with sensory needs.



2.5 Sensory Triggers

A central theme in the literature is that when a person with sensory overload enters a busy environment they are quickly bombarded, for example by encountering strangers, bright lighting, loud noises, new scents, and tactile information. Understandably this can cause the person to feel overwhelmed, stressed, and uncomfortable (Wood et al., 2019). The physical environments where therapies are delivered are intrinsically linked to rehabilitation outcomes (Fadda et al., 2019). As previously outlined, Acquired Brain Injuries can result in

permanent sensorimotor and cognitive disabilities including long-term sensory processing deficits (Alwis et al., 2012).

The ever-increasing number of people with an ABI unfortunately far exceeds the number of rehabilitative services available in Ireland. As a direct result, many ABI survivors reside in the community and too often they are inappropriately placed in nursing homes. Unfortunately, this situation is not unique to Ireland and the need for more rehabilitative services is only set to increase globally due to health demographic trends and ageing populations (Wren et al., 2017).



For people inappropriately placed in residential settings, there are currently many environmental factors that are outside of their control. They not only have to adapt to a space that may be at odds with their physical, cognitive, and social needs, they also have to continuously navigate a setting that is ill equipped to match their sensory needs. Therefore, for people with sensory overload in Ireland it is not just community settings that are

triggering, it is highly likely their home environment can also be triggering setting . This reinforces the need for every therapeutic setting to adapt to the sensory needs of the people it serves. Building awareness of sensory processing disabilities through research may serve as the first step towards change so that sensory informed settings become the norm as opposed to the exception.

2.6 Tailoring the rehabilitative environment to be sensory informed

Researchers emphasise how crucial it is for care providers to adapt their settings in a way that is sensory informed and reflects the diverse needs of the people it serves. By doing this, the therapeutic environment can become a safe place where the person can engage in rehabilitation effectively and the positive nature of the experience is increased (Wood et al., 2019). The term “*sensory informed*” has been described as a new way of thinking, highlighting that the relationship between a service provider and the service user must acknowledge and facilitate the person’s sensory needs. It is recognised that this requires advance preparation and open communication so that the unique sensory challenges each person faces can be understood and accommodated. In 2019 a research team, who were working in a busy emergency department, carried out a study. The primary goal of their study was to provide a sensory friendly environment for their patients. One of their main findings was the effectiveness of a sensory menu, a simple and highly effective strategy that allows each person to identify what environmental adaptations appropriately address their needs (IBID).

Therapeutic spaces have to respond to the varying, and often contrasting, needs of each person it serves (Chrysikou, 2014). Irish Acquired Brain Injury rehabilitation organisations will benefit from learning how service users perceive their rehabilitative spaces. By providing each

person with the opportunity to use a sensory menu, valuable insights can be discovered about the type of settings best suited to facilitating individual and group activities.

Evaluating the therapeutic environment in this new way will provide fresh opportunity for ABI service providers to examine how the personal and collective sensory needs of service users are currently catered for, and how they can be improved. Recent research on therapeutic landscapes reinforces the findings in Acquired Brain Injury studies that recognise the contrasting experiences of each person to the same environment, for example what may prove therapeutic for one person may be anxiety inducing to another (Meijering et al., 2017).

The literature emphasises how important it is to carefully consider design, aesthetics, acoustics, and amenities when building or renovating therapeutic settings. By introducing and employing a sensory menu into ABI rehabilitation, considering these key environmental factors could become routine instead of exceptional. It has been proven that when a person's sensory triggers and subsequent emotional responses are identified, their anxiety reduces, and they have greater freedom to explore and identify coping strategies (Collins and Miller 2012). Identifying each person's unique sensory preferences could play a pivotal role in creating a rehabilitative environment that is engineered to help the individual to thrive. From an accessibility point of view, creating a sensory menu could provide the individual with a record of what kind of community settings and amenities reduce their triggers and help them to relax, allowing for greater personal planning also.

[2.8 Chapter Conclusion](#)

For rehabilitation organisations in Ireland, examining the therapeutic environment through a sensory lens could provide valuable insights into the rehabilitative process. It offers an opportunity to pinpoint where service users feel most consistently comfortable, focused,

attentive, and what type of settings promote wellbeing. Critically it will also illuminate environmental factors that evoke negative responses. The evaluation process may also serve as a valuable and informative resource for professionals planning group content and when organising activities, individual keyworker sessions and community outings.

It is envisioned that this study will alleviate the burden on clients to endure environments that are incompatible to their needs. The overall aim is to explore sensory overload and its impact with the participants and to highlight how Acquired Brain Injury rehabilitative settings can be tailored to the sensory needs of each individual they serve. This study aims to provide a foundation for the use of sensory menus in rehabilitative settings in Ireland. Moreover, it is envisaged that the research findings will not only inform how sensory menus can be utilised in ABI rehabilitation but how they can be developed over time into sensory portfolios and incorporated into other rehabilitative environments to enhance service provision.

Examining and marrying the theories of therapeutic landscapes, careful trigger management and adopting the seed of the concept of a sensory menu, the current researcher set out to document the lived experiences of people with sensory overload post Acquired Brain Injury in Ireland. The researcher studied the rehabilitation environment as an evolving critical piece of the puzzle in the rehabilitative process. Instead of viewing the four walls as a definite and solid structure, the building can be regarded as a canvas for each person to explore and tailor to their own sensory palette. This approach diverges from the traditional bricks and mortar view and acknowledges the aforementioned bodies of research that conclude that sensory experiences are an intrinsic part of the rehabilitative environment.

By creating and incorporating a sensory menu into social care services the rehabilitation setting becomes a malleable therapeutic resource that is tailored to each individual it serves.

This study is the first of its kind in Ireland and has the potential to lead the way for further research into sensory menus, portfolios, and their unique rehabilitative applications.

Chapter 3 Research Methodology

3.0 Introduction

This chapter will provide an overview of the data collection methods used in the research study and the rationale behind each one. The researcher's decision to adopt a qualitative approach is explained, tables are used to outline the questions asked during the semi structured interviews and the rationale and inspiration of each. The chapter is concluded by addressing the ethical considerations of the study.

3.1 Overview of Data Collection Methods

Once the literature review was explored and completed it was decided the study would use four instruments of data collection. The researcher conducted two pilot studies, one with a service user and one with a professional working in the ABI sector. Semi structured interviews formed the central part of the research, eleven semi structured interviews with ten participants were carried out. The interviews were carried out with four service users and six professionals working in the ABI sector. A sensory menu was created and introduced as a rehabilitative tool to highlight service users' sensory needs and preferences (please see appendix 1). An observation journal was used to document the researchers experiences and observations throughout the study.

3.2 Rationale for Data Collection Methods

3.2.1 Method 1. Pilot Studies

Two pilot studies were carried out, one with a person who has experienced sensory overload following an Acquired Brain Injury and one with a professional working in the ABI rehabilitation sector. The purpose of these pilots was three-fold.

- To ensure the consent and information forms were explanatory and helpful.
- To confirm the interview questions were easy to follow and welcomed discussion.
- To gather feedback on the sensory menu and ensure it was user friendly.

3.2.2 Method 2. Semi Structured Interviews

Semi structured interviews were used as the main form of data collection. The researcher chose semi-structured interviews for the flexibility and adaptability they provide to the data collection process. Semi structured interviews allowed for fluid conversations and the interviewer was free to delve into any unpredicted topics as they arose. Semi structured interviews are considered a good way to generate discussion and to capture data on participants' experiences and the meanings they give to them, which is particularly important when researching an under-researched area (Wethington and McDarby, 2015). The interviews were purposefully comprised of open-ended questions to capture the first-hand experiences, encourage detailed answers and to allow for opinions to be freely expressed and suggestions to be explored.

In light of Covid-19, the researcher and her supervisor thought it worthwhile to capture and reflect the impact the pandemic is having on ABI rehabilitation services in Ireland. The

researcher created an additional interview and recruited a participant to discuss their experiences of accessing ABI rehabilitation services during the Covid-19 pandemic. The researcher also added additional questions to the original interview for professionals working in the ABI sector to reflect their experiences of working throughout the Covid-19 pandemic.

[3.2.3 Method 3. Sensory Menu \(please see Appendix 1\)](#)

The interviews included an introduction to a sensory menu. The menu was created in a simple format and included visual aids. Communication difficulties that interfere with speech and language such as aphasia are very common post Acquired Brain Injury (Kirshner and Wilson, 2021) so this menu was purposefully created in a service user friendly format. The researcher gathered the participants feedback on the concept of sensory menus and how sensory menus could potentially be incorporated into the rehabilitation environment. The aim of this menu was to gain insight into how ABI rehabilitative spaces can be tailored to the individual sensory needs of the people it serves. As the statistics suggest, there is a present and ever increasing need to cater for this target group in rehabilitation settings.

The sensory menu received praise from all participants. This feedback shows the enthusiasm from ABI rehabilitation service users and professionals working in the ABI rehabilitation sector for tools that address sensory challenges in the rehabilitation environment. The researcher believes that a sensory menu could be created for each existing service user and over time this could lay the foundation for sensory portfolios in rehabilitation settings. A sensory portfolio would recognise the evolving nature of sensory overload as each person gradually identifies their triggers and what soothes them. The portfolio could be built up over time and expanded to incorporate digital and physical maps identifying sensory informed settings in the person's community and further afield.

Over time this could aid a person's integration back into social settings or the employment sector. It could have the added advantage of building more sensory informed settings and increasing public awareness about sensory overload.

As a direct result of increasing awareness about sensory overload in the autism spectrum society Irish retailers responded and launched sensory friendly shopping evenings. These evenings prioritise the opportunity for customers to shop without music, harsh lighting, or loud announcements, they ensure ease of accessibility at checkouts and reduced queuing times (Checkout, 2018). Sensory friendly shopping is a relatively new phenomenon, it was trialled in Ireland for the first time by Scally's Supervalu Clonakilty in 2015 (Ring, 2017).

There is an equal and arguably greater need for rehabilitation centres to incorporate these sensory considerations into therapeutic environments so that service users' needs are addressed, and sensory impairments form part of the rehabilitative framework. Introducing a sensory menu into ABI rehabilitation is a step in the right direction for prioritising sensory needs in therapeutic settings.

[3.2.4 Method 4 Observation Journal](#)

The researcher anticipated that she would learn a lot about sensory overload and Acquired Brain Injury during the course of the study. In order to document these teachings, the researcher opted to use an observation journal. The journal proved to be invaluable, the researcher could reflect on what she was learning over time. Observations and ideas, that may have been otherwise been lost in unconscious thought, were documented.

3.3 Data Analysis

The methods of data collection and analysis were designed to directly reflect the information the participants so generously shared and to communicate their self-reported personal experiences. The interviews were audio-recorded and transcribed verbatim. Using thematic analysis, the interviews were carefully examined and explored to lay out the participants personal accounts of living with sensory overload and navigating their lives post Acquired Brain Injury. Thematic analysis identifies and analyses themes in qualitative data. It is used to highlight patterns in the data and it is a useful tool when the researcher seeks to explore and understand the life experiences of participants and their perspectives (Clarke and Braun, 2014).

3.3.1 Qualitative Research

A qualitative approach was adopted throughout the study. The key aspect of qualitative research is that it explores the lived experiences of participants, which mirrored the aim of the present study. When conducting qualitative research new information, that hasn't been examined in previous studies, can come to the forefront during the data collection process. This qualitative approach contrasts with the quantitative method in which a set group of factors are identified prior to data collection and findings seek to measure the prevalence and strength of each factor. Qualitative researchers focus on exploring participants' life experiences and lived encounters and the meaning connected to them (Merriam and Grenier, 2019).

3.3.2 Constructivist Paradigm

The methodology of this study aligns with the constructivist paradigm. The constructivist perspective is rooted in the qualitative approach to research (Merriam and Grenier, 2019). This study supports the constructivist paradigm by asking clients to describe and reflect on how sensory overload impacts on their daily lives. It also offers the opportunity to explore new experiences by examining the therapeutic landscape and reflecting on how it can be adapted to suit a range of sensory needs. By employing qualitative methods, participants had the opportunity to ask questions, individual experiences could be discussed, and participants could be supported throughout all stages of the study.

3.3.4 Ontology

Ontology prompts the researcher to examine what constitutes reality. When research is undertaken it needs to be grounded in a viewpoint in relation to what is real. Researchers hypothesise that reality is constructed and open to interpretation (Denzin, 2005). The present research study aims to explore the lived realities of the participants. The personal experiences of the participants are essential to this study and their world views are critical to the research findings. The ontology of this paradigm acknowledges that the participants may have varied lived realities based on their personal experiences of sensory overload post Acquired Brain Injury.

3.3.5 Epistemology

Epistemology, when broken down into its Greek origin, is compiled of two words, knowledge and to understand. Epistemology essentially prompts researchers to study the concept of knowledge, to consider the theory and nature of understanding. Epistemological assumptions

are concerned with how knowledge can be created, acquired, and communicated, in other words what it means to know (Cohen et al., 2007).

3.4 Ethical Considerations

Ethical considerations are defined as “the standards of behaviour that guide conduct in relation to the rights of those who become the subject of your work or are affected by it” (Saunders et al., 2019). This study was approved by two ethical boards, Munster Institute of Technology (MTU) and Headway, an Acquired Brain Injury Specialist Rehabilitation organisation in Ireland.

3.4.1 Informed Consent (please see appendices 2 and 3)

3.4.1.1 Informed Consent with Service Users

All participants were asked to take part on a voluntary basis. The researcher carefully verbally explained her background, the purpose of the study and what taking part in the study would involve. This was explained in an information sheet also (please see appendix 2). The participants were informed that they could withdraw from the study at any time, and this would not affect their ABI rehabilitation service in any way. The researcher explained that the study would be organised to suit the days and times the participants attend their rehabilitation service, as routine and structure are often significant pillars for clients following an Acquired Brain Injury. The researcher informed all participants that all names and identifying features would be kept confidential, the data collected would be kept safe and secure in

accordance with the Data Protection Act 2018 and the data would be destroyed after five years. The researcher explained the criteria for taking part in the study and informed the participants that ethical approval was granted for the study from two ethical boards, MTU and Headway Ireland. The researcher explained that the results of the study would be presented to the participants upon completion. Consent was obtained from all participants prior to participation.

3.4.1.2 Informed Consent with Professionals working in the ABI sector

All participants were asked to take part on a voluntary basis. The researcher carefully verbally explained the purpose of the study and what taking part in the study would involve. This was explained in an information sheet also (please see appendix 2). The participants were informed that they could withdraw from the study at any time. The researcher informed all participants that all names and identifying features would be kept confidential, the data collected would be kept safe and secure in accordance with the Data Protection Act 2018 and the data would be destroyed after five years. The researcher explained the criteria for taking part in the study and informed the participants that ethical approval was granted for the study from two ethical boards, MTU and Headway Ireland. The researcher explained that the results of the study would be presented to the participants upon completion. Consent was obtained from all participants prior to participation.

3.4.2 Do No Harm

The rights and dignity of the participants was respected and treated with paramount importance throughout the research process. The researcher balanced the potential

benefits of this study against the potential risks and treated the safeguarding and protection of participants with the utmost importance. The researcher carefully considered the emotional responses that participating in this study may trigger for each person. The researcher allowed plenty of time for each stage of the study in case any emotional responses arose. The researcher supported the participants throughout the study, extended an invite to each participant to bring a family member or friend with them and offered to link participants with their service keyworker if desired.

3.4.3 Power Dynamics

The service user participants potential vulnerability and the professional/service user work relationship was carefully considered throughout this study. All participants were informed, prior to taking part, that they could withdraw from the study at any time without any repercussions. All participants were given the option to have their keyworker, family member or any other person of their choosing present with them throughout the research study. The researcher consulted her colleagues in the Acquired Brain Injury sector to recruit service user participants who she has not previously worked with as much as possible.

3.4.4 Insider Researcher

The researcher has been working in the ABI rehabilitation service since 2008. This provided the researcher with unique understanding of the sample group and the topic being studied. However, the researcher was aware that professional background and experience may also cause bias and a lack of objectivity. These factors and the potential pros and cons of each were carefully considered and balanced throughout the study. The researcher aimed to

interview service users she had never worked with before and complete the study with professionals from different departments of the Acquired Brain Injury rehabilitation organisation to strengthen the objectivity of the study and to minimise researcher bias.

3.4.5 Confidentiality

The researcher informed all participants that all names and identifying features would be kept confidential. The data collected will be kept safe and secure in accordance with the Data Protection Act 2018. All data collected will be destroyed five years after its collection.



3.5 Participants

3.5.1 Purposive Sampling

Due to the undocumented nature of sensory overload post Acquired Brain Injury the researcher opted for a non-probability purposive sampling method for all participants. The researcher consulted her colleagues in the Acquired Brain Injury rehabilitation sector to identify a sample of potential service user participants for the study.

A team of psychologists purposefully established a group of ABI rehabilitation service users who have been diagnosed with sensory overload and who commonly report the significant impact it is having on their lives. The psychology team offered to inform the service users that a research study about sensory overload would be taking place and offer to put them in touch with the researcher if they wished to take part. The service user participants represented a homogenous sample. This approach allowed the complexities of each service users personal experiences to be explored and the nuanced nature of sensory overload to be captured.

Due to the Covid 19 pandemic the researcher decided to invite participants to share their experiences of the pandemic and how ABI rehabilitation services were impacted. The researcher employed non probability purposive sampling for this part of the study too . The

researcher once again consulted her colleagues working in the ABI rehabilitation sector. A staff member working in the vocational department identified a service user who was accessing Acquired Brain Injury rehabilitation services five days a week prior to the Covid-19 pandemic who expressed interest in taking part.

The professionals working in the ABI rehabilitation sector participants were recruited using a purposive sampling method also. The researcher informed each department that she was undertaking a research study and invited anyone interested in taking part to contact her.

3.5.2 ABI rehabilitation service users

Three participants with sensory overload took part in the study. Originally six people accepted the invitation to be involved but two people unfortunately could not participate due to health problems and one person was unable to attend to the task of the pilot. One additional participant took part to shed light on how the Covid-19 pandemic impacted on ABI rehabilitation services which brought the service user participants to four.

Two men and two women participated in the research study, all participants were Irish, they ranged in age from 35-72 years old and they had their Acquired Brain Injury between 4-16 years ago.

Table.1 Background Information on Participants (Service Users)

Name	Age	Gender	Cause of ABI
Liam*	73	Male	Stroke
Tom*	45	Male	Farm Accident
Rose*	42	Female	Fall
Joan*	35	Female	Road Traffic Accident

* Pseudonyms have been used throughout the study to respect confidentiality

3.5.3 Professionals working in the ABI sector

Six professionals working in the ABI sector took part in the study. The participants were working across a range of departments in the ABI sector. All professionals who participated were Irish, they ranged in age from 25-44years, they were all female which is a common representation of the social care sector workforce and the participants have been working in the ABI sector for between 3-12years.

Table 2 Background Information on Participants (Professionals working in the ABI sector)

Name	Age	Gender	Years working in the ABI sector
Sinead*	40	Female	3 Years
Lucy*	25	Female	4 years
Fiona*	37	Female	4 years
Ellie*	33	Female	5 years
Ciara*	35	Female	9 years
Sarah*	44	Female	12 years

*Pseudonyms have been used throughout the study to respect confidentiality

3.6 Pilot Studies

Three pilot studies were carried out, two with service users and one with a professional working in the ABI sector. The purpose of these pilots was three-fold.

- To ensure the consent and information forms were explanatory and helpful.
- To confirm the interview questions were easy to follow and welcomed discussion.
- To establish if the sensory menu was user friendly.

In November 2019, the researcher consulted her colleagues in the ABI sector to establish a group of service users and professionals who matched the study criteria and may be interested in participating in the pilot study . The researcher Initially chose one client and one professional using random selection from the suggested purposefully sampled list and invited them to take part.

3.6.1 First Pilot (Service User)

The first pilot with a service user was attempted but not completed. Anne (53) has been attending ABI rehabilitation services for ten years, she had her ABI in 2008. The researcher invited Anne (53) to participate in the pilot and she accepted and expressed that she would be happy to take part.

In December 2019, the researcher and Anne (53) met to carry out the pilot study. Anne (53) appeared in great spirits and after an engaging chat about Anne's personal news and general conversation topics the researcher suggested they talk about the study and get started on the pilot. Anne (53) expressed how happy she was to contribute to the study and how much she values the importance of research having previously worked in academia. However, when the researcher tried to introduce the first stages of the pilot Anne (53) became distracted and

started to discuss non-related topics. It is very common for people to experience difficulty with selective attention following an ABI and service users can often report feeling compelled to communicate their thoughts, no matter how unrelated they are to the current topic of discussion. In the researchers experience it can be helpful to give the person the freedom to share their thoughts and then direct them back to the initial topic of discussion. The researcher tried doing this five times, but each time Anne (53) became distracted by her own thoughts and was unable to focus on the study. The researcher decided to discontinue the pilot study and just let Anne (53) chat. When it was time for the scheduled break the researcher thanked Anne (53) for attending the meeting. Anne (53) noted that she “took over” the meeting and stated that she “didn’t help”. The researcher assured Anne (53) that she helped very much just by volunteering to take part. The researcher explained that when completing a study everything is a valuable lesson that shapes the next part of the study and helps the researcher to adapt and strengthen the format. Anne (53) seemed reassured by this explanation. Due to scheduling conflicts the researcher decided against trialling the pilot with Anne (53) again.

3.6.2 Second Pilot (Service User)

The researcher used the lessons learned from the unsuccessful first pilot to inform how she set up the second pilot. Once again using random selection from the purposefully sampled list the researcher invited a service user from the list of potential participants who matched the study criteria. The service user, Liam (72), was sent an information sheet (please see appendix 2) and he accepted the invitation to participate. The researcher and Liam (72) met in January 2020 in the ABI rehabilitation centre. Taking the lessons learned from the previous pilot into account, the researcher structured the pilot meeting a little differently. The

researcher decided to meet Liam (72) in the kitchen for a chat and a cup of tea first, and then move into a mixed purpose activity room for the pilot. This approach seemed to work well, and Liam (72) responded to the cues each space provided. By dividing the meeting into two parts, the researcher informally created a social and a work zone. The kitchen provided a relaxed space where Liam (72) and the researcher could get acquainted and chat about general topics. The activity room provided a cue that the pilot was about to begin. This change in setting seemed to benefit concentration and gave Liam (72) an opportunity to shift his focus from social discussion topics to the task at hand.

The researcher went back over the information sheet with Liam (72) and reiterated the purpose of the study. Liam 72 gave positive feedback on the consent forms and information sheets noting that they were straight forward. Liam (72) had expressed interest in completing the interview when he was invited to be part of the pilot. Liam (72) asked if he should share his own experiences as we read through the interview questions and the researcher explained it would be very helpful if Liam (72) would like to do that. As Liam (72) spoke he explained his personal challenges with sensory overload and the strategies he employs to alleviate his symptoms. Interestingly, Liam (72) has been adapting to his symptoms for years and in the absence of any guide on how to alleviate his symptoms of sensory overload he has had to develop his own coping mechanisms. For example, Liam (72) always wears a cap, which to the casual observer may seem like a common wardrobe choice of his generation but as Liam (72) explained, he experiences sensory overload from light sensitivity and the cap shields his eyes. It was educating to talk to Liam (72) and to learn how sensory overload impacts his daily life. Liam (72) really connected with the sensory menu and spoke of how helpful it would be if his rehabilitative space could be tailored to his needs and personal preferences.

3.6.3 Pilot (Professional working in the ABI sector)

Ellie (33) is a rehabilitative trainer who has been working in the ABI sector for five years. She gave positive feedback on the consent forms and information sheets, she suggested small layout changes which were taken on board. Ellie (33) was enthusiastic about the interview questions as she noted they promoted good discussion. The sensory menu was well received, and Ellie (33) noted that having a space at the end of the menu to give participants the opportunity to further tailor the menu to their personal sensory requirements was a particularly good idea.

3.6.4 Summary of Pilot Studies

By conducting the pilot with Liam (72) (service user) and Ellie (33) (professional working in the ABI rehabilitation sector) the aims of the pilot were achieved.

3.7 Semi Structured Interviews

Semi structured interviews were used as the main form of data collection to explore the effects of sensory overload post ABI and how the participants are navigating it on a daily basis. Semi-structured interviews were used for flexibility and adaptability. They allow for fluid conversations and the interviewer can delve into topics that may not have been predicted as they arise. Given these features of the semi structured interview, they are considered a good way to generate discussion and to capture data on participants' experiences and the meanings they give to them, which is particularly important when researching an under-researched area.

The researcher carried out eleven interviews with ten participants, this consisted of two male and eight female participants. The participants were selected by purposive sample in

order to capture the first hand experiences of service users and the professional opinions of people working in the ABI rehabilitation sector. The participants were attending and working in different areas of the ABI rehabilitation sector in order to gain a range of opinions.

The interviews were purposefully comprised of open-ended questions to capture the first-hand experiences, encourage detailed answers and to allow for opinions and suggestions. The views of participants will be presented with raw data using the participants quotations verbatim to support the research findings.

3.7.1 Preparation for Semi Structured Interviews with service users

The researcher sent out the consent and information pack (please see appendices 2 and 3) to four people attending ABI rehabilitation services who expressed interest in taking part in the main study. The researcher followed this up with a phone call to each prospective participant. Unfortunately, two people had to withdraw from taking part at this stage due to health problems.

The researcher carefully planned the interviews with service user participants. Due to Tom's (45) (service user) fatigue, caused by his sensory overload, the interview was rescheduled twice. Due to Rose's (42) (service user) memory difficulties, caused by her Acquired Brain Injury, the interview was rescheduled once. This was invaluable learning in itself and clearly demonstrates the number of strategies and amount of prior planning service users must employ in their daily lives due to symptoms of Acquired Brain Injury.

To capture the impact of the Covid-19 pandemic on service users two additional interviews were conducted. One socially distanced interview took place, and one interview took place virtually.

3.7.2 Preparation for Interviews with Professionals Working in the ABI Sector

Six professionals working in the ABI sector volunteered to take part in the main study. Due to this stage of the study coinciding with a peak in the Covid-19 pandemic it was decided between the participants and the researcher that all meetings would be held virtually.

3.7.3 Semi Structured Interviews with Service Users

The researcher carried out four semi structured interviews which formed the central part of the study, three initially with people experiencing sensory overload. Additionally, two interviews were carried out to capture the impact of the Covid-19 pandemic on service users, one participant had taken part in the main study and expressed interest in contributing and one additional participant agreed to take part.

For the interviews with participants experiencing sensory overload post Acquired Brain Injury an 18-item interview was employed. This consisted of an opening question about how the service user acquired their injury, followed by two questions about the sensory changes the client experienced as a result. The 15 remaining questions centred around therapeutic setting itself and capturing how each service user experienced the space, how it could be improved to be more sensory informed and what elements make each person's own individual favourite places relaxing and therapeutic. The interviews questions generated good discussion, each conversation was free to be explored and personal experiences were discussed.

Table 3. Interview Questions, Rationale, and Inspiration (Service Users)

Interview Question	Rationale	Inspiration
Can you please tell me a little bit about how you got your brain injury?	Introductory question to gather background information	Get the conversation started so researcher and participant have an opportunity to ease into the interview
How does sensory overload impact on your daily life?	The researcher asked this question to capture the first-hand experiences of each person.	A central theme in the literature is that when a person with sensory overload enters a busy environment they are quickly bombarded, for example by encountering strangers, bright lighting, loud noises, new scents, and tactile information (Wood et al., 2019).
Is there any noise/activity/place that make your symptoms worse or “trigger” your symptoms?	Establishing personal triggers	Recent research on therapeutic landscapes reinforces the findings in ABI studies that recognise the contrasting experiences of each person to the same environment, what may prove therapeutic for one person may be anxiety inducing to another (Meijering et al., 2017).
Are there environments or places that make you anxious or uncomfortable?		

Do you have any strategies that you use to ease the effects of sensory overload?	Learn about clients coping strategies and how they are navigating sensory overload in their daily lives	A 2012 study highlighted the process of people experiencing sensory overload, having to source information for themselves in order to understand what they were experiencing (Landon et al., 2012)
What kind of environments or places help you to relax/make you feel peaceful? What is it about these spaces that make them peaceful/relaxing?	Explore the properties of service users' favourite places to learn how the rehabilitative environment could replicate the soothing elements of service users' relaxing spaces	Each individuals' sensitivity and responsivity are different, even to the same environmental encounters and conditions (Pluess, 2015).
Can you please describe your favourite places?		
What do you like about this space?	Provide each participant the opportunity to share their personal opinions on the existing ABI rehabilitation environment	Treating each client as the expert in their own sensory needs and asking each person to mentor staff and designers (the mentor-model approach proposed by Bennett et al 2014).
Is there anything you dislike about this space?		
How could this space be improved?		
If you could add one thing to this space, what would it be?		
If you were to take something out of this room, what would it be?		

What does this space feel like, sound like, look like to you?		
Do you think a sensory room would be beneficial?	Gathering information to support sensory informed spaces in ABI rehabilitation	
Thinking about everything we have discussed, how could ABI rehabilitation settings become more sensory informed space?	Give service users the opportunity to share their opinions and capture any further information the interview questions may not have addressed.	The most up to date research concludes that ABI rehabilitation needs to adapt and be tailored for each individual in order to respond to clients evolving needs and wants (Wells, 2018).

3.7.3 Semi Structured Interviews with Professionals working in the ABI sector

The researcher carried out six interviews with professionals working in the ABI sector. For these interviews, a 17-item interview was employed. These interviews were very free flowing and so the researcher learned as she went along that the interview questions worked best as a loose guide rather than a structured sequential format.

Table 4 Interview Questions, Rationale, and Inspiration

(Professionals working in the ABI sector)

Interview Question	Rationale	Inspiration
How long have you been working in the ABI sector?	Introductory question to gather background information	Get the conversation started so researcher and participant have an opportunity to ease into the interview

<p>This study is exploring service users' first-hand experiences of sensory overload. In your experience and observations what are the kind of sensory challenges that can present for clients?</p>	<p>Capture each professionals' personal observations and experiences.</p>	<p>Each individuals' sensitivity and responsiveness are different (Pluess, 2015).</p>
<p>In your experience what are the kind of environmental barriers that cause difficulty for clients in the building and in the community?</p>		<p>Each individual responds differently to the same environmental stimuli (Nold, 2009)</p>
<p>As part of my research, I have developed a sensory menu which clients can use to indicate how they would like their rehab environment set up prior to a meeting/ session. Do you think this would be useful and is there anything you would add or change about it?</p>	<p>Gather feedback on sensory menu</p>	<p>Researchers emphasise how crucial it is for care providers to adapt their settings in a way that is sensory informed and reflects the diverse needs of the people it serves. By doing this, the therapeutic environment can become a safe place where the person can engage in rehabilitation effectively and the positive nature of the experience is increased (Wood et al., 2019).</p>

<p>During my interviews with service users, they spoke about the various ways their ABI and sensory overload has changed their lives, for example their professions, their hobbies, their roles in the family unit. Having an ABI seems to have impacted on their overall sense of identity, have you experienced this through your work?</p>	<p>Follow up on data gathered during the service users' interviews</p>	<p>As a result of Acquired Brain Injury (ABI), a person's identity can quickly become fragmented and loss of identity is commonly reported (Walsh et al., 2015).</p>
<p>Sensory overload appears to be isolating for some service users as they experience the rehabilitative environment differently to others and some of their triggers can be quite individualised. Have you ever observed clients getting isolated due to their sensory needs?</p>		<p>Participation restriction due to cognitive and/or physical impairment is a common barrier. The injury can lead to intense changes in peoples' lives, it can completely disrupt previous habits and routines. Regaining or developing valued roles and adapting to a new self has been described as an ongoing struggle, and a common consequence is to experience uncertainty in everyday life (Olofosson et al., 2018).</p>

<p>The big question of the moment, how has it been working through the Covid-19 pandemic?</p>	<p>Gather professionals first hand experiences of working through the Covid-19 pandemic.</p>	<p>Unique opportunity to gather information on what it has been like to work in the ABI rehabilitation sector in Ireland during the Covid-19 pandemic</p>
<p>The pandemic has thrown up lots of challenges for people across the globe, professionally and personally. If you don't mind me asking what you have found challenging in the Covid-19 era?</p>		
<p>In your experience how has the Covid-19 pandemic impacted on ABI rehabilitation services?</p>		
<p>When providing a face-to-face service how has the necessity for PPE and safety protocols impacted on the service users?</p>		
<p>In your opinion how can the rehabilitative environment be designed to cater for clients who experience sensory challenges in the Covid-19 era?</p>		
<p>Are there any key strategies to alleviate sensory</p>		

challenges that you have observed working for clients pre and post Covid-19?

The support of a peer group is often pinpointed by clients as a key part of their rehabilitation, in your view how has Covid-19 impacted on peer group support?

Tailoring the rehabilitative environment to each client as much as possible seems to one way to alleviate sensory overload, do you find it easier or harder to tailor the rehabilitative environment post Covid-19?

Finally, in a strangely interesting way it seems possible that how services are provided in the Covid-19 era might benefit clients who experience sensory overload. For example, they can access sessions online from the comfort of their own home instead of travelling to environments that may be triggering for them. What do you think? Does this new way of

delivering services help or hinder clients in your opinion?	
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3.7.4 Interviews with service users about how the Covid-19 pandemic has impacted their rehabilitation services

The researcher developed a 16-item interview to explore the impact the Covid-19 pandemic has had on ABI rehabilitation services in Ireland. Similarly, to the other interviews the semi structured nature worked well as each person's personal experiences could be discussed. The questions, rationale and inspiration for these interviews all revolved around the same goal, to capture service users' experiences of Acquired Brain Injury rehabilitation services in Ireland pre and post the Covid-19 pandemic.

3.8 Sensory Menu

The interviews included an introduction to a sensory menu (Please see Appendix 1). The researcher gathered the participants feedback on the concept and how sensory menus could be incorporated into the Acquired Brain Injury rehabilitation environment. The aim of this menu was to gain insight into how ABI rehabilitative spaces can be tailored to the individual sensory needs of the people it serves. As the statistics suggest, there is a present and ever increasing need to cater for this target group in rehabilitation settings.

The sensory menu received praise from all participants. This feedback shows the enthusiasm from Acquired Brain Injury rehabilitation service users and professionals working in the ABI rehabilitation sector for tools that address sensory challenges in the rehabilitation environment. The researcher believes that a sensory menu could be created for each existing

service user and over time this could lay the foundation for sensory portfolios in rehabilitation settings. A sensory portfolio would recognise the ever-evolving nature of sensory overload, as each person gradually identifies their triggers and what soothes them. The portfolio could be built up over years and encourage the use of maps of sensory informed settings in the person's community and further afield. Over time this could aid with the persons integration back into social settings or the employment sector and could have the added advantage of building more sensory informed settings and increasing public awareness about sensory overload.

As a direct result of growing awareness about sensory overload in the autism spectrum society Irish retailers have responded and launched sensory shopping evenings. These evenings place importance on providing consumers with the opportunity to shop in stores with no music, dimmed lighting, additional accessibility at checkouts, reduced queuing, and no instore announcements (Checkout, 2018). Sensory shopping evenings are a relatively new phenomenon and have only been launched in Ireland in recent years with the first trial taking place in a Supervalu in Clonakilty in 2015 (Ring, 2015). There is an equal and arguably greater need for rehabilitation centres to incorporate these sensory considerations into therapeutic environments so that service users' needs are addressed and form part of the rehabilitative framework.

[3.9. Observation Journal](#)

The researcher noted her observations throughout the study and formulated them into a journal to learn from them along the way. Sensory overload is far more nuanced than I could have ever prepared for. While I shared the space with the service users, I learned a lot and began to tune into the global aspect of noises I routinely and subconsciously tune out.

Three central themes emerged from this method of data collection.

Observation Journal Theme 1. Simply having senses does not make a person sensory informed and creating a sensory informed space requires careful consideration, input from people experiencing sensory overload is critically important. The people experiencing sensory overload post ABI are the experts on this condition and spaces need to be designed for people with sensory overload by people with sensory overload. Rehabilitation settings need to be adaptable so that at their core they are a neutral canvas that can be tailored to the needs of the people they serve.

Observation Journal Theme 2. When tuned into the sensory charged world of the participants the enormous daily challenges they face were illuminated. The participants highlighted how difficult sensory overload is to describe in a way people without it can understand. Educating ABI rehabilitation professionals and family/friends of ABI survivors may be one way to strengthen community appreciation of the enormous challenges people with sensory overload navigate daily.

Observation Journal Theme 3. The participants were incredibly generous with their time and knowledge. Learning about each person's lived experiences in depth can deepen one's understanding of sensory overload. The experiences the participants shared could prove invaluable to other people at the start of their ABI rehabilitation journey and help them identify sensory overload symptoms. Furthermore, proven strategies to alleviate the symptoms of sensory overload could be shared.

[3.10 Chapter Conclusion](#)

This chapter detailed the methodology of the research study. It began by providing an overview of the qualitative data collection methods and the rationale behind each one. The constructivist paradigm, the ontology and epistemology of the research were addressed, and the ethical considerations of the study were explained. The researcher focused on the research participants and the use of purposive sampling. The main data collection method, semi structured interviews, were explained and the rationale and inspiration of each interview question was provided. The researcher explained the additional interviews that were carried out to capture how the Covid-19 pandemic has impacted on ABI rehabilitation services. The sensory menu, the tool the researcher is putting forward as a new tool to reflect the sensory needs of ABI rehabilitation service users was explained and the main themes of the researcher's observation journal were summarised. The next chapter will lay out the research results and discussion.



Chapter 4 Results and Discussion

4.0. Introduction

This study explored the complex challenges sensory overload causes for people following an Acquired Brain Injury.

Three robust themes emerged:

- Life Altering Consequences and Loss
- Sensory Overload Triggers
- The Importance of Sensory Informed Education & the Rehabilitation Environment

Each theme will be discussed as a chapter in the next section.

4.1 Life Altering Consequences and Loss

Acquired Brain Injury can result in a wide range of physical, cognitive, and sensorial disabilities which can have a devastating impact on the individual and their family. For many, sustaining an Acquired Brain Injury means facing a very different life course to the one they had been living, and planned to live pre injury (Muldoon et al., 2017). The debilitating effects of sensory overload can create enormous and complex physical challenges for the person. This is in addition to the emotional distress sensory overload can cause for the individual and their family/social unit. The result is substantial social and environmental challenges in the home and in the community (Tavassoli et al., 2019).

“I still don’t want to be brain injured; I still fight with that” (Tom, 45) (Service User).

The researcher discovered through the interview process that sensory overload post Acquired Brain Injury is having a profound impact on the participants lives. It has changed the way they work or taken away their employment altogether. It has impacted on each person’s independence by making them reliant on others and it has changed their roles in their family units.

“Young children make a lot of noise, so they are really struggling with being in that space so it’s impacting their ability to parent but also their perceptions of themselves as a loving father as well, so it’s above and beyond you know kind of making sure the room is ok, sometimes people don’t even understand the impact on their actual functioning and their relationships”.

(Sarah, 44) (Professional Working in the Acquired Brain Injury Rehabilitation Sector)

Sensory overload has impacted each person's social identity also, participants reported no longer engaging in sports and other pastimes, as the effects of sensory overload are too great. Service users explained that life with sensory overload requires constant methodical management and careful planning.

“You don't go to the pub, you manage your energy very well, I don't drink, very careful what environments you go into, you don't go into crowds, careful what matches I go to, don't go out late, if you do go out late make sure you manage your next day very well”

(Tom, 45) (Service User).

Sensory Overload prevented all participants from carrying on their professional roles in the same capacity. The participants all reported being very passionate ambitious professionals who worked hard and took great pride in their respective professions. Each person reported enjoying their professions pre injury and a large part of their identity seemed connected to their livelihoods. For Liam (72) (service user), a previously fiercely independent man, he lost his independence when he could no longer work. Liam (72) (service user) had worked very hard to succeed in his chosen profession, he had enjoyed working throughout his life and his profession seemed previously stitched into his core identity.

Tom (45) (service user) and Rose (42) (service user) reported their sense of chaos when they were unable to return to their previous professions and carry out life roles in the same capacity following their injuries. By losing their ability to work, either altogether or to the same level as they used to, the participants seemed to lose a piece of themselves.

“I've scaled back unfortunately in my lifestyle, I would have been a very go getter type of person, always on the go, you know from the minute you wake up in the morning until you go to bed in the evening” (Rose, 42) (Service User).

All participants spoke about the necessity of lifestyle restrictions and the cruciality of fatigue management due to sensory overload. Tom (45) (service user) spoke in detail about running his family business and how sensory overload has impacted on his ability to do his work. Tom (45) (service user) explained that elements of his job which were routine prior to his injury, such as using a measuring tape, now cause him to become exhausted.

“Following the tape with your eyes, that would wipe me out” (Tom, 45) (Service User).

Furthermore Tom (45) (service user) detailed the impact sensory overload had on the professional relationships he has with his customers. He explained that making a mistake once, for example saying the wrong thing while making a sale, can be easily overlooked. However, a pattern of mistakes during a sale is damaging because you lose the customers trust and confidence.

“It becomes a question mark about the whole thing rather than just an end product. There just becomes question marks about is he able to deliver? Do they have confidence in my ability to deliver a service?” (Tom, 45) (Service User).

Following his injury, Tom (45) (service user) felt like he needed to take a step back from working directly with customers. Tom (45) (service user) noticed that his sensory challenges and the severe fatigue they caused, was impacting how customers viewed him and his family business.

“I would begin to sound drunk so slurring my words, couldn’t remember their names and couldn’t remember simple stuff...and already my catch was, because I had trouble with my balance, I was beginning to look drunk, I was beginning to sound drunk”

(Tom, 45) (Service User).

Rose (42) (service user), a successful entrepreneur with a busy family life, reported thoroughly enjoying her work prior to her injury. She described herself as someone who was living a full and very active life prior to the injury. The effects of sensory overload have forced Rose to restrict her lifestyle.

“I’ve had to slow right down and limit what I’m doing” (Rose, 42) (Service User).

Rose (42) (service user) has returned to work in her business two mornings a week but due to sensory overload she now employs two people to fill her previous professional role. She explains that even though she has scaled back enormously professionally, the sensory overload induced fatigue forces her to go to sleep as soon as she finishes work, which she reports is completely at odds with her previous self.

“It’s a busy environment and I never saw it being a busy environment but now that I have what I have, it’s a busy environment” (Rose, 42) (Service User).

Tom (45) (service user) reported that, in addition to forcing him to scale back professionally, experiencing sensory overload has made his family business much smaller. Tom (45) (service user) explained the audacious development plans he previously had for the business; post injury these plans have had to be shelved. Despite these sacrifices and meticulous trigger management Tom (45) (service user) reiterated that sensory overload induced fatigue is still extremely limiting. Tom (45) (service user) reported that since his Acquired Brain Injury he is now very rarely alone, for safety he requires a companion. Tom (45) (service user) explained that he can’t drive on top of working, the fatigue makes driving alone very dangerous and driving is a necessity of his profession.

“It’s changed the whole business” (Tom, 45) (Service User).

Loss emerged as a universal theme that all service users experienced in different ways due to sensory overload. It has been discovered that an acquired disability can cause the person and their family to feel overwhelmed, hopeless, and intensely frustrated as questions naturally begin to arise about life roles, work, finances, and social engagements. The research notes that as the consequences of the acquired disability become more apparent, a mourning period for one's previous self can often follow (AU NDIS, 2020). Furthermore, one professional working in the ABI rehabilitation sector highlighted that people some people have lost their sense of being connected to their own body and being grounded physically to the world around them.

“The touch is you know having aphasia or hemiparesis on top of that and so you've lost that sense of the feeling of or even feeling grounded”

(Sinead, 40) (Professional working in the Acquired Brain Injury Rehabilitation Sector)

Rose (42) (service user) explained that after her fall she initially felt relief. Rose (42) (service user) thought she had narrowly avoided a serious injury. This unfortunately led to delayed medical treatment which in turn led to a delayed Acquired Brain Injury diagnosis. Rose (42) (service user) explained the tremendous sense of loss she felt when she learned that she had suffered an Acquired Brain Injury which severed her olfactory nerve causing her to lose her sense of smell and taste. Rose (42) (service user) spoke about previously being a busy self-employed mother and the pride she took in running her household. She explained the loss of being able to cook for her family and the loss of traditions and previous joys like Christmas dinner and the smell of a fir tree.

“Christmas time in particular you can't smell the tree, you can't taste the food when you're trying to cook Christmas dinner” (Rose, 42) (Service User).

Recent reports from people who have recovered from the Covid-19 virus but have not regained their sense of smell and taste report similar feelings of loss. People reported that the sensory changes were impacting on their mental health, their ability to connect with family and friends and their activities of daily living (Bromwell, 2021). These findings were reiterated by other researchers who reported links between post Covid sensory changes, depression, and anxiety. Researchers highlighted that people's responses to these sensory issues ranged from mild longing to intense grief for their senses (Newhouse, 2020). One professional working in the ABI rehabilitation sector who took part in the study explained the additional challenges that can present when a person's sense of smell is impacted

“We would have had clients who have been quite distressed and conscious of whether they smell which had led to excessive washing because of the fear that they were smelling because they couldn't smell themselves”

(Sarah, 44) (professional working in the ABI rehabilitation sector).

As a result of Acquired Brain Injury (ABI), a person's identity can quickly become fragmented and lost (Walsh et al., 2015). Sensory overload seems to compound this sense of loss because in many cases life roles can no longer be fulfilled due to sensory challenges. Sensory Overload prevented all the service users from carrying on their professional roles in the same capacity, causing one person to exit the employment sector completely. The loss of profession seemed significantly tied to a loss of identity. Furthermore, there may be significant role reversals in the person's home and social lives and thus the person's family, social, professional, and personal identities can become permanently altered. The enormity of each person's identity bereavement was palpable when they discussed their pre injury selves.

“It became about self-confidence, about self-values, about self-worth, depression and that’s where I really found it very difficult” (Tom, 45) (Service User).

Tom (45) (service user) explained that while he had initial problems with his speech and balance, these difficulties were explained away by his doctors as concussion. He thought he was healing and improving. Tom (45) (service user) explained that this made the eventual diagnosis of severe sensory overload especially difficult to accept. Tom (45) (service user) described himself post Acquired Brain Injury as

“Not wanting to be sick, not accepting it, not wanting to be brain injured and still fighting it” (Tom, 45) (Service User).

Professionals working in the Acquired Brain Injury rehabilitation sector highlighted the painful tug of war that takes place when service users try to adapt to their new identities post injury. The professionals explained that service users are trying to negotiate their new sensory challenges while simultaneously their family, friends, colleagues, and community expect them to be their pre injury selves.

“Clients would often say they’re adjusting to their new strengths and their new challenges and you know going through their life with that and then they might meet a friend in the street and they’re asking them to come to the pub or to come and play the soccer match and then like you know the client is almost saying that they have to explain to them that you know I can or can’t do that anymore I do or I don’t enjoy it anymore and then like clients would say you that they are trying to dip back into that and then you know that’s where the struggles and challenges crop up again”

(Ciara, 35) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

Regaining or developing valued roles post Acquired Brain Injury and adapting to a new self has been described as an ongoing struggle, and a common consequence is to experience uncertainty in everyday life (Olofosson et al., 2018). It has been reported that people often lose their pre injury circle of friends within twelve months of having an Acquired Brain Injury (Walsh et al., 2014). Consequently, Acquired Brain Injury survivors can often experience a rapid decline in their social outlets. During the interview process, professionals working in the Acquired Brain Injury rehabilitation sector described the painful experiences service users go through when sensory overload prevents them from spending time with their families and friends.

“They desperately want to integrate with friends and family, be social and go to that wedding, or be at that christening, and there becomes a point where they have to make a trade off you know and people will often... people will try to fight it”

(Sarah, 44) (Professional working in the Acquired Brain Injury Rehabilitation Sector)

Liam (72) (service user) identified that unfamiliar places make him uncomfortable since his ABI. Liam (72) (service User) explained that his balance, vision, hearing, sense of taste and smell were all impacted by his injury which has made unfamiliar environments very difficult for him. He has stopped going on family holidays since getting lost during a trip post injury

“Going on holidays now, I don’t be taken, I hate going on holidays because I don’t know where I’d be” Liam (72) (Service User).

Rose (42) reported being an avid sports fan prior to her injury but being unable to participate in sports following her Acquired Brain Injury. This was echoed by Liam (72) (service user) who

explained that due to sensory overload he can no longer attend rugby matches, a pastime he previously thoroughly enjoyed

***“I couldn’t go to a match now because the shouting
and roaring would be too much for me like” (Liam 72) (Service User).***

Sensory Overload has significantly altered the participants daily lives, they have experienced the loss of their pre injury careers, hobbies, their ability to socialise, and as one participant pointed out, their ability to visit settings that are important to them

***“I don’t go to mass as much as I used to because I found mass very difficult”
(Tom, 45) (Service User).***

During the interview process it became apparent that sensory overload acts as a thief, robbing people of their opportunities to socialise, to engage in activities they previously enjoyed and traditions they once held dear. The literature indicates that even when a person’s circle of friends remains intact post Acquired Brain Injury, the person is far more likely to receive social visits rather than attend social gatherings (Milligan et al., 2013). A 2020 study reported that a common experience was that, after initial shows of concern and support, friends and even family withdrew, and social life contracted. The rejection inherent in this response prompted appraisals of reduced self-worth and a revaluation of one’s social identity (Villa and Riley, 2020).

***“I suppose it comes back to my own personality and not wanting to be sick, not
accepting it” (Tom, 45) (Service User).***

The most up to date research concludes that ABI rehabilitation needs to adapt and be tailored for each individual in order to respond to service users evolving needs and wants (Wells,

2018²). This appears to be particularly relevant for people with sensory overload, as their experiences are often so individualised. During the present study professionals working in the ABI rehabilitation sector highlighted that sensory overload compounds the loneliness and depression initially caused by an Acquired Brain Injury, as the very nature of the condition can prevent people from attending ABI peer support groups and some sensory soothing activities can lead to further isolation.

“Obviously people will come up with solutions like well why don't you try noise cancelling earphones which are fine if you're engaged in a solitary activity but the whole point for instance of a peer support group is that you're coming because you're enjoying the company of others and then sitting there having to wear earphones until you speak and taking them off for a small while and putting them back on again is counterproductive”

(Sarah, 44) (professional working in the Acquired Brain Injury Rehabilitation Sector).

When exploring the impact of the Covid-19 pandemic on ABI rehabilitation services Joan (34) (service user) explained that the closure of services severed her peer support and stopped her daily outings which represented a significant loss to her. Joan (34) (service user) explained that while she has been able to connect with groups virtually there is simply no comparison to the peer support received in person during formal Acquired Brain Injury rehabilitation groups and often even greater peer support informally during tea and lunch breaks.

“I'd be like I'm tired today, and they would be like yeah, I feel like that too or something, you know whereas at home here if I say tired they'd be looking at me going what? You're tired? Why?” (Joan, 34) (Service User)

Professionals working in the ABI rehabilitation sector highlighted that when rehabilitation services moved online in response to the Covid-19 pandemic the focus was on services users' internet connection, IT literacy, equipment, and software while services users sensory needs and triggers were not factored in.

“At the moment so much focus is on the IT literacy and broadband access but at no point in the conversation is a service user asked if they are ok with screens, with blue light, etc”

(Fiona, 37) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

Poor social outlets, lack of community and peer support have all been linked to poorer well-being (Holloway and Jefferson, 2012; Murray et al., 2009). The professionals working in the ABI rehabilitation sector emphasised that it is important for people to be able to create new social circles and to benefit from peer group support from other people who have experienced an Acquired Brain Injury, but sensory overload seems to create an extra barrier in this regard.

The effects of sensory overload are profound and can impact every facet of life. Sensory overload can disrupt family traditions, force people to exit the employment sector and impede on the individual's independence. Sensory overload post Acquired Brain Injury can cause people to lose their role in their family units and social networks, their place in their communities, in addition to their professions, their hard-earned skills, and their hobbies. The activities that sparked joy or helped them relax and unwind pre injury can suddenly become sensory triggers and perhaps act as reminders of loss. When ABI rehabilitation recommends rest and stress reducing activities, this may put extra strain on service users who can no longer engage in activities they once found enjoyable and now represent a life skill lost or evoke an overwhelming negative response due to sensory overload.

4.2 Sensory Overload Triggers

A central theme in the literature is that when a person with sensory overload enters a busy environment they are quickly bombarded, for example by encountering strangers, bright lighting, loud noises, new scents, and tactile information. Understandably this can cause the person to feel overwhelmed, stressed, and uncomfortable (Wood et al., 2019).

“One of the clients said that overload was like an assault on their brain which I think, is you know, is a very profound way of saying they're walking around the world and sometimes it feels like their brain is being assaulted”

(Sarah, 44) (Professional working in the Acquired Brain Injury Rehabilitation Sector)

Environmental triggers following an ABI commonly include noise, light, new situations, crowds, and unexpected changes to routine (NHS Scotland, 2020). For the participants in the present study who developed sensory overload post Acquired Brain Injury in addition to these common post ABI triggers, they reported experiencing a new, negative relationship with sensory information. Tom (45) and Rose (42) described intense feelings of being acutely aware of every single sound in their surroundings.

“I was in a group once where one gentleman was saying what is that noise? and I mean it was so quiet and he could hear the battery dying in another group members hearing aid”

(Sarah, 44) (Professional Working in the ABI Rehabilitation Sector).

Tom (45) (service user) described how sound encircles him, sometimes the sounds are distinct and do not encumber him, more often sounds are amplified and distressing. Tom (45) (service user) used an analogy to describe what it is like to experience sensory overload. Tom (45)

(service user) equated sensory information to water, explaining that he never knows what volume and intensity he is going to be hit with.

“If you can imagine sitting in a dark room and imagine sound is water, not sound, and imagine water is coming at you in different ways, and it can be a bucket or a spray or a power hose” (Tom, 45) (Service User).

In a 2012 study, people with sensory overload reported feeling overwhelmed as they struggled to cope with the multitude of new sensory challenges in their lives and their complete lack of control over these changes. The 2012 participants explained that sensory overload changed their definition of noise, they also reported a new and amplified awareness of sounds. These noises often included what many people would categorise as everyday sounds, which previously did not demand any attention or cause any negative reactions. The participants reported that their new intensified awareness levels of noise lead to physical discomfort and psychological stress (Landon et al., 2012). The participants in the present study echoed these findings. During our interview Rose (42) (service user) winced as she pointed out the sound the exit sign in the room was emitting, it was obvious that the noise was causing her discomfort. Rose (42) (service user) explained that common sounds which she wouldn't have taken any notice of in the past, blare out for her now

“People rubbing their hands off their jeans and things like that or the crackling of a crisp bag beside me “(Rose, 42) (Service User).

One professional working in the ABI rehabilitation sector recalled a phone call with a service user during our interview and explained the intensity when someone is overloaded sensorially

“She was crying, she was in her car, she didn't know what had happened, she'd ran out out of Tesco, left her shopping there and it was total flooding, sensory flooding, the lights, the music, the divided attention, you know the notoriously difficult trolleys that always end up going in the wrong direction, loads of people and really bright stimulation you know rows and rows of the products”

(Sarah, 44) (Professional Working in the ABI rehabilitation Sector).

It has been discovered that the rehabilitative environment and how it is designed plays a crucial role in service user recovery outcomes (Grevan et al., 2019). However, as the professionals working the in the ABI rehabilitation sector highlighted, Acquired Brain Injury peer support groups and ABI rehabilitation services are currently being delivered in sensory triggering environments which severely restricts access for people with sensory overload. They explained this is largely done unknowingly by ABI rehabilitation service providers due to widespread lack of awareness and understanding of the sensorial impact of Acquired Brain Injuries. The professionals working in the ABI rehabilitation sector explained that for service users with sensory overload, attending rehabilitation services in a triggering setting can be extremely difficult, especially when there is an accumulation of triggers over the course of the day, for example, a plane passing overhead or a fire drill being carried out. Fiona (37) and Sarah (44) (professionals working in the ABI rehabilitation sector) described the intense impact on one service user during a rehabilitation session that triggered her sensory overload

“It was like we hit her”

(Fiona 37) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

“She suffered so much, like she she ran out of the building, I actually ran out of the building with her because I knew it was going to really trigger her and she really... so she came in for a service and she just really struggled that day”

(Sarah, 44) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

A 2015 study concluded that rehabilitation programmes are broadly designed and routinely aimed towards improving function. Sensory needs and experiences have historically not been the primary focus in rehabilitation settings (Shull and Damian, 2015). In relation to sound sensitivity, professionals working the Acquired Brain Injury rehabilitation sector explained the ticking of a clock is enough to trigger a person with sensory overload. The sound does not have to be loud to be triggering. The professionals highlighted that in a group setting it can be especially difficult to strike a balance that suits all members of the group. Some people may find a certain noise comforting while others find it intensely triggering. Some service users may find a scented candle soothing, it makes other people nauseous. Temperature is another environmental factor which is hard to balance, some service users may seek fresh air to alleviate their fatigue but the noise that travels in when a window is open can completely flood another service user. The professionals working in the ABI rehabilitation sector explained that they also observe service users becoming frustrated because they are constantly trying to be heard over their ever-present triggers.

In the community the professionals working in the ABI rehabilitation sector pointed out the wide range of community settings with fluorescent lighting, the intense sensory bombardment in a supermarket and how overwhelmed service users become when walking beside traffic. The participants emphasised that service users with sensory overload are constantly bartering with their sensory triggers. They explained that people with sensory

overload must decide what activities are worth putting themselves through the onslaught of being overloaded. Each person has a finite amount of energy before their body reaches saturation and they are forced to rest, so they have to choose what they spend their energy on very carefully. For a person with sensory overload this is not a temporary state, it is a daily chore they endure at the expense of their wellness. The professionals working in the ABI rehabilitation sector carefully explained that the cost for service users attending a family event and being overloaded is splitting headaches, vomiting and an inability to get out of bed for three days afterwards.

“Grandparents that we’re working with, who love their children their grandchildren dearly but just the noise that they make and the unexpected noise. I think that’s another factor, the noise that the clients can predict it’s kind of ok but the sudden shrieking, or dogs barking is another one, clients will report something that’s unexpected and comes out of the blue”

(Sarah, 44) (Professional Working in the Acquired Brain Injury Rehabilitation Sector).

No matter how cautious people with sensory overload are, no matter the huge personal effort they go to manage their sensory needs and create a home and work environment that is responsive and reflective of their needs, every time they take personal leaps forward, they seem to be getting knocked back by social and rehabilitative environments that are not sensory informed. The importance of settings that sooth the senses instead of triggering them came through strongly in both the service user and professional interviews. The service users explained their unique triggers, each one complex and multifaceted. The individualised nature of sensory overload came to the forefront as each person shared their lived experiences. It

was clear from listening to the service users that they are surrounded by sensory triggers daily and this constant onslaught of sensory information is physically and mentally exhausting.

“If you are working really hard to tune in to what someone is saying to you and tune out all the bits that are irrelevant, that your brain no longer does for you, that’s going to come at a cost and that cost is cognitive fatigue”

(Sarah, 44) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

Professionals working in the ABI rehabilitation sector highlighted that by working closely with people who experience sensory overload post ABI they have become more sensitive to noise. Sarah (44) (professional working in the ABI rehabilitation sector) explained her experiences of trying to highlight to contractors that electrical items in a rehabilitation room are intensely triggering for people with sensory overload. She explained that she has been told by the contractors that machines are completely silent as they cannot hear them, but from being regularly tuned into the sensory charged world of service users’ she can hear it loud and clear.

“You don’t realise how loud things are until you’re tuned in....the IT man said it was silent, he didn’t hear it and I had to explain that the machine was incompatible with people with sensory overload”

(Sarah, 44) (professional working in the Acquired Brain Injury rehabilitation sector).

Notably, Sinead (40) (professional working in the ABI sector) highlighted the disrespectful tone the rehabilitation environment can set for services users when it is not sensory informed.

“You’re asking them to be vulnerable and share the depths of very personal pain...and you can hear other people laughing and joking in the building... and there’s competing noises, it feels disrespectful”

(Sinead, 40) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

Sinead (40) (professional working in the ABI sector) explained that each person working in the ABI rehabilitation sector tries their best to be sensitive to service users' needs. However, she highlighted that this could lead to bias and incorrectly assuming that one understands what it's like to have sensory overload when in fact the only people who truly know what it is like to experience sensory overload are the people experiencing it.

“Thinking that one understands, forgetting that sensory overload is so individualised... that triggers are not universal, they are unique, what overloads one person may not overload another”

(Sinead,40) (Professional working in the Acquired Brain Injury rehabilitation sector).

Psychologists working in the ABI rehabilitation sector highlighted that they are regularly receiving referrals for anger management, however over time the psychologists are learning that the service users don't have anger management issues, they have sensory overload.

“This investigative work is particularly poignant for people who are displaying irritability”

(Sarah, 44) (Professional working in the Acquired Brain Injury rehabilitation sector)

The professionals working in the ABI rehabilitation sector noted that light and sound sensitivity are the most prominent sensory barriers they observe in the rehabilitation environment. The participants explained sensory overload not only negatively impacts service users one to one rehabilitation, but it also significantly impacts the person's ability to benefit from group work. The professionals working in the ABI rehabilitation sector highlighted that service users report thoroughly enjoying the peer support that engaging in group work offers,

but the service users with sensory overload have to trade being flooded sensorially for this invaluable support.

4.3 Education & the Rehabilitation Environment

“It permeates all aspects of peoples being”

(Sarah, 44) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

The Australian government National Disability Insurance Scheme highlights that due to the enormity of life changes experienced, acquired disabilities can be very difficult to accept, both for the person and their family. The process of understanding and accepting an acquired disability can take many years. In the beginning the person and their loved ones may experience joy and relief that they survived a serious illness or injury. Over time, the focus moves toward the multitude of life changes being experienced (AU NDIS, 2020).

Liam (72) (service user) spoke during the pilot of having no guide and having to come up with his own strategies to cope with sensory overload. Tom (45) (service user) reported that in an attempt to understand what he was experiencing, and due to a lack of accessible data on sensory overload, he had to collect his own information.

“I call it gathering, I was gathering information and symptoms, and the gathering was the first process, and the learning was the next process, so the gathering was

maybe six months, a year”

(Tom, 45) (Service User).

It's vital to make information and education related to brain injury more widely available and to ensure it is accessible for families (McDermott et al., 2013). In reference to sensory overload, service users talked about it being a hidden consequence of Acquired Brain Injury that they find difficult to explain, and family members have difficulty understanding.

"I would say both my brothers would be not...they would have trouble accepting... the extent, not what happened but the extent of the damage that's been done"

(Tom, 45) (Service User).

In addition to self-acceptance, research has also pointed to the importance of acceptance by family members. In order to create a supportive home environment, close family members need to accept their relative's sensory loss and associated care needs (Sarason et al., 2018).

"She's had to deal with some amount of brain injury and every time.... she's run the business; she's taken on extra jobs.... and every time she comes to the house she would still smile, she's incredible"

(Tom, 45) (Service User).

While some participants received invaluable support from family, especially significant others in some cases as outlined above, tension remained around discussing the person's Acquired Brain Injury and understanding sensory overload and the challenges it presents from wider family and social networks.

“At home they’re very negative, they give me the impression...they’d be saying to me there’s nothing wrong with you, do you know I’d be saying Jesus Christ almighty you know after fifteen years now they surely know something about strokes, that it effects people”

(Liam, 72) (Service User).

Brown (2017) calls the type of loss associated with illness a “*spectre*” and suggests that this spectre grows when the surrounding community lacks awareness and understanding of an illness. She suggests that there is much to be learned from people living with illness, navigating its effects and experiencing a fragmented identity. (Brown, 2017).

Awareness drives sensory informed spaces and names the condition for people struggling to understand their symptoms post Acquired Brain Injury. Increasing awareness levels could help inform each person’s families, friends and communities about sensory overload and the challenges it presents which may be one way of addressing the tension in relationships reported.

Building awareness is key, professionals working in the ABI rehabilitation sector highlighted how under researched sensory overload is currently. The professionals acknowledged their own lack of expertise in regard to sensory overload and highlighted how participating in this study has given them new appreciation into the cruciality of creating sensory informed settings in the Acquired Brain Injury rehabilitation environment. All professionals acknowledged how overlooked sensory needs currently are in ABI rehabilitation services.

“I would definitely feel it actually is an area that you know doesn't get the same amount of focus as perhaps physical difficulties or cognitive difficulties and that's through no fault of anything really, I suppose it's just all down to awareness”

(Ciara, 35) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

In the ABI rehabilitation organisation where the study took place, the interview process revealed that one department is trying to address people's sensory needs, however the people who work in that department explained that this is a continuous learning process because of the individualised nature of sensory overload. Professionals from all other interviewed departments highlighted that the settings where services are being delivered are currently completely lacking in sensory informed spaces. The professionals working in the ABI rehabilitation sector explained that they felt the present study is very timely research as the rehabilitation centre where the research took place is due to relocate which presents a rare opportunity.

“The opportunity to negate some of the triggers so routinely present in services at the moment”

(Sarah, 44) (Professional working in the Acquired Brain Injury Rehabilitation Sector).



The professionals working in the ABI rehabilitation sector explained that they regularly observe service users arriving to services exhausted and nauseous. The service users explain this is due to the intensity of sensory flooding they experience while travelling to ABI rehabilitation services. The professionals explained that the sun peeking through tree branches while the person is in a moving car is enough to make service users with sensory overload physically sick. It is crucial that the rehabilitative environment provides a sensory soothing environment for people who have put themselves through the gruelling task of being overloaded for the sole purpose of attending rehabilitation.

“For some of our clients things like movement, so being in a car and having just that movement of passing fields or power cables can make them really really sick”

(Sarah, 44) (Professional working in the ABI rehabilitation sector).

Rehabilitation programmes are broadly designed and routinely aimed towards improving function. Sensory needs and experiences have historically not been the primary focus in rehabilitation settings (Shull and Damian, 2015). It has been discovered that the rehabilitation environment and how it is designed plays a crucial role in service user recovery outcomes. However, despite these findings, sensory processing conditions that amplify the person's awareness to negative and positive environmental factors remain largely unresearched (Grevan et al., 2019).

***"I can't focus at all if I'm in a noisy environment,
I tend not to put myself into a noisy environment"***
(Rose, 42) (Service User).

During the interview process the professionals working in the ABI rehabilitation sector reported how service users' physical needs are routinely accommodated, while sensory needs are often forgotten or completely overlooked. They explained that people with sensory overload sometimes need to sleep before they can even engage in conversation. The current building does not offer any suitable spaces for service users to rest, staff offer up their offices in an attempt to provide a quiet space. When service users try to participate in services, the lights, sounds, smells, and furnishings are all overloading them simultaneously.

Professionals working in the ABI rehabilitation sector spoke about how distressed service users can become if they do not have the right furniture for their sensory needs, this can be as simple as having a soft chair, and how much this can dominate the person's focus. In contrast the professionals explained the calming effect having suitable sensory sensitive furniture can have on service users' overall form and opportunities to relax and benefit from the rehabilitation session.

The professionals reported how service users' physical needs are routinely accommodated, while sensory needs are often forgotten. Professionals spoke about their own lack of awareness about how sensory overload can present and how it impacts on service users. They discussed how helpful it was to talk about sensory issues that can regularly fall beneath the collective radar. Professionals noted that if awareness is lacking at a staff level in ABI rehabilitation services there is a high possibility that service users are experiencing sensory issues that staff are not in tune with. Furthermore, some service users could be experiencing sensory overload but may not be able to express themselves due to communication issues. The professionals discussed how some helpful measures are common place, for example placing a cushion on a person's chair prior to a group session to alleviate back pain. However, the professionals acknowledged that settings are never prepared in advance like this to address sensory needs..

If there's not a level of professional awareness around that or trying to I suppose get the bigger picture for that it can be really damaging to the persons recovery"

(Sinead, 40) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

A huge danger that professionals working in the ABI rehabilitation sector flagged was sensory overload being labelled as challenging behaviour when in fact the person is being triggered by their environment.

"Where that becomes dangerous is when clients are interpreted as having challenging behaviour and something official is written up"

(Sinead, 40) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

The professionals working in the ABI rehabilitation sector highlighted that if reports are written up documenting a history of challenging behaviour (due to a lack of understanding or awareness of sensory overload from the professionals working with the service user) this follows a person throughout their rehabilitation care, even though they are just trying to navigate through their sensory overload triggers. The lack of awareness of sensory overload can lead to further problems for the service user because they may become frustrated which can be misinterpreted as further examples of challenging behaviour resulting in a vicious cycle.

“You become the forefront of their anger because they feel unheard or misheard when they have tried to be honest with professionals about their challenges”

(Sinead, 40) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

In the ABI rehabilitation service where the research was carried out there is currently no sensory room in any department. As mentioned, staff offer their offices to service users when they need to sleep due to sensory flooding and fatigue but the offices are clearly not conducive to rest and relaxation.

“Fatigue and sensory overload are irrevocably linked”

(Sarah, 44) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

By exploring the participants personal experiences and observations it became clear how difficult it is for people with sensory overload to benefit from their rehabilitation if the setting is not sensory informed and properly equipped to accommodate sensory needs. Sensory needs and the importance of sensory informed rehabilitation environments need to be at the forefront of the planning process in the same way physical needs are when new rehabilitation

centres are being designed and built or existing centres are being renovated and upgraded. For many people, the rehabilitation environment provides an incredibly important social outlet. For Liam (72) (Service User) during the pilot study, eliminating the fluorescent lighting, allowing fresh air into the room, and having his favourite music playing were small but significant environmental changes that seemed to enhance his overall rehabilitation service.

The primary aim of ABI rehabilitation settings is to aid recovery and to provide an opportunity for service users to develop skills that promote independence. For service users with sensory overload the benefits of attending rehabilitation settings currently comes at a high cost. In order to engage in rehabilitation, clients must enter environments that not only ignore their sensory needs but actively trigger them.

The sensory menu put forward in this study may be one way to alleviate the enormous current physical and mental strain on service users when they engage in rehabilitation. The service users and professionals working in the ABI sector were in resounding favour of the sensory menu and commented on how valuable it would be if incorporated into ABI rehabilitation services. The professionals working in the ABI rehabilitation sector noted there may be people post ABI living with their families, or residential care settings who may have never heard of sensory overload and may be trying to live with sensory overload symptoms without knowing it's a sensory processing disorder.

“If the person has physical and cognitive impairment that would lead them to require nursing home care, it is highly possible that they have sensory issues as well but may not be able to verbalise this, they may attribute their challenges to personal impairment without knowing sensory overload is a condition that other people experience post ABI”.

(Fiona, 37) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

By recognising that the therapeutic environment is a crucial cog in the wheel of rehabilitation, the paramount importance of tailoring rehabilitation settings becomes clear. By creating a sensory informed space that is tailored to the individual or group it serves, the setting can be transformed from triggering chaos into a soothing oasis.

“That’s what we should be aiming for, that the clients come into the building, and it has a soothing effect on them, as opposed to adding additional factors that they have to manage in order to get the most out of their service”

(Sarah, 44) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

The study introduces a sensory menu as a rehabilitative tool that can be used to represent varying responses to different settings and reflect how environmental factors promote or hinder rehabilitation.

“If something is obvious or I see somebody wincing or you know I'm aware that they have a difficulty beforehand you kind of take that in your stride and and integrate it but it's those pieces that where it's not as salient that you might not necessarily ask so formalising this, I guess what I'm trying to say formalising this into standard practice is a really good idea”

(Sarah, 44) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

Lighting and acoustics are particularly important, the type of room used for sessions needs to be factored in, scheduling of groups and safety drills need to be carefully considered for example choir/alarm tests/fire drills and can all make a big difference to the service people with sensory overload receive.

Prior planning to set up the environment in a way that respects the persons sensory needs is important (use of menu). Small environmental changes can make a big sensory impact for example having shiny surfaces (whiteboard/notice board) on one wall so people can turn their back to it instead of being surrounded by triggering surfaces.



The service user participants were incredibly generous with their time and knowledge. Each professional working in the ABI rehabilitation sector acknowledged the services users remarkable resilience, the researcher noted this throughout the study also. Learning about each person's lived experiences in depth can develop one's knowledge and understanding of sensory overload. The experiences the participants so generously shared could prove invaluable to other people at the start of their ABI rehabilitation journey, critically it may help other service users to identify sensory overload symptoms and individual sensory triggers. In addition, by educating professionals working in the ABI sector about the challenges sensory

overload presents, it strengthens the growth of sensory informed settings in Acquired Brain Injury rehabilitation.

While physical and cognitive symptoms are well documented the sensory impact and profound challenges conditions like sensory overload cause for people post Acquired Brain Injury is under researched. Professionals working in the ABI rehabilitation sector shared their insights into how much remains unknown about sensory challenges post ABI and how little sensory needs are currently factored into Acquired Brain Injury rehabilitation.

It's really important because I don't think a day goes by without becoming aware of being made aware of a sensory issue or challenge, so it makes sense in terms of moving forward
(Sinead, 40) (Professional working in the Acquired Brain Injury Rehabilitation Sector).

The researcher's observation journal highlighted how important it is to acknowledge that simply having senses does not make us sensory informed, in fact it can lead to a sensory blind spot where imagining things as louder/brighter/stronger can lead to a perceived understanding that is nothing like the lived experience of sensory overload. It is crucial to recognise that each individual is the expert in their own sensory needs. It is only by asking each person to share their lived experiences of sensory overload that we can begin to educate families, social circles and professionals working in the ABI rehabilitation sector about the daily lives of the sensory overload community.

4.4 Chapter Conclusion

This chapter explained the three robust themes that emerged throughout the study in detail. It addressed the life altering consequences and the many different types of loss that people can experience due to sensory overload. The chapter highlighted the enormous

variety of sensory triggers people can encounter post ABI and the highly individualised nature of sensory overload. The researcher used the participants own words to reflect their personal lived experiences that they so generously shared. The critical importance of sensory informed education and rehabilitation environments was emphasised. The next chapter will conclude the research study.

Chapter 5 Conclusion

5.0 Introduction

This chapter will begin by explaining the research findings in relation to their implications for practice. The strengths and limitations of the study will be summarised. The researcher will lay out four recommendations in detail and the overall conclusion of the research will be presented.

5.1 Implications for Practice

5.1.1 Offering a Sensory Menu as part of Acquired Brain Injury Rehabilitation Services

The findings from this study argue for the introduction of sensory menus into ABI rehabilitation services in Ireland. Currently, when a person applies for Acquired Brain Injury rehabilitation services, they are asked to fill out a great deal of paperwork prior to their initial assessment. This paperwork consists of service application forms, lengthy medical information, and consent forms. The initial assessment meeting takes approximately two hours, this is a discussion about the person's injury and their rehabilitation needs, wants, and goals. During the meeting a large amount of data is collected through further form filling.

By introducing a sensory menu into standard service provision, the sensory needs of each person can be considered from the outset. The meeting rooms where initial assessments take place are routinely adapted to serve physical needs, for example the removal of furniture to ensure a person in a wheelchair has enough space to manoeuvre. Sensory menus could be used to ensure sensory needs become routinely accommodated in the same way, for example by considering the number of electrical devices in the room, or scheduling building

maintenance works carefully so there isn't excessive noise during assessments which people may be triggered by.

For people who are currently attending ABI rehabilitation services, offering a sensory menu as an additional resource may offer people a completely new opportunity to identify sensory challenges. It may assist in sensory trigger management and build transferable skills which people can also use in their home environment and in community settings to advocate for their sensory needs. The sensory menu can act as a physical reminder to professionals working in the ABI sector that if a person is presenting irritable or unable to focus, they may be reacting to a sensory charged environment as opposed to wilfully opting out of rehabilitation.

Professionals working in the ABI sector can use the sensory menu as a rehabilitative tool and invite service users to share their needs and explore ways to dampen down the sensory stimulants in their rehabilitation spaces. The menu could also be used in home environments so families can learn about triggers and sensory soothing techniques together. This activity may reduce the tension and misunderstandings that some participants reported experiencing in their family units.

Over time, learning what works for each person and what doesn't, and by documenting the benefits of sensory informed rehabilitation settings, our collective understanding of sensory overload will increase. Sensory menus could evolve into sensory portfolios that not only create a deeper appreciation for this currently largely undocumented condition in ABI literature but lay the foundation for sensory informed settings to become the norm in ABI rehabilitation settings in Ireland.

5.1.2 Creating Sensory Informed Rehabilitation Settings

The research findings illustrate the importance of creating sensory informed environments in ABI rehabilitation. Sensory informed settings require careful consideration, input from people experiencing sensory overload is critically important. The study highlights that people experiencing sensory overload post ABI are the experts on the condition, no one has a greater understanding of sensory overload than the people who experience it every day.

The ABI rehabilitation service, where the present research study was conducted, is due to move location. The primary aim of the move is to create a purpose-built state of the art rehabilitation centre which will serve a large geographical area. Presently, services are delivered in old, converted warehouses that are ill equipped to serve the complex needs of people recovering from an Acquired Brain Injury. These settings limit the rehabilitative scope of the service. This research study illuminates the unequivocal requirement to build the new rehabilitation centre, and to design it in a way that treats sensory disabilities with equal importance to physical and cognitive disabilities.

In the meantime, there are a range of practical sensory soothing measures that can be adopted into service provision in the current rehabilitation settings. For example, considering alternative light sources to fluorescent strip lighting such as table and floor lamps with dimmer switches. Mindfully planning group session content depending on the sensory needs of those attending, for example carefully scheduling music groups or metal/woodwork groups that include the use of power tools. Thoughtfully organising activities that some service users may find triggering, so they occur outside of service provision hours, for example building maintenance or alarm tests. Providing a relaxing sensory soothing space that people can visit if they have been overloaded on the journey to services or a space that service users can

simply go to rest throughout the day as part of their fatigue management routine. Offering service users the opportunity to discuss and express their sensory needs on a regular basis is an important step towards incorporating sensory needs into service provision as standard practice.

5.1.3 Education and Training

This study illuminated the lived experiences of people with sensory overload post Acquired Brain Injury. Increasing awareness of sensory overload through education and training appears to be a central cornerstone to bringing sensory needs to the forefront of ABI rehabilitation services in Ireland. Educating professionals working in the ABI rehabilitation sector is of critical importance so they can not only recognise sensory overload when it presents, but fully support people experiencing sensory issues, and advocate for the sensory needs of people who have communication difficulties.

The participants were incredibly generous with their time and knowledge. Learning about each person's lived experiences in depth can inform and broaden one's understanding of sensory processing disorders. Learning from these first-hand documented experiences could support families who are caring for their loved one's post ABI, and it could aid professionals who are diagnosing people post Acquired Brain Injury and identifying rehabilitation services based on the person's needs and wants.

Currently Acquired Brain Injury rehabilitation services provide educational workshops in an effort to assist families caring for their loved one's post ABI. The aim of the workshops is to educate, teaching people the different kinds of disabilities and challenges people can experience post injury. Creating a new workshop about sensory overload using the generously

shared information from service users' first-hand accounts could alleviate the burden on ABI survivors to continuously try their best to explain what they are experiencing.

The research provides a new unique rehabilitation resource by documenting first-hand accounts of sensory overload from ABI survivors. The experiences the participants shared could prove invaluable to other people during their recovery and ABI rehabilitation. By making this information freely available to people at the very beginning of their ABI rehabilitation journey, it may provide a valuable, referenceable source of information to people struggling to identify and communicate their own sensory challenges. Furthermore, it may assist people who have been living with undiagnosed sensory overload long term. The identifying phase of sensory overload was reported to be a particularly difficult and lengthy process by the participants due to the current lack of information on sensory overload in ABI literature. In addition to learning about triggers and common challenges, proven strategies to alleviate the symptoms of sensory overload could be shared.

By asking the participants to share their experiences of sensory overload I was invited to tune into an unfamiliar, sensory charged world. When connected to this intense, sensory fuelled domain the enormous constant challenges people with sensory overload navigate every day were illuminated. The participants highlighted how difficult sensory overload is to describe in a way people without it can fully appreciate and clearly understand. Educating ABI rehabilitation professionals and family/friends of ABI survivors may be one way to strengthen community appreciation of the enormous challenges people with sensory overload navigate daily.

5.2 Research Recommendations

5.2.1 Recommendation 1: Introduce Sensory Menus into Acquired Brain Injury

Rehabilitation Services

By reflecting on the introduction of the sensory menu, and the positive feedback it received from all participants, the researcher suggests the menu could be the first step in creating a sensory portfolio for each service user. This could be a buildable ABI rehabilitation tool that is created at the start of each persons' rehabilitation journey and evolves throughout the recovery process. The portfolio would be a working document that reflects the person's sensory needs and preferences over time. The portfolio could become a valuable resource that allows each person to clearly identify their sensory triggers, highlighting what soothes them and pinpointing what kind of settings promote their recovery. These portfolios could pave the way to make rehabilitation settings more sensory informed and give family, friends, and ABI service providers a clear representation of the key environmental factors needed in order to meet each service users' sensory needs.

In community settings referring to a sensory portfolio may prove to be a useful resource also. Crucially in settings such as nursing homes, portfolios could be used to promote the importance of examining the setting as a possibly challenging sensory environment as opposed to viewing people with sensory overload as presenting challenging behaviour.

5.2.2. Recommendation 2: Create Sensory Informed Rehabilitation Settings

Rehabilitation settings need to be adaptable, so that at their core, they are a neutral canvas that can be tailored to the evolving needs of the people they serve. When creating sensory informed settings, regular, consistent consultation with service users is paramount. People

who experience sensory overload report being acutely aware of every piece of sensory information in their surroundings. Over time, they have had to become the experts on their own sensory needs due to the individualised nature of their condition and the current lack of information on sensory overload post ABI.

It is critical to acknowledge that simply having senses does not make a person sensory informed or well equipped to design sensory informed settings. The observational journal used in this study highlighted the careful curating required to truly create sensory informed settings. The process is far more nuanced than someone without sensory issues can fully appreciate and requires the expert input from people navigating sensory overload every day. Sharing space with someone with sensory overload underlines that it's not necessarily the obvious, for example a ringing phone that paralyses them sensorially, it's the hum of someone else's hearing aid that the person can not only hear but be intensely triggered by.

When new centres are being built, information from service users about the primary sensory issues a new building will have to respond to, respect, and serve is vitally important.

5.2.3 Recommendation 3 Education and Training

Education is key and building sensory overload awareness in the ABI community and rehabilitation services is the first step in a long journey. By asking the participants to share their experiences of sensory overload I was invited to tune into an unfamiliar sensory charged world. When connected to this intense, sensory fuelled domain the enormous constant challenges people with sensory overload navigate every day were illuminated. The participants highlighted how difficult sensory overload is to describe in a way people without it can fully appreciate and clearly understand. Educating ABI professionals and family/friends

of ABI survivors may be one way to strengthen community appreciation of the enormous challenges people with sensory overload navigate daily

By learning about the challenges sensory overload can present for people post ABI, appropriate existing rehabilitation services can be identified for example job and life coaching and new services can be developed for example informative sensory overload workshops for family members.

5.2.4 Recommendation 4: Roll out to a National Pilot

The sample size of the study was small. If, for example, the study was exploring the impact of strokes, there are large community of people currently attending rehabilitation services in Ireland to rehabilitate post stroke. It is a defined, commonly recognised, and generally well understood condition. The same cannot be said for sensory overload post ABI. Sensory overload awareness and recognition is in its infancy, even among professionals working in the ABI sector. A small cohort of service users have reported this condition post ABI, and these were the people invited to take part in the study. Equipped with the findings from the present study, the researcher recommends a national pilot be conducted in order to gain a greater understanding of how many people are experiencing sensory overload post ABI nationwide. A national pilot would broaden our current understanding about sensory triggers and strengthen the need for sensory informed settings in ABI rehabilitation services in Ireland.

5.3 Research Strengths

The study explores the first-hand accounts of people living with sensory overload in Ireland following an Acquired Brain Injury, this is the first Irish study to study this topic.

A range of research methods were used to generate data and findings, namely a pilot study, semi structured interviews, an observational journal, and a sensory menu. Semi structured

interviews allowed personal experiences to be expressed which demonstrated the dual aspect of sensory overload, the individualised and isolating nature of sensory overload symptoms as well as the commonalities between participants lived experiences. The study fills a gap in the literature by documenting a condition which is relatively unknown in the ABI sector. The study compared people's experiences of Acquired Brain Injury rehabilitation services pre and post Covid-19 and documented staff experiences of working through the pandemic. This research will add value to the literature as there have been no studies to the researcher's knowledge carried out into sensory overload post ABI in Ireland and the relationship between sensory experiences and the ABI rehabilitation process.

5.4 Research Limitations

This study focused on one geographical area; therefore, it does not represent the broader experiences of other people living in Ireland with sensory overload. The findings from this research cannot be generalised due to the small sample size, however they can be used to offer some insights into sensory overload post ABI and provide a foundation for further research.

The Covid-19 pandemic presented challenges as the researcher was unable to meet the participants in person from March 2020. Wi-Fi, lack of computer hardware and digital literacy levels lead to delays.

5.6 Conclusion

This qualitative study documented the experiences of people living with sensory overload following an Acquired Brain Injury. The study provides detailed first-hand accounts of sensory overload and illustrates the highly charged, unfamiliar, sensory minefield people experience in their daily lives post ABI. It is envisaged that by raising the profile of sensory overload, currently a relatively unknown condition in ABI rehabilitation, research studies will grow and awareness in the ABI rehabilitation sector will increase. The present study aims to provide an informational resource for people experiencing sensory overload, in addition to providing vital information to families supporting their loved one's post injury.

The findings highlighted the profound impact sensory overload is having on the participants lives. It has changed the way people work or taken away their ability to work altogether. It has impacted on service users' independence by making them reliant on family and it has changed their roles in their family units. Sensory overload has changed the service user's social identity also, participants reported no longer engaging in sports and other hobbies as the effects of sensory overload have turned activities once thoroughly enjoyed, into triggering events.

The research highlighted how different environmental settings and factors trigger sensory overload responses. The participants explained how difficult it is for people with sensory overload to benefit from their rehabilitation if the rehabilitative setting is not carefully designed to be sensory informed. This is a critical point of learning for ABI service providers in Ireland and of particular importance when new ABI rehabilitation centres are being designed and built.

In response to these findings, the study introduces the use of sensory menus into Acquired Brain Injury rehabilitation settings in Ireland. The researcher recommends that sensory menus are developed into standard practice in ABI rehabilitation services. The sensory menu is an innovative tool that has the potential to strengthen the arsenal of health care practitioners and professionals working in the ABI sector. Critically, the research findings can provide a solid tangible reference for people with sensory overload, who reported experiencing a new and sudden, intensely challenging, relationship with sensory information post ABI.

The study supports sensory menus as a new rehabilitative resource that can be used in Acquired Brain Injury rehabilitation settings to identify how service users respond to different settings and how environmental factors promote or hinder rehabilitation. The study promotes the use of sensory menus to tailor therapeutic spaces to service users' individual needs and preferences. Creating a sensory informed environment can transform the rehabilitative atmosphere from a triggering chaos into a soothing haven.

Sensory overload is providing a consistent, unmovable roadblock for people who want to regain their family roles, return to work, and integrate back into their community's post Acquired Brain Injury. In the hyper charged world that surrounds us, there are a multitude of voices highlighting the benefits of unplugging, of meditating and mindfulness, of connecting to nature instead of connecting to devices. There is a plethora of studies that point to the importance of quietening our surroundings, and taking regular breaks from our intensely stimulating, ultra-bright, ultra-loud all-encompassing environs but these recommendations are so often ignored. Are we prepared to listen to this present study? Are we willing to listen to the people, who due to sensory overload are being bombarded in their daily lives in

amplified spheres of sensory chaos? Are we ready to acknowledge that post ABI some people cannot ever fully disconnect, cannot ever fully unplug, the unwilling victims to the relentless sensory onslaught of our hyper charged world? Are we prepared to listen to the quietest voices, who are so politely asking us all, to please turn it down?

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Appendices

Appendix. 1 Sensory Menu

Please circle the options below to indicate how you would like the room to be set up for your next key worker session.



Windows Open / Closed



Lights On / Off / Dimmed



Music On / Off

(If you would like music on, please give examples of songs/music you enjoy listening to)

- 1.
- 2.
- 3.

Heating On / Off



Type of chair With arm rests / Without arm rests



Tactile items

Would you like to use a stress ball during the session? Yes / No



Are there any other tactile items that you would like to be available? Yes / No

- 1.
- 2.
- 3.



Coffee



Tea

Would you like tea/coffee during your session?

Alternative beverage _____

Is there anything else that would aid your sensory needs?

Appendix. 2 Information Sheet for Research Participants

Name of Researcher: Jennifer Cotter

Background: I am a [REDACTED] [REDACTED] I am completing a master's degree in Munster Technical University (MTU). I have received a scholarship from MTU to complete this study. I am researching Sensory Overload post Acquired Brain Injury.

Purpose of the study:

The primary aim of this study is twofold.

- To highlight the lived experiences of people living with sensory overload post Acquired Brain Injury in Ireland.
- To investigate how the ABI rehabilitation environment can be improved and tailored to reflect the sensory needs of service users.

Important points to note:

- ❖ If you have any questions or queries or you simply just want to talk about the study at any stage, please feel free to ask me or my supervisor, our contact details are at the end of this information sheet.
- ❖ All participation in this study is voluntary, there will be no payment or reward for participating. You can withdraw from the study at any time.
- ❖ The information you provide will be used in the research study. All details are completely confidential and no names or identifying features will be used. The data collected will be kept safe and secure in accordance with the Data Protection Act 2018. The data will be destroyed after five years.
- ❖ In order to take part in this study participants must give their consent.
- ❖ This study has been granted ethical consent from the MTU Ethics Board and the Headway Ethics Board.
- ❖ The results of the study will be presented to the participants when it's finished.

Contact Details

Jennifer Cotter – [REDACTED]

Dr Joe Moynihan – [REDACTED]

Appendix. 3 Consent Form for Research Participants

Participant:

Researcher: Jennifer Cotter

- I confirm that I have read and understand the information sheet for this study and have had the opportunity to ask questions

- I understand that my participation is voluntary, and I can withdraw from this study at any time

- I agree to take part in this study

- I agree to the interview being audio recorded

- I agree to the use of anonymised quotes in this study

Signature

Date

Appendix 4. Sensory Portfolio Prototype

Name Jane Doe

Date

Current Sensory Needs

Home

Jane reports that she needs a quiet place in her home to gather her thoughts and to rest when she is feeling overloaded. A lamp with a dimmer switch, a soft blanket and an eye mask help Jane relax after a busy day.

Community

Jane likes to travel to the community mid-morning. Jane explains that this is generally a quiet time to meet friends and do errands as it avoids the commuter rush in the mornings and the lunch time rush later in the afternoon. When booking appointments 10am to 11.30am is Jane's preference.

ABI rehabilitation service provider

Jane has informed the team that she likes a seat with arm rests which is positioned away from the window. Jane does not like to sit near the laptop due to the sound the charger emits and prefers to go to the sensory room during the lunch break as the sounds of tea/coffee being made and the general increase in noise in the room at this time of day can be overpowering.

Current Sensory Triggers

Jane reports being triggered by the dishwasher being loaded or unloaded in her home or similar noises in the community – particularly coffee shops.

If noises are competing Jane reports finding it difficult to concentrate, for example recently during a routine dental appointment the dentist was trying to speak to her while the radio was on in the background and Jane could not take in the information.

If her nieces and nephews are visiting Jane can be triggered by toys clattering together such as Lego blocks, Jenga and toys with loud sound effects.

Current Sensory Soothing Activities/Aids/Places

Jane likes to go for a walk on the local greenway, she finds 4pm is generally a good time as it's not too busy.

When her nieces and nephews visit Jane has a basket of soft stuffed toys and puzzles for the kids to play with or she reports enjoying gardening with them in the warmer months.

Jane likes Smiths coffee shop as they have outdoor seating at the back in their garden which is sheltered and quiet.

Appendix 5. Interview Transcripts

Interview 1 Transcript

Pilot interview

Service User Liam (72) pseudonym

After a short discussion about the researchers studies and Liam's background the interview got underway.

Researcher So will we look through this?

Liam Ah yeah, very good

Researcher So I'll read it out there for you, so it's just a consent form for this, the pilot, the interview, and the emotional mapping exercise

Liam Yeah that's interesting, I never heard of emotional mapping before

Researcher It's new to the social care world, it's not new to the geography world but it's new to the social care world

Liam Ah I'm with you

Researcher So I say here in the consent form my name is Jennifer Cotter as you know, I'm completing a research study, I would like to invite you to take part in this study as your input would be greatly appreciated. That's first off.

Liam I'd love to

Researcher Fairly self-explanatory there?

Liam Absolutely, very clear

Researcher This study will explore what it's like to experience what it's like to experience sensory overload following an Acquired Brain Injury. So that's the next thing we're going to do

Liam That will be interesting too

Researcher Sensory overload affects some people, not all people after a brain injury

Liam Yeah my problem, if I was talking to three or four people at the same time I get completely confused, I wouldn't be able to look at them all at the same time you see

Researcher Yes and do you find it hard to filter out what each person is saying?

Liam Oh I wouldn't have a clue, I wouldn't have a clue

Researcher That can be a common difficulty as well, so just as you said if three or four people were talking it can be hard to decipher who is saying what

Liam Your head starts going around (gesturing spinning)

Researcher Yes, so when someone is experiencing sensory overload it could be their vision or their sense of hearing that's effected, a lot of people will find really loud noises will affect them

Liam That affects me too

Researcher Does it affect you as well?

Liam Oh yeah

Researcher It might make you feel overwhelmed or a little bit full up?

Liam Well you see the thing is, the head starts to spin around like, and I could fall down like, I could fall down

Researcher Yes,

Liam I'd have to sit down

Researcher Would you have to just sit down and take a break maybe?

Liam That's right

Researcher So looking at sensory overload, let's just say now we started this session and if I had really loud music going on in the background, if I had flashing lights, a bit of a disco going on or these really bright fluorescent lights aren't the best

Liam Jesus Christ (laughing). Well, I have this on (referring to his cap) to keep the light out because if too much light gets in, the eyes close,

Researcher Ah yeah, so the hat helps?

Liam have no problem with that (gesturing to his cap) so that's why I have to wear it all the time

Researcher and that helps you does it?

Liam Oh it makes an awful difference

Researcher Well it's good to have those strategies in place

Liam Oh it is, you have to

Researcher Exactly if we had too many bright lights or if it was too hot maybe?

Liam That affects me too

Researcher If the heating was on and there was blaring music...

Liam Or too cold, extremes of anything affect me

Researcher That's a good way of putting it, the extremes. So, people with sensory overload find that very difficult and it can affect people in different ways, you just mentioned a few of your own examples there and it can affect people in lots of different ways

Liam Yeah

Researcher So even tactile, something you can feel

Liam That's true

Researcher Sometimes you know like kind of putting on an itchy jumper

Liam That's right it would begin to annoy you like

Researcher Yeah exactly, so I'm looking at just here where it says (referring to the info pack and reading it out) the study will explore what it's like to experience sensory overload, just what we were discussing, following an Acquired Brain Injury, when a person's sensory processing skills are altered, the person may become overwhelmed or distressed by common stimuli, the stimulus may be external for example fluorescent lighting

Liam Yeah, the lighting

Researcher (reading) or internal for example fatigue

Liam Yeah

Researcher so it says (referring to the info pack) this study...

Liam Fatigue

Researcher That could be a big one, this study will involve emotional mapping, this is a tool traditionally used for geography research, for example to find out where residents feel calm or stressed in their local area, the aim of this research is to use emotional mapping to identify what kind of settings and environmental factors Headway clients find most therapeutic for their sensory needs.

Liam Oh yeah

Researcher and explore how these can be incorporated into Headway services

Liam Very good, that's interesting now

Researcher so another example would be for a key worker session, if we could tailor it to each person, so for example let's just say if you said I'd love the windows open, not too extreme, not too hot not too cold, I'd like maybe a dimmer light and a little soft music playing in the background , then straight away your environment is being tailored

Liam Yeah, it's true

Researcher To yourself, yeah and improved

Liam That's right

Researcher So that's what we're looking at doing for each client cause everybody's needs would be different

Liam That would be lovely altogether

Researcher The next piece says (referring to the info pack) all participation in this research study is voluntary, so you're volunteering to do it

Liam I'd be delighted

Researcher (reading through the info pack) I acknowledge this might be a sensitive topic, if you agree to participate and you would like someone with you for example your Headway keyworker, a family member, a friend, or any person of your choosing while you take part in the study please just let me know

Liam No I'm happy out

Researcher You're happy out

Liam Absolutely

Researcher and you can withdraw from the study at a time, so if we were just looking at it (referring to going through the interview questions) and you decided, do you know what I'm getting a bit tired here or I've kind of lost interest, that's ok, you can withdraw

Liam Ah no problem, I know I'm very interested because it's good for me finding out more about what Headway can do to make me feel happier

Researcher That's exactly it

Liam Yeah

Researcher It says (referring to the info pack) the information you provide will be used in the research study, all details will be kept confidential, so I won't be putting your name or anything like that

Liam Ah no problem

Researcher and no names or identifying features will be used, the data will be kept safe and secure in accordance with the Data Protection Act, and all collected data will be destroyed after five years

Liam No problem at all

Researcher It says by signing this form you are agreeing to take part in the study and there's just a place for a signature

Liam Oh grand

Researcher and at the end it says if you have any questions or queries, please don't hesitate to contact me and my details

Liam So will I sign it for you so?

Researcher If you like, if you want to sign it

Liam I'd be delighted

Researcher and then we'll go through the study, we'll go through it then together, yeah wherever you like now, that's the line there for it (referring to the signature line)

Liam The old writing isn't so good

Researcher That's quite alright, make your mark

Liam That's the job now

Researcher Thank you very much

Liam and will we be told the results at the end?

Researcher Yes, that's a very good question

Liam We'll be looking forward to that you see

Researcher That's a very good question, I will, I will be presenting all the details at the end

Liam That's fabulous

Researcher So we'll have another session just like this and I'll go through exactly what the study found and the results

Liam That would be great

Researcher Perfect, so this is what I'm going to send out to each person who's taking part in the study and then I'm going to send out the information sheet,

Liam Yeah

Researcher The information sheet just gives a little bit of background which we've mentioned a few things here, (reading from the info sheet) I'm a Headway staff member and I'm completing a master's degree in Cork Institute of Technology,

Liam Yeah CIT

Researcher Yeah

Liam and who are you working with there? Who's your supervisor?

Researcher Joe Moynihan

Liam Joe Moynihan

Researcher He's in the Social Care department

Liam Oh I wouldn't know them fellas

Researcher I know that you were in (previous workplace) yourself

Liam and I know -----

Researcher Oh very good yeah you would know -----

Liam He was working in ----

Researcher So you'd know him

Liam I'd know him well

Researcher All the connections

Liam I'd often meet him like

Researcher Yeah

Liam We'd go for a few pints sometimes, I shouldn't be saying that though (referring to ABI rehab's no alcohol policy) (laughing)

Researcher So it just explains here (referring to the info sheet) I've received a scholarship from CIT to complete this study, so I got a scholarship to do this

Liam Great

Researcher (reads out rest of info sheet)

Liam That's fantastic

Researcher (reads out the important points to note on info sheet)

Liam No problem, I have no problem doing it because I have overload problems all the time

Researcher Yeah, you're finding that you have it

Liam All the time

Researcher Hopefully this study will-

Liam It will help

Researcher I hope it will, this next piece (reads out the rest of important points to note including the ethics board approval)

Liam it's all kind of been given the ok (referring to the ethics board approval)

Researcher It's been given the ok

Liam It's great to be able to do something and for me a client to be able to give something back is great too

Researcher Well I appreciate it, I appreciate your input (reading the last section of the important points to not sheet) the results of the study will be presented to the participants when it's finished, so just as you asked there

Liam That would be nice

Researcher and here are our contact details. So, this first task is, these are just interview questions and we're just going to see if they are clear and if they are easy to understand first ok? So, the first one asks can you please tell me a little bit about how you got your brain Injury

Liam Yeah no problem, will I tell you?

Researcher Yeah of course you can

Liam It was...I had retired from ---- in October of 2005 and I had a little business set up at home for testing food products for their microbiological qualities, so I had two or three people working in a laboratory testing for bacteria like salmonella, listeria and all that sort of stuff and I was hoping that I would retire and be able to help them in the lab, something to do when I retire.

Researcher Of course

Liam So as I say I retired in October and then what I used to do for the first couple of months was I used to drive around Cork and Kerry and collect the samples back to the lab and then the lads in the lab would look after them you know?

Researcher Ok

Liam But of course I used to get up in the morning at about six o'clock, I'd be on the road at about seven o'clock and say one day a week I'd head down to Clonakilty and Skibbereen and West Cork and collect loads of samples and I'd drive back as quickly as possible to bring the samples back, kind of lunch time, if possible the lads would put them on

Researcher Yeah

Liam I'd stay in the lab then for the rest of the day with the lads and I'd help them out like, and then in the evening the lads would finish up about half past four or five o'clock, there were two girls there from ----- and they used to have to drive home and then if there was a few jobs cleaning up and things I'd do the cleaning up and then I'd go home around six or seven o'clock myself

Researcher Great

Liam I'd do that most days, it was grand, something to do but then unfortunately coming up to Christmas, normally on Christmas Eve I'd go down to the kids mass at half past six down in the new church and it was great craic because the priest would be talking to Santa Claus and everything (laughing)

Researcher (laughing) Oh ye would have fun

Liam and he'd be telling the kids now if ye're not quiet he won't stop at all

Researcher A very good strategy

Liam They'd shut up straight away of course (laughing). After that then about half past seven I'd meet up with my sons if they were at home, the three of them, two or three of them and we'd go up to town and we'd have a few pints inside in ---- and then we might go over to ---- - because that was a great place because you'd want to be known to get in there, it was that kind of a pub

Researcher Ok yes so you needed to be local

Liam that's right and going back, this is going back fifteen years ago now women weren't allowed in at all, it was only a man's pub

Researcher They were very brave (laughing)

Liam Oh we were and we'd break in if we weren't left in (laughing) and we'd go in there and of course the music, it was all pints like you know, and we knew that Santa would come at the end of the night but generally Santa might not come until one or two in the morning so we'd be locked in and we'd be drinking away. We'd love to be locked in (laughing) I think that night I had to go back to the lab, this was Christmas Eve 2005, I had to go back to the lab to do a bit of work that the lads hadn't finished so at about 11.30 I left ---- and walked away home and went into the lab, and we had a little computer there where we'd put in results you know positive or negative and you'd put down the results and I did that for an hour or two and I was finished at about half past one or that, I went home then, my house my was behind the lab, it was only about fifty yards away and I went home and I went in and locked up the place and made myself a nice cup of tea

Researcher Yeah

Liam and sat down and I was drinking my cup of tea and seemingly I had my shoes and all sitting down and I didn't know anything I was feeling grand altogether and I must have keeled over because my son ---- who's living down in the garden he was coming up for Santa Claus about six or half past six in the morning because we used to open the Santa presents early

Researcher Of course

Liam and didn't he find me there on the floor

Researcher Oh my goodness

Liam and he rang the ambulance and he had me inside in the hospital for 7 o'clock or something and lucky enough there was a neurosurgeon I think they call them inside in the hospital who was looking after someone else who had gotten kicked from a horse down in -- ---- the same day and he said to the lads in the ambulance leave him there and I'll have a look at him because he said he doesn't look too good now and I'd prefer to leave him there for an hour or two to see if he'll come around a bit before doing anything so he said look let ye head away home and have ye're dinner or whatever was going on and I'll be in touch with ye later. That was....he found me at 6 o'clock in the morning so it must have been 7 o'clock in the day when I got to the hospital

Researcher Yes

Liam and he sent them away home to have their dinner and then at about 6 o'clock he rang them to say your man isn't getting any better so I'm going to take him up and do a little operation and hopefully things work out ok so they gave him the permission and off I went. I was taken over then and I think my brother (name) was with me because to have somebody with me and I don't know a couple of hours and when we were coming down anyway sure I

was out I didn't know what happened, my brother (name) he told me after he asked the doctor (name) how did the operation go and he said to (brother's name) it was as good as an operation as I've ever done and like he's still awake or alive anyway I might not have been awake but I was alive

Researcher Yeah

Liam and he was happy out

Researcher Good

Liam So that was a great start weren't it?

Researcher and that was the stroke that you had

Liam and that was Christmas Eve

Researcher My goodness

Liam and I was in hospital then I suppose for a month I suppose before I was left home

Researcher Yeah

Liam People used to come in and see me in the hospital and sure I couldn't see or hear or anything like you know after the stroke

Researcher Yes

Liam I think my talking was only mumbling

Researcher you've come so far (client's name), you put in the work, and you've come so far over the years

Liam I was like that for two or three years until I got to Headway and when I got to Headway, I didn't know what was wrong with me you see, and I would wake up in the morning and I couldn't see anything, and I'd be saying Jesus what am I going to do for the day

Researcher and was your vision was affected?

Liam Yes I lost the sight in this eye (referring to his eye)

Researcher and you said your hearing as well was it?

Liam Oh yeah, I couldn't hear properly either, do you know I was mumbling with my talking, and I couldn't walk either because my balance was gone, the balance was very bad, and the balance is still bad

Researcher So that was your vision, and your hearing and your speech and your balance

Liam Yeah and my left side was damaged as well, my arm, I couldn't move it too well

Researcher Yeah

Liam and my leg , I couldn't move my leg properly, and that's still a bit iffy like

Researcher and how was your sensation, how was your sense of sensation in your hands and things?

Liam Well I can feel things but smell now , I can't smell anything like you know

Researcher No? and is that still the way?

Liam Oh it is yeah, if you were cooking now (sniffing) like the wife would be cooking different things at home and she'd be saying I have lovely...for the weekend now she had bacon and cabbage, and you know you can smell that, sure I couldn't smell it at all

Researcher Oh

Liam But I knew what it was I didn't care

Researcher Yeah

Liam But I can see it

Researcher and when your smell is affected is your taste effected?

Liam It is yeah, it is, it is

Researcher Is it kind of dulled? or how would you describe it?

Liam Well sometimes you'd be eating, and you wouldn't know what you're eating

Researcher Ok

Liam You couldn't get the taste of it

Researcher Yes

Liam You'd know if it was tough though

Researcher and Liam (laughing)

Liam Have to be eating it longer and longer

Researcher Of course, you'd know a tough piece of meat as opposed to the good piece of meat

Researcher Well you've answered question 2 here (client's name), were your senses altered after your injury? And they very much were

Liam Very much so

Researcher and (reading through the question) how were they altered? And you explained that perfectly, you explained your vision and your hearing, your sense of smell and your sense of taste

Liam Yeah and my peripheral vision on the left side was gone completely

Researcher and that's still gone?

Liam It is yeah, and I can't see to my left and I can see an image of you, but I haven't a clue who it is

Researcher Ok

Liam and this eye, I know who you are (referring to right eye)

Researcher you know who I am

Liam That's right

Researcher Will we look at question 3? Thank you for sharing that. It asks what kind of environments or places make you anxious or uncomfortable?

Liam Oh

Researcher Is there anything, any place?

Liam Places that I'm not familiar with

Researcher Ok

Liam Like going on holidays now, I don't be taken, I hate going on holidays because I don't know where I'd be

Researcher Yeah

Liam Because one time, and this only goes back I'd say ten years ago, my son (son's name) did his third level in (city name) and was doing (name of course) and one of the girls in his class (name) they were going together and they eventually decided to get married so we went over to (city name) for the wedding and we went over for four or five days and the day before the wedding anyway I was trying to make a little speech and there was a nice park a couple of hundred yards from the hotel and so I said lads I'm going to go down there now for a walk, I'm going to practice my speech down there so off I went to a lovely park, I don't know what it's called and there was a big lake and loads of people around so I went down a good bit near the lake and I sat down and I practiced the old bit of writing I suppose and I practiced it for about half an hour and I was happy enough you know

Researcher Yeah

Liam I didn't want to say too much (laughing) but I got up then and I went back , I thought the same way as I came in but Jesus Christ I couldn't find the way out

Researcher You got a little bit turned around

Liam I got lost I suppose

Researcher Yeah

Liam and I spent half an hour walking around, Jesus says I how do I...so instead of going back I decided I'd go over this way and eventually I found a way out but when I got out sure I didn't know where I was, it wasn't the same road I had gone in at all

Researcher Did you have to ring somebody in the end?

Liam I had no phone and no money so I couldn't get a taxi or anything

Researcher You were rightly goosed

Liam I was goosed so Jesus says I'll chance this road and we'll see what happens because it was interesting the day before we had been taken down to the church to show us where we were sitting and (wife's name) and a couple of her friends from the flower club were doing the flowers and they were doing the flowers when I went down to do my speech and says I, I know the name of the church (names church) if I see somebody I'll ask them where that is and if I go in there they might be in there

Researcher That was good thinking

Liam So I went up the road and Christ there was nobody originally, I came across a few houses and there was fella's outside drinking coffee and says I, I'm looking for (names church) and they said you're only just across the road from it so I hadn't a clue where I was and I said gee that's great so I went across the road and into this big huge church and went in and do you know it was it was an unusual church kind for a name, it wasn't a Catholic church or a Protestant church, it was communal, is there such a name?

Researcher Oh Yeah there might have been some kind of community church

Liam there was nobody and I find the stairs and I went out and down the stairs and there was someone and he said are you all right are you looking for someone? I said I'm looking for the girls with the flowers, Oh Christ he said they were there up to a half an hour ago and all the flowers are here now, and they have them all set out for tomorrow. Oh, Christ he says they're gone, Oh Jesus says I, I said I went for a walk in the park over across the road and I was practicing my speech for the wedding tomorrow, and I got lost and I don't know where I am. He says where is your hotel? Whets the name of your hotel? Jesus Christ I didn't remember

the name of the hotel, I hadn't a clue, but I said it's a new hotel and there's loads of windows in it

Researcher That was good, you described it, that's very good

Liam He was saying I'm driving up that direction, I must go up and do another job if you want to sit in with me and if you see the hotel you can let me know so he drove a bit, we were driving away and sure I hadn't a clue, I didn't see any hotel and after a while...I think he drove around a couple of different times and...

Researcher Do you need a glass of whatever or anything?

Liam No I'm grand now

Researcher Are you sure?

Liam Ah yeah, after a while I said do you know I think was there loads of glass windows back there a little while and he said oh there was that's the (name of hotel) Jesus I'd say that could be the one so he left me out anyway and off he went on his way and I went back and went in and sure is God it was the right hotel alright and they were all inside, first thing where in the name of Jesus where you? We were waiting for you there for the last five or six hours and we said surely to God you were gone to the pub and I said I couldn't cause I had no money. That's the first thing I said I'd be gone if I had money

Researcher No money

Liam and they were giving out like stink, Jesus Christ you can't go out anymore, (inaudible)....for tomorrow

Researcher That would be the important one for the wedding

Liam It was yeah

Researcher but you made your way back in fairness

Liam I did, I did yeah

Researcher So unfamiliar places make you a little bit-

Liam I get completely lost there so I was told I'd never again be taken away on holidays because if I get lost they'd never find me like. I tell you, I didn't have my mobile with me, or I didn't have money so by Jesus I said I'd never again go without my money and my mobile

Researcher Yes exactly you need to bring those two

Liam and the name of the hotel,

Researcher This is it,

Liam Jesus Christ I never knew where we were staying

Researcher but sometimes we learn those lessons don't we

Liam The hard way

Researcher The hard way a little bit absolutely

Liam That was an awful state, Jesus

Researcher Is there any noise, activity or place that make your symptoms worse? Or trigger your symptoms?

Liam Oh...loud noise

Researcher Loud noises

Liam Like say, if the radio or the television was on loud I'd have to go and turn it down straight away, I love listening to the radio for music but only at a certain sound level

Researcher Yeah, it has to be at a certain-

Liam Or like I couldn't go to a match now because the shouting and roaring would be too much for me like

Researcher That's a good example

Liam I couldn't do it

Researcher You'd like to watch the rugby on the tv, big game coming up

Liam Oh Sunday I think

Researcher Yeah

Liam I'll be shouting and roaring myself

Researcher I know I know but that's different

Liam Oh it is yeah, I'm allowed do that

Researcher You're allowed do that, is there any kind of place or environment (name) that helps you to relax?

Liam Yeah, coming to (name of service) is fantastic, I love coming Tuesday, Wednesday, Thursday, Friday because I know everybody is nice and polite over here because at home they're very negative, they give me the impression...they'd be saying to me there's nothing wrong with you, do you know I'd be saying Jesus Christ almighty you know after fifteen years now they surely know something about strokes that it effects people

Researcher Yes

Liam I'd say they'd be trying to put me down you know and what I'm afraid of now is they're trying to put me into a nursing home and sure is God the last place I'll go is a nursing home

Researcher I understand

Liam If I go to a nursing home I'd be out the following day and I'd get the bus down to (holiday home address) and go into my own little house down in (holiday home address) and I wouldn't tell anybody and I could f*cking stay down there and they could shag off

Researcher I understand

Liam I wouldn't, I wouldn't

Researcher So you like coming to (name of service) is there any other place that helps you to relax?

Liam I have a lovely conservatory about the size of this room or maybe a bit smaller, it's about 12ft square onto the conservatory looking out onto (holiday home address) and beyond (holiday home address) then you have (other locations)

Researcher So it's beautiful

Liam You can see all that like you know, and of course when I go down I (talks about scenic location specifically) the conservatory now, it's built onto the gable of the house and it's kind of 12ft square so there's three sides of it and the rest of it is onto the gable and there's a door on the gable end going to the main house and the three sides then, there's a little wall going up about fifty inches and you have a what do you call it window boards, there's glass then going up about five feet up to the ceiling and tis like say each twelve feet the roof is half up

by a little steel bar every like say into the gable and they're four inches square and then six feet and then four inches square and then in the corner there's another one so in between there's glass about six foot wide and you have about five feet double glazed, it's extra tough so you can't break it and tis tinted or something so it wouldn't blind you, you know

Researcher You've thought of everything

Liam Looking out to the sea that's the happiest place, heaven, sitting down there and looking out to the sea and my music on and just be bopping away

Researcher Is it the scenery? Is it the space itself? Is it a bit of everything?

Liam A bit of everything yeah and it's the comfort because like tis facing south so when the sun gets up in the morning you can see out the window at 8 o'clock in the morning and when you go in there, like if I'm down there now I always get up about half past seven, 8 o'clock and I go out and tis 18 or 19 degrees inside there in the morning

Researcher Beautiful

Liam and then at lunch time tis about 22 or 23 or 24

Researcher Yeah

Liam and sure Janey mack and there's heat in there as well, in the winter time I turn on the heating

Researcher That's your happy place

Liam Happy as Larry, happy as Larry but unfortunately I'm not allowed go down there anymore

Researcher I know

Liam and that's a killer

Researcher and maybe we'll discuss that a little bit more in a keyworker session

Liam The problem I have now presently is that I can't...

Researcher You can't get down there enough

Liam I built this house myself, I started in 1982 with the bulldozer, that's 82, 92, 2002 and I suppose after about twenty years I had the roof on and you could sit outside in it then and then I did the bedrooms first and then you could stay in it and you could still work away you know and I used to drive up and down for work, of course I was working at (place of employment) from 82 until 2005 so that was 25 years, I used to take long weekends, I used to finish in (place of employment) about 2 o'clock on a Friday and I wouldn't go back then until Monday morning and I'd be down in the house for the weekend

Researcher A labour of love that house is

Liam I'd get all my buddies to help me over the weekends like people I used to work for myself

Researcher Yeah

Liam I had carpenters and plumbers and electricians, and we'd all go and do all the work for me (laughing)

Researcher (laughing) you had the lot, you had the lot (name)

Liam it was a labour of love, I had an account with the credit union and my money used to go in there from (employer), no it wasn't the credit union, it was the (name of bank) and my money used to go in there and I'd go into them and I's explain look I'm building a house down

the road, and I need five or six thousand to continue the building and they'd give a loan then for a couple of months and then the money going in from (employer) would pay it off you see

Researcher Yes

Liam and I'd go back then and get another one and I'd say I went up to ten then at that stage cause the five wouldn't keep me going too long (laughing)

Researcher (laughing) you were spending

Liam and after, well I don't know how many years, I'd say about 25 years anyway the place was finished

Researcher Yes

Liam I had no mortgage or anything on it because I had it all paid off as I went alone

Researcher you had it all done, that was the way to do it (clients name)

Liam amazing

Researcher that was the way to do it

Liam I can't go down there now

Researcher I know that's a difficulty (name)

Liam I was just checking the other day now, August weekend was the last time I was down there now, that's almost six months

Researcher That's a long time

Liam about two weeks ago then, my buddy (friend's name) asked me to take a day off, it was last Tuesday two weeks and I said to (service manager) my buddy is doing a job down in (place

name) he was measuring up a small farm of 45 acres and he was checking it out to see if it was 45 acres and he wanted somebody to hold the tape so I hold the tape no problem and he said he'd put in his little report and I'll get paid but he said we'll go down now to the (holiday home name) and have a look because it was a sunny day and we'll got through (place name) and if we're going through (place name) we'll stop in front of (name of restaurant)

Researcher I know the one

Liam and across the way there's a tourist office and we'll go in there and get the bus schedules

Researcher and you have a meeting with (keyworker) and (name of Liam's friend) on Thursday about that

Liam Do I? he didn't tell me that now at all

Researcher I think that's the case

Liam I have a problem because I don't want to be asking (name of friend) to take me down because Jesus Christ he has his own things to do

Researcher We might discuss that outside of this with (keyworker)

Liam No problem, no problem

Researcher Thank you for sharing though

Liam Ah no

Researcher So this space-

Liam If I get distracted now because I have a terrible habit of rumination, I always go back to (name of holiday home)

Researcher I understand

Liam and the problem I have down there cutting the grass and everything

Researcher and that's ok that's alright. This particular space (name), what do you like about this room? Anything in particular?

Liam It's lovely and comfortable in here now

Researcher comfortable

Liam It's lovely and bright

Researcher Good

Liam You know I can see the lockers there now and I can see the photos, but I can't see who's who, It's nice its comfortable

Researcher Ok,

Liam It's comfortable

Researcher You like it, the comfortable space, and the brightness,

Liam I see the social outings up there, but I can't see the pictures, they're too far away

Researcher Yes, the pictures

Liam but it's nice to see them

Researcher That's great

Liam and then behind me, that's gardening pictures I think

Researcher I think these are some sayings like, be kind

Liam Oh that's right, there's a lovely one there, small steps at a time

Researcher Yes exactly

Liam That's a good one

Researcher That is a good one

Liam I have a habit of running

Researcher What about...is there anything that you don't like about this room? Anything that could be improved maybe?

Liam Is there a crack in the glass? (referring to damaged panel in glass door)

Researcher There sure is

Liam Yeah that should be replaced, in case it falls in and we get cut

Researcher Absolutely, anything else about it

Liam It's grand, it's grand, it's lovely and bright and the ceiling is grand and white and the wall is kind of creamy,

Researcher It sure is

Liam Happy out

Researcher If you could add one thing to this space, what would you add?

Liam Put a few pictures on the wall, pictures of maybe the building, the outside of the building and the garden like

Researcher You love the garden, yeah

Liam They'd be lovely, I'd be pulling all the weeds and the flowers and everything

Researcher and if you could take something out of this space what would you take out?

Liam Not really no

Researcher No

Liam You'd have to leave the fire thing there,

Researcher The fire extinguishers, do you think we need the two tables? are you happy with the two tables?

Liam Do they be used? We use them on Friday for the...(word finding)

Researcher Art therapy?

Liam Art therapy yeah, that's right yeah

Researcher That's fine, so you wouldn't take anything out

Liam There Are a pile of chairs there, but they're needed across the way sometimes

Researcher That's true yeah, could we declutter the space a little bit like maybe with the chairs

Liam I don't know, they're nicely stacked up there behind

Researcher Ok so (reading) what does this space feel like, sound like and look like?

Liam Well with you talking now the sound is very good, there's great vibration or something

Researcher You can hear, it's clear

Liam Perfectly, perfectly

Researcher Good

Liam It isn't too loud it's just nice

Researcher Good

Liam It's nice and bright

Researcher Good

Liam I wouldn't change anything here

Researcher and we already kind of discussed this one, the last question is could you please describe your favourite place? and you described (holiday home address) perfectly

Liam Well (ABI rehabilitation service provider) number 1, (holiday home address) number 2 and (home address) in there somewhere 3 or 4 or 5.

Researcher Well those are all the interview questions (clients name) thank you so much for sharing. I'm just going to lastly show you the sensory menu that I'm looking at, so for example if you were coming in for a key worker session or you were coming in for maybe an Individual Goal Planning (IGP) meeting or your first meeting in -

Liam That's the goals is it (referring to the Individual Goal Planning meeting)

Researcher That's the goals, spot on. We would circle the options to indicate how you would like the room to be set up for your session

Liam Oh

Researcher So for example windows open or closed is the first question and we'd ask everybody this.

Liam Yeah

Researcher We'd say would you like the windows open or closed? You mentioned the extremes of heat for yourself

Liam well if it was hot, I like the fresh air

Researcher Yeah

Liam When I get up in the morning I come up to my room and I have one or two tablets to take and I take them and then I get up, oh yeah and there's a kind of a French door on one side and the blinds would be pulled so I pull the blinds back to leave the light in and then I have a big window looking west and then I'd pull up the blinds and I'd open the window to see how cold it is and let the fresh air in, I love a blast of fresh air in the morning it wakes me up

Researcher That's nice and fresh absolutely, so for example the windows open or closed and we have a window here (referring to the photo on the sensory menu) the lights on, off or dimmed

Liam I'd say dimmed mainly

Researcher Dimmed yeah (filling out the menu)

Liam Because if they were off it would be too dark

Researcher Might be too dark

Liam and if I didn't have my hat on it would be too bright, if I had my hat on I'd be happy out

Researcher I'm just going to circle these (circling Liam's choices as we went along)

Liam Oh very good

Researcher Music on or off?

Liam Oh I love a bit of music, nice and not too high anyway

Researcher and if you would like music on could you give an example of a song or maybe the type of music you enjoy listening to?

Liam I suppose the stuff I like more, my favourite is Christy Moore

Researcher Christy Moore

Liam You know Ride on is one of the songs, who asked me...

Researcher (writing down preference) you were talking about it recently were you?

Liam It must have been at the choir or something

Researcher Oh, probably was

Liam Yeah they were asking people their favourite songs and I was Christy Moore and they said which one and I couldn't remember the name of it and I said it was all about horses, I couldn't remember the name of it, my God, Jesus Christ, I'll never forget it

Researcher We discussed this one a little bit, heating on or off?

Liam Like today now is perfect,

Researcher Perfect ok, so temp we'll say not too hot, not too cold

Liam Body temperature

Researcher Yeah that's a good way of putting it

Liam 30 or thereabouts like, or below

Researcher (writing down preferences) and then the type of chair you're sitting in (name)

Liam Oh that's fab, I like one that I can lean back like that (demonstrating) because it helps me sometimes breathe (demonstrating by taking deep breaths)

Researcher Yeah kind of opens up the chest a small bit

Liam Yeah it does yeah, and I put my arms back like that (demonstrating)

Researcher So you wouldn't like one with armrests you prefer without?

Liam Oh sometimes, I have ones with arm rests at home and they're good too, I probably would, either way I wouldn't be worried about the arms

Researcher You wouldn't be worried about the arms, ok, so maybe without arm rests maybe you can breathe a little better (makes note on sensory menu)

Liam Yeah they'd be lovely now those ones (referring to photo in sensory menu) with the backs

Researcher These ones (referring to the photo)

Researcher Would you like to use a stress ball during the session

Liam No

Researcher Or any other tactile item you would like? Anything else, you don't find the chairs itchy or anything like that?

Liam Oh no, no,

Researcher Perfect, what about the old beverages (referring to the photo on the sensory menu) what do you think? Green Tea?

Liam Green tea or a glass of water either way

Researcher Yeah

Liam Probably the green tea, because I love the old green tea. The thing is when I go to - I don't bring my own bags at all now because I take a bag of Barry's in the morning and I get five or six cups out of the one bag, It's grand

Researcher That's great going

Liam Oh it is yeah and it's still green at the end of the day, or black Barry's, it's kind of black

Researcher Yeah , will we just try here just a few things with our space here (gets up to change setting in small ways) for example we were talking about the light, so this is with the fluorescent lights on this is with them off

Liam I'd have no problem with it but it's gone a bit dark now like, I could take my hat off now no problem

Researcher and you'd be ok

Liam I'd be happy as Larry

Researcher Maybe if we had like we were saying the lights dimmed, so maybe a dimmer?

Liam That's right yeah

Researcher So maybe a lamp instead of the fluorescent?

Liam Yeah

Researcher It's a little bit of a cold day now today but juts as an example let's just see If we opened out the door here (opens door)

Liam Oh the sun is shining,

Researcher That's quite nice isn't it

Liam I like that now, the fresh air, yeah, oh that's lovely there now

Researcher (stands outside)

Liam Oh I wouldn't stand out there now

Researcher It is a little bit windy

Liam I can see your hair going mad but its lovely out

Researcher Yeah it is nice out, will we try maybe a little bit of music as well?

Liam Ah yeah

Researcher Let's see how that works for us

Liam Oh that has a grand screen on it (complimenting researchers mobile phone)

Researcher Let's see if we can get a little Christy Moore going here now and see if it changes up our space a small bit

Liam Lovely

Researcher Just small changes

Liam it's amazing now what you can do on that (referring to mobile phone) you couldn't do that on mine at all anyway

(Liam and Researcher talk about mobile phones for a moment)

(Researcher plays Christy Moore)

Researcher How's the volume?

Liam Perfect

Researcher It's good?

Liam Yeah because we can chat away and it doesn't bother me

Researcher Does it kind of change the space a small bit?

Liam It makes me feel much more happier

Researcher That's good

Liam That would be my kind of station, (continues to describe enjoying listening to music at home)

Researcher those small changes made a little bit of a difference, the lighting, letting some air in, the music in the background

Liam Aw it's lovely, it makes an awful difference

Researcher so that's what we're going to try out (referring to the study)

Liam and you see for a good number of years I didn't want any light

Researcher Yes it was affecting your vision?

Liam Because of the eyes but in the last five or six years things are coming back better and I'm getting back to normality I think

Researcher you're working hard at it

Liam you can be sure

Researcher (name) thank you so much for taking part

Liam I'm delighted, I'm delighted to be involved in a project like this now because (explains previous employment history)

Researcher That you so much for helping

Liam Ah no I would be delighted if we can help in any way

Researcher and what I'll do then is I'll come back just as you asked and I'll present the findings

Liam That would be beautiful

Researcher Ok we'll finish there, thanks again

Interview 2 Transcript

Service User Tom (45) pseudonym

Researcher My first question is if you could tell me a little bit about how you got your brain injury?

Tom Ok my recollection is to what happened prior to the accident, I was sitting in my office, I run my own business

Researcher Ok

Tom I have an office that runs parallel to a yard than runs parallel to a road, a public road, and it's not a very busy road, and there is a local farmer moving young cattle up the farm from his, outside farm he calls it, so he was moving cattle up the public road and I was head down in the office doing drawings, hadn't noticed the cattle coming into the yard so when I lifted my head I saw the yard full of cattle so I popped up and we had a bit of fun about it and we said I'd give him a hand just to move them up past the business, the houses that are just beside our business so our neighbours built a new house and just put down a new garden and the farmer said he's stand in the gate of the new house to stop the cattle from going in, we already had a barrier stopping them from going into our house so that was fine, I went behind the cattle, we were moving them on up and that's the end of my memory and now I have lots of different memories of this which- from now on I have two or three memories of this which kind of tells me they're made up memories because I've hear the story over and over so I've made up the memory almost of how this has happened because the farmer really has relayed the story of what happened to me, we were pushing the cattle up, we have a golden retriever and our neighbour has a golden retriever and they started to get excited about the cattle so they stated barking at each other with all the excitement the cattle got excited and they

double backed, I went to move and the farmer said he can't quite understand what exactly happened because as I moved it's as if someone caught me and flung me on the floor because on the road he saw it, he just can't explain what happened, his own words were he can't explain what happened because my feet just went up and my head went down, straight and I landed on my head and he heard the impact, he heard my skull cracking, he knew I was in trouble so he tried to stop the cattle and all the cattle came back over me and he came down and he saw my eyes rolling in my head and he thought I was gone. My wife was on night duty so he knocked on the house couldn't wake my wife up, he went down to the workshop to find some of the lads who work in the workshop, and I was lying out on the road so you can imagine the panic so after that what happened I was moved or moved and walked I really don't know, and I was in the office, and I was moaning or talking but my next memory is... I can remember the light as I was wheeled in (referring to hospital) I know I can remember that because the next time I was rolled into (name of hospital) I remember the light because the same thing happened months later (referring to being in hospital) and when I was rolled in I was saying I remember that light, it was the one thing I remember I saw the light going and I said it

Researcher It stuck out

Tom it stood out, that was I don't know how many days later days later when I remember that there were people in the beds beside me so that's the accident. When I got out of hospital I thought I was recovering, I thought I was very good. I knew I had problems but because there was no bleed really I thought I had really escaped with a minor injury because there was no bleed and according to the doctors I had dodged a bullet. Headaches, minor problems with

speech but that was just concussion, that would be fine, minor problems with balance which can often happen when you get a bang on the head

Researcher Of course

Tom That would be fine after a couple of weeks, that was how it was out to me and I was improving. I could see my rate of improvement was like that (referring to going upwards). I said fine, I'll be fine, give myself a month

Researcher yeah

Tom and I was, it happened in November, and I thought by the time we get back in January (referring to family business). I'll be able to....

Researcher New year and

Tom Yeah I'll step back, and I'll be fine and probably went back to work in January and I knew words were a difficulty, when I'd start conversation. Once I was doing stuff, let's say I was drawing and having conversations as well I noticed that words were coming out the wrong way, so I began to slow things down a small bit, I began to slow my conversations down and even still I was being caught in my sentences, when I was building the sentence in my conversation the beginning and the end of the sentence was the wrong way

Researcher The sequencing

Tom Yeah, so whatever is going on the first and last words were the wrong way around or there were things going wrong without catching it until it was out, sometimes I wouldn't hear it so I would have it said in conversation without realising because it was out, it just seemed normal to me, the brain wasn't figuring it out it was just my conversation

Researcher and in your head it was clear? But when it came out it was -

Tom yes and sometimes you wouldn't hear it because you would say it so fast and that's fine at home because we could have a bit of fun at home but when you're actually at work or selling (describes business) and you're in the sales process and you get it the wrong way around a few times, you know people are looking and saying somethings wrong here you know, once maybe a mistake but when it becomes a pattern...

Researcher maybe questioning? people start to question a small bit

Tom yeah they're not looking at the design anymore, there just becomes question marks about is he able to deliver? Do they confidence in my ability to deliver a service so it becomes a question mark about the whole thing rather than just an end product. So that began to creep in and then there's almost a difficulty to find words, difficulty in remembering names, and after a while if the conversation ran over a half an hour, three quarters of an hour and often the sales process can run in an hour maybe an hour and a half I would begin to sound drunk so slurring my words, couldn't remember their names and couldn't remember simple stuff. And already my catch was , because I had trouble with my balance, I was beginning to look drunk, I was beginning to sound drunk, so people didn't really know me that well, you waddle like a duck, talk like a duck you know, so that was the beginning of the new year, and it went on and then there is a reaction the medication which caused me to get...when you turn yellow?

Researcher Jaundice?

Tom jaundice (nods) and that wasn't picked up until I was...like one of those things you'd see on the phone, an emoji except it wasn't smiley face

Researcher No

Tom I was in the Mercy for Oh God another week, very sick, I was a week maybe a week and a half, after that then I got very sick, then it turned to, really it became a brain issue it became about self-confidence, about self-values, about self-worth, depression, and that's where I really found it very difficult, that was a very tough six months and that lead on from... the...what was it when I turned yellow?

Researcher Jaundice

Tom Jaundice, it led on from that and when I went in, the reaction to the medication, they doubled the medication rather than taking it off, there's a ..something happened, don't ask me, it was one cock up after another

Researcher It sounds like an incredibly tough time

Tom It was, it was yeah, I had to wear mittens because I was tearing my skin off with the itch from the jaundice, yeah it was

Researcher When you left hospital then...

Tom Even thinking about it is....yeah that was, it gets...

Researcher It's still very much with you (clients name)

Tom Oh Ya

Researcher and that's more than understandable. It sounds very live for you and that's only to be expected

Tom Yeah, I have great kids and I have a great wife, yeah it was unfortunate that it happened around leaving cert, junior cert, you know, but gee they've done great, the three kids have done great considering that it was around that period of their lives

Researcher Yes of course

Tom and the three of them have gone into, ironically, the medical area (laughing)

Researcher (laughing) Oh really, three out of three? That's amazing

Tom yeah (wife's name) a nurse, my wife is a nurse so the first one is (names profession), she qualified four months now

Researcher Congratulations to her, that's an amazing achievement

Tom yeah, second one is (name's profession) and the youngest is (names profession and college) so yeah that's it, that's what they wanted to so

Researcher That's amazing, so much to be proud of

Tom yeah they're great and (names wife) is incredible, what she's done right through this and kept doing with what she's had, she's had to deal with some amount of brain injury and every time, she's run the business, she's taken on extra jobs, and every time she comes to the house she would still smile, she's incredible

Researcher she's your partner

Tom Yeah she's my wife

Researcher she's your team member in that sense,

Tom yeah, absolutely

Researcher she sounds like an incredible lady

Tom She is, yeah

Researcher you said it there and unfortunately with brain injury it happens to the person, and it happens to the family unit as well so that's very very difficult but it's great to have such a support network

Tom Oh it is

Researcher It's great to have (Tom's wife's name). Those are huge pillars I suppose

Tom Yeah

Researcher and you mentioned there about your balance being affected, like your vision coming up in the car (referring to chat about vision prior to interview starting) were your senses altered after the brain injury? Did you find...

Tom Vision is...certainly it's better than what it was, immediately its where at work... I thought it was fine and the first test I gave it was before I went back to work, being a man you go and I put it to the test through physical work so I remember going out and we had got a load of blocks so I went out and I got a hatchet and I remember spending the day breaking blocks, that was my first test, I said if I can spend the day breaking blocks then I'm ready and really I was breaking a sweat all day and I said I'm ready to go back to work, I'm breaking blocks, loading them, stacking them in the shed I said if I can do that then I'll go back to work on Monday, I said if I can do all that on Friday, yeah sure I'm tired, if I can go back to work on Monday I said if I'm tired I can take a rest day on Tuesday but I'm ready to go back to work, that was my test. I went back to work on Monday because there was some enquiries and there was drawings to be done and I would do most of the design work so went in Monday,

9 o'clock opened up the computer, got out the drawing package and went designing. Jesus by half an hour done and within half an hour I was in trouble, I was in a lot of trouble, and I couldn't figure it out. I had done a full day's work and a good long day's work, of physical hard labour and within a half an hour of the computer where you're just sitting down pressing buttons, tap tap tap , one finger, maybe two, Jesus and I was wiped, I was absolutely....

Researcher spent

Tom Like I needed help to walk from the office,

Phone makes noise* researcher apologises

Tom which is 700m, I couldn't walk it and I couldn't understand what was after happening and I just didn't see the connection, I didn't understand what brain injury was and I was beginning, that was my first... that was the beginning of seeing what brain injury is and beginning to pick up the symptoms of brain injury and that was my.. I can't gather, I was gathering information and symptoms and the gathering was the first process and the learning was the next process, so the gathering was maybe six months, a year

Phone makes noise* researcher apologises and starts a new recording to prevent any further interruption.

Tom Gathering process was I suppose it comes back to my own personality and not wanting to be sick, not accepting it and that was a big...there's still a bit of the there., being straight and honest about it

Researcher Yeah

Tom I still don't want to be brain injured, I still fight with that

Researcher Understandably

Tom yeah and there are times when I feel very good, there was February, no sorry, September, October, November last year right up to December I really felt very well, I felt great and we were...we said it at home...I went through November, December where I was almost normal

Researcher Yeah

Tom We said it at home, but that took serious managing, almost normal means you don't go to the pub, you manage your energy very well, I don't drink, very careful, what environments you go into, you don't go into crowds, careful what matches I go to, if I...don't go out late, if you do go out late make sure you manage your next day very well and I wasn't doing...for November December I wasn't taking naps during the day, I might take sometimes just put my head down but I wasn't sleeping, I might just put my head down for fifteen minutes but I was never sleeping which was the first time since the accident, and that was all...it was great, I was actually tapping myself on the back and I drove into Christmas and there was no...there was no reaction over Christmas, I didn't fall flat on my face I was almost expecting it, didn't happen I had a great Christmas. The actual reaction came in...probably the second week...the end the middle of the second week in January and it was like someone too the battery out. It's been a struggle since then. We've been...I've been struggling since then...big time...and so it's taken a lot of management since the second week of January to manage my energy levels and pain levels but with...we've got it right and I've been able to work and manage pain but all of the sensory...highly sensitive...can't what's the word...can't challenge them in any way at all that's why I wouldn't come up early this morning

Researcher and that makes perfect sense, you had to manage that yourself

Tom yes I just know, I know because if I did I would have to sleep before I could talk to you

Researcher you'd be putting yourself backwards

Tom yeah and I can hear it even in my voice, my voice is slightly gravelly and that's one of the symptoms, my chords, it's the right side of my head, down my throat and right shoulder that's the nerve that kind of kicks off and so I can...I know...once I recognise the symptoms I know where I am and I know you know what time I have and if I'm away from home sometimes if I'm out pricing a job or measuring a job and if I'm an hour from home three quarters and hour from home sometimes its two hours from home. I'm rarely out on my own, normally I have someone with my doing the driving

Researcher Yeah

Tom because if I have to measure, that means following the tape, following the tape with your eyes, that would wipe me out

Researcher that would be enough that you would be tired

Tom well by the time I have measured the room spoken to the customer, jotted it all down if I'm...we found out earlier on...following the tap up and down and around the room made me very dizzy, very nauseous, gave me sea sickness so there was no way I was allowed outside to measure up, so the idea of me driving home afterwards was a no no anyway.

Researcher Yes

Tom but it's tiredness and to have me driving afterwards is just too dangerous, it's like driving after alcohol, it's the same,

Researcher The same effect

Tom Yeah, so just for everybody's sake, other people, and me, we just put into practice that I have to be with someone else who can drive. So, it's usually (names wife). So, we've kind of put that into practice and it's helped, a great help. Now it's changed the whole business and it means that...it puts...it's made the business a lot smaller, but it's manageable, it doesn't matter. It's about survival and the whole attitude of the business has changed so we don't drive the business, where before the accident I would have been about driving the business on and trying to...I would have been business like about it to a certain extent whereas we're not that way any more

Researcher Yes,

Tom so it's about survival and managing it so that we can survive until...until I get better but we're kind of coming to the realisation that this may be as good as I might ever get so it isn't a question of getting better, this is best.

Researcher maintaining your best maybe?

Tom so yes so this is the best rather than looking at a target that I might be as good as that someday, this is today this is the best I am today so whereas before I was target driven

Researcher Yes

Tom so and have plans and 3 year plan and a 4 year plan and big hairy audacious five year plan

Researcher of course

Tom so that kind of changed things because of my condition I've said maybe we need to focus on...and maybe have it a one year plan

Researcher Yes

Tom Simplify things

Researcher or a weekly plan or a monthly plan

Tom well yeah so that's where I am so it makes life simpler and everybody...we have a much smaller staff and they all understand where I am, they don't know the full picture, only (names wife) and myself would know the full picture but they understand that if I need to go I need to go

Researcher yes

Tom and sometimes in the work shop they will see the symptoms and they'll say (clients name) I think you need to take a break, they'll see them before I'll see them sometimes

Researcher yes

Tom so (name) the foreman in particular, because he suffers from migraines from time to time he'd say to me...he's kind of see my eye drooping and he's seen it before I see it, someone else wouldn't know, it's my right eye gets...I get pain behind my right eye and he'll see my right eye just twitch and he'll say yeah I think you need to go for a break (clients name) and I'd say is it at it again and he says yeah (laughs)

Researcher it's good to have that team around you I'm sure

Tom Yeah, they're good, they're great, they're great, they all stood up

Researcher Yeah and it sounds like there's a good balance, where they're honest about it but also that you take that on and that you can accept that

Tom Yeah there's no point... they've all seen it where I've tried to...I've tried to run with it where they've seen the consequences of me trying to run with it, where...they've seen me drunk

Researcher Yeah

Tom Yeah and so the consequences are ugly and

Researcher Better to get in early and kind of say

Tom prevent it

Researcher Yeah prevent as opposed to...

Tom yeah

Researcher and as you started to have a tough time in January (clients name) I hope you don't mind me asking was it something that triggered that? Or was it-

Tom It...I would say...I would say it was just exhaustion to be honest because we were all suffering it...really, we were all...because we had been on such a run of work...where all suffering from tiredness, burnout

Researcher Ok

Tom we had six months of serious high volume high value work high demand customers and...

Researcher so was it almost a saturation point at that

Tom yeah look if...coming up to Christmas some of the hours...finishing at ten at night starting at 5 o'clock in the morning

Researcher Ah yeah

Tom six days a week, sometimes seven days a week

Researcher without an injury that would be burn out

Tom I wasn't doing those hours but some of the lads were but because I'm running the business you're kind of conscious of it and if there's somebody working, I 'm working so I would have been working seven days a week and that was tough before Christmas and that came back to haunt me in January and that and customers, yeah

Researcher dealing with the public is very difficult, very demanding so to have that on top of that

Tom yeah

Researcher so you kind of touched on there about how sensory overload impacts on your daily life when you mentioned about avoiding crowds, being careful about the matches and things like that, is there any other way that it impacts that you would have to plan out your day very well or?

Tom Well I've learned to figure out exactly what sound what particular part of noise bothers me so it isn't just noise there are particular noises that bother me, metallic noises, pottery, dishwasher, I don't mind unloading the dishwasher but if I'm in the room when someone else is unloading the dishwasher it's the noise over there that's more of an issue rather than the noise here if you understand that

Researcher I understand

Tom where as if I'm clattering the knives and forks it doesn't bother me but If I'm sitting in the room over there and you're clattering the same noise that you make seems to be much harder for some reason

Researcher yeah

Tom now if I explain it (uses personal objects to visually demonstrate) that to you

Researcher take your time now if you need a break or anything like that

Tom No I'll just get (gets personal items)

Researcher or more water or anything

Tom Just explain it in mass, I don't go to mass as much as I used to because I found mass very difficult and mass...big...it's a small church...when you go into mass...you sit in your place, and we'll say you arrive five minutes early and its typical country church and most people sit in their same places all the time so (names person) has four kids (describes kids) and the kids will always be up to something so they'll be a bit of mischief in that seat which will be at the back and then (names person) will have a cough and she'll be over there and who else there would be... we'll say the choir will be over here and there might be nobody in the choir but we'll say there's somebody up the front and we'll say they have a child that is just a bit unsettled, not crying or anything but just a bit unsettled but the four...three sounds are not loud but they're almost like the sounds that are here now

Researcher Yes

Tom but those four sounds aren't huge or anything, but the four sounds tend to have an impact on the brain but it's not the volume but it's almost the pitch that they come at now how I explained it to people. If you can imagine sitting in a dark room and imagine sound is water, not sound and imagine water is coming at you in different ways and it can be a bucket or a spray or a power hose so it's sound is coming at it like different ways and so you're reacting to it in different ways

Researcher of course

Tom so it's like my brain is reacting to the different sounds but it's all over here on this side (refers to right hand side of his head) it's like my brain moves just ever so slightly so that's what's happening and it's all over here (referring to right side of head) and... I can see it's actually happening now, the tinnitus kicks off, my tinnitus gets louder because the church is particularly quiet and if the choir was singing it wouldn't be so bad because the noise...you wouldn't hear all these noises

Researcher Yes

Tom because its constant noise but if the little sounds are coming from different areas then it's like the brain is reacting to the noise the same way you would if you were in a darkened room all these darts of water coming from different areas and you don't know how to react and is it power hose, is it just a squirt is it a bucket of water that you're reacting to?

Researcher Yes

Tom but the brain is reacting kind of to the sound on this side of my head (referring to right side of head) and that's what it feels like it's like the brain is just moving to the sound it's just reacting to the sound, it's like it's unsure of it, that's what it feels like, that's the only way I can describe it just like putting it down as if you're in a dark room and someone was testing you with water or different types of water

Researcher It's an extraordinary description of what's happening, like I can almost sense it myself when you say if you sit in a dark room and you're not sure...you're anticipating it

Tom Yeah

Researcher and also you don't know what frequency is coming at you or how it's coming at you and it's all going to come at one side, and you know that but you don't...you kind of don't know what to do next

Tom well we went...before I realised that...see I thought it was all sound until we were at...we were going up to a friend of ours in Dublin and they were going out to a party and...I'm a big rugby fan...and it was the world cup was on at the time and the party was on in a pub and the rugby match was on in the pub as well so I said yeah we'll go along and (names wife) was asking how are you going to cope with this and I said look we'll go in and I said don't say a word and we'll see how we get on so I parked myself under the speaker and the screen was there (demonstrating) it was a pub with lots of tv screens but the party was on in this small area and there was a tv screen here (demonstrating) the DJ was over there, the speaker was here so I parked myself under the speaker with the tv screen here and it had no effect on me, none because...and I was thinking about it afterwards because it's like being in the darkened room but I was immersed in water so it has no effect

Researcher Yes,

Tom because I was the same as everybody else, everybody else had their ears ringing so the sound had the same effect on everybody

Researcher and is it happening to you at the minute (clients name) did you say?

Tom my ear is...I have tinnitus but it's not too bad but when there's people running around (gesturing to the noises in the building)

Researcher and if I played music, would that alleviate it for you just some white noise or

Tom shakes head no

Researcher no that wouldn't help

Tom no because there's still....it's the footsteps...there's too much competition

Researcher I understand

Tom that's kind of for you to blot out that noise you'd really want to have a really loud speaker

Researcher I understand

Tom so yeah to be immersed in it (referring to size of speaker needed)

Researcher yes I understand that, so is there anything I can do to alleviate that

Tom I've tried it and I've tried to put on ear plugs and listen to music, but I don't think it actually does it because you really want to hear what's going on outside and I find it almost uncomfortable

Researcher Yeah

Tom so the benefit isn't worth it, even when, sometimes I travel on a plane I listen to music and I put in the ear plugs and listen to music that helps just to drown out the noise of the plane but the noise, particularly if it's a propeller plane it gives me a headache more than anything else, whatever it is that's more to do with the headache than the tinnitus because everybody will have a pain in their head from loud noise so the ear buds keep the loud noise out and give me a better noise so they're different issues but the likes of people up and down the stairs that will, and trying to have a conversation, I notice that the tinnitus will kick off but that's any day so if I sit in my office there will be cars going up and down, there will be telephones taken in the other office, I need to kind of beware of that area but I need to know

who is ringing in the other office so I need to be kind of tuned into what's happening so I can't cut myself off from what's going on in the office

Researcher From the daily goings on

Tom Lots of people have said why don't you just put on headphones, I can't cut myself off so it's a kind of catch 22

Researcher I understand

Tom So the tinnitus is a nuisance but it's not...it kind of comes and goes and as long as it stays on the one note it's fine, it's when it goes two notes that's when I go mad

Researcher Yeah

Tom and there are times, that it happened last week for about Jesus half, about 30 seconds, my head, that would drive me mad, it will just be the changing of two notes but for some reason that's alarm, that's really like an ambulance going off in your head and I don't know why, I put it down to anxiety or stress because we had a particularly difficult scenario going on with a customer and God the customer just kicked off, for some ungodly reason we don't know why but sometimes they do they just get excited and because were a big ticket item at the end of the project we become the target and I'm the focus of that target sometimes so we arrive with the kitchen and we become the focus of their frustration and they just let vent because when we arrive and we come to fit we will say Jesus who put the socket there and we told them it should be, they shoot the messenger

Researcher you become the focal point like you said

Tom yeah it was just twenty minutes of just total, absolute, where three adults stood in front of me and ripped me to....

Researcher shreds

Tom and left the room I'd say delighted with themselves

Researcher Oh that sounds horrendous, that's awful

Tom I've seen a lot worse than that, oh yeah

Researcher the public can just be...

Tom never go into our business if you think that's bad,

Researcher my husband was the manager of a restaurant for thirteen years

Tom ah sure he's seen it all as well

Researcher just wouldn't believe, like that, somebody who has never experienced it can quite grasp what goes on when you're dealing with the public so it can be very very difficult I understand that

Tom Yeah

Researcher Do you feel anxious in unfamiliar places, would you go unfamiliar places, or would you plan out?

Tom Unfamiliar, no, that wouldn't bother me no, it's, no that's not what bothers me

Researcher well that's good to know, and what kind of environments help you to relax where would be your place that you could just turn off?

Tom When I need to, quiet and where any...it's actually when I need to any place at all, I actually take a blanket, I lie down and put the blanket over my eyes, that's all, I just cover my eyes and don't cover my nose and mouth, that's all I do,

Researcher Ok

Tom as long as my eyes are covered, I cut out the light, that's all, I can do it in a car, 99% of the time I do it either on my sofa or on my bed because I'm at home but for the first three years I drove with a pillow and a blanket in the car just to be ready, very rarely used it but I had it

Hand dryer makes noise in the bathroom next door, R apologises for the noise

Tom Having them was a great security, knowing that when I drove out, I had that...I had ..almost like a child I had my blankie

Researcher you had your safety net

Tom My youngest came down from Dublin on Thursday, last Thursday, she was home and she sat up in the kitchen having her cup of coffee, she came home on the train, sat up the island unit and she was having her cup of coffee and she made a slice of toast a cup of coffee she got her blankie and (gestures wrapping himself up) her baby blankie, I couldn't get over it. Well...and she did that for about three quarters of an hour, yeah she was home

Researcher Aw

Tom and she was smelling it (gestures sniffing)

Researcher yeah your place where you can just turn off and tune out and be yourself and relax

Tom and she has it since she was a child

Researcher That's amazing isn't it, as long as it gives her lots of comfort

Tom 20 years old

Researcher that's fantastic, so-

Tom but yeah darkened, dark and quiet that's where...don't need music, don't need any special apps just dark and quiet

Researcher dark and quiet is your go to, that's good, it's good that you've found that

Tom I've tried all the meditation, I've got better at it, I couldn't do meditation, I still don't do it but I'm more...I'd say if I tried now I might be able to, I've learned a lot about my own...about me in the last couple of years as to why I... even in the last couple of weeks as to why it has taken me so long to get better. I got to cranio sacral therapy and unfortunately the cranio sacral therapist I was going to...what is it when you get cancer of the blood...

Researcher Leukaemia

Tom Leukaemia she suffers from Leukaemia she has referred to me a second cranio sacral therapist who is very good as well so the first one would be bordering on psychology as well and she often said that there is something that's stopping me from getting better, as we were doing it she says I need to look at myself, she said I don't need to talk to her about it, I need to look deep into myself to figure out what it is, there's a blockage somewhere she said because your injury is your injury and you control it and she always said there is a blockage within you that is preventing you from getting better and you have the ability to make yourself better always, everybody has the ability to make themselves better now that's obviously not the way with every illness but she was saying within the cranial fascia you have the ability to correct your own fascia, she was saying said there are issues that my fascia are always...how many years have I been going to her...that there are issues there constantly so she can't figure it out, they are issues that I have to figure out that your happiness is up to you in other words

Researcher Yeah

Tom So I'd often wonder, Jez, I thought I was very happy (laughs). Obviously I'm not happy walking around with a fractured skull, my skull was kind of healing itself I thought so she says no it's not the bones, bones heal but it's the...it's what's inside the bones and the muscles and the brain, all that emotional stuff that's going on inside there she said there's lots of happiness inside there that's got to be sorted so you've got to think about this because it's inside there that all these issues are stored in your own decision making process so the lady that I'm with stepped into the area as well and she wasn't talking to the old one about it but she just mentioned about...you know... a Buddha saying is that your happiness is your happiness and as I was going out the door she said that she resurrected the memory of the conversation that I used to have with the first cranio sacral therapist so I just brought it up, it had been maybe two years since I had the conversation first therapist so am I remember doing meditation In Headway and (names staff member) will tell you...I think I was the worst in the room at it, that I couldn't...I don't think I could stay in the room, I just could not sit and relax, not sit there and...I couldn't figure out what we were doing to actually sit and sit steady and be with your thoughts, I was saying I have too much to do, sit and be with my thoughts (pretends to be meditating) I should be room measuring (laughing)

Researcher (laughing) you weren't turning off

Tom (laughing) No I wasn't no, (pretends to be meditating) my thoughts my thoughts I'm supposed to be here at 12 o'clock (laughing)..I can't get this at all

Researcher (laughing) it was more of a challenge than a benefit

Tom I was organising my thoughts and (pretends to be meditating) I was saying these are my thoughts, I can't...my thoughts, (names wife) will fucking kill me (jokingly says this referring to not being able to meditate) and then (names daughter) is supposed to be....I'm supposed to collect her...I was organising all my thoughts and then I was thinking next week (name's daughter) is doing the leaving cert...fucking hell...car insurance and then they were saying (referring to the person leading the meditation) now your mind is empty...f*ck! My mind ain't f*cking empty! (laughing)...Jesus empty!

Researcher (laughing) it's crammed full

Tom Yeah and I said...empty? Empty?...f*cking empty...I can't even meditate f*cking hell...I'm at the opposite end of this, I bought the wrong ticket (laughing)The thought process that was going through my head, I was half thinking I was in the wrong room (laughing) I didn't know whether to laugh or cry so I think I left that session (laughing). I'm not too sure if (names staff member) wanted me to give an idea of what was going through my mind that day (laughs) I think it was the shopping list or...the demands of the...(names daughter) my middle one...(names daughter) would be very...explosive...if....(names daughter) is coming down on the train from Dublin...if you're not at the railway station five minutes before that railway...before that train comes in...you'll hear about it on the news (laughing)

Researcher (laughs) she'll let you know

Tom she's very good in fairness to her...oh she'll let everybody know, yeah...so yeah was that an answer to your question?

Researcher It was, absolutely was...so since the therapist has said there is something blocking that...you seemed to have made strides then

Tom Yeah I would say yeah I've put in a lot of work...I could be wrong but...I was up in (names place) last week and we did a test, an audiology test

Researcher Ok

Tom it was the first time since my accident that I had seen any result that...this is kind of a funny thing to say...sometimes I listen to myself and I wonder...but it was the first time that I had seen anything on paper that shows a conclusive result on paper that I have a brain injury and that sounds like fucking hell an awful thing to say because I know I have a brain injury but it's...now...this is a lot of...me dealing with me on...not wanting to be...coming back to the person I was telling you about...

Researcher Yes

Tom don't want to be...and not only me dealing with it but other people around me that would be...brothers particularly brothers but not sure my sisters as well...not sure if they have a full understanding...or even accepting of my brain injury, they call it a head injury but I don't know if they have an understanding of the brain injury, one sister might have but it's the first time that I've seen something on paper that says...that shows a conclusive test that says yeah he was this...as a result of the accident and he's now this as a result of the accident, unfortunately its far worse but it was an audiology test to do with balance, ear and eye and three years ago I was at 20% deficiency and now I'm at 50% deficiency...now that's not a big deal but in some ways it was kind of almost nice to see it, now that's kind of funny to say, that I could say, I could show somebody because I wouldn't...I know for a fact well I don't know for a fact but I would say both my brothers would be not...they would have trouble accepting...they would have...I would say they would have trouble accepting...

Researcher What happened?

Tom The extent, now what happened but the extent of the damage that's been done but even I'd say if you gave them a sheet of paper they wouldn't...they would still have trouble accepting it I'd say and they don't talk about it, they still haven't mentioned it...ever, again it doesn't bother me so I talk about it more than they do which would be very little, it's not something I...I don't wear it...I don't

Researcher Doesn't-

Tom No I don't talk about it at all, the only place I talk about brain injury is here

Researcher Yeah

Tom in (name)

Researcher and you mentioned that family around you call it a head injury as opposed to a brain injury and you mentioned rugby back along, with rugby I suppose in the last three, four years maybe Head Injury Assessment has come into the game a lot more

Tom Yeah I looked up here (referring to notice board) and I'm just amazed to hear about Johnny Sexton (laughing)

Researcher I know a lot more has come into the game, I suppose working in - and working with people with Brain Injury there does seem to be that divide I suppose in the sense that people almost expect oh sure he was out with a head injury last game but sure he got assessed and he's fine now for this week's game and you're trying to explain that that's not the same you know that having a concussion absolutely where he needed to go off and get assessed he shouldn't come back on the pitch not should he be playing next week if it's serious but trying to explain that that's very different from a brain injury and there is that divide so I can only

imagine with family members if they call it a head injury as opposed to a brain injury even that use of words is a little bit...

Tom Yeah oh yeah a head injury could be a scar

Researcher Yeah

Tom a few stitches

Researcher Yeah he hit his head, or he injured his head is very different from she or she injured their brain

Tom Yeah, HIA is different. I've heard it said as well, but I don't...

Researcher you don't wear it as you said

Tom Well funny enough people are kind if wary of discussing it around me but recently more recently I noticed a few people have said...they're going the other way...they're...at a match a couple of weeks ago there was a young guy brought in at half time and he wasn't started in the game because he was held off because of HIA and when I asked as to why he was held off he was held off because of HIA, this was a GAA game and when I asked was it right that he was brought on at half time nobody could answer the question, why was it right to be brought on if he wasn't able to start at the beginning of the game where does that line...

Researcher What changed in forty minutes or thirty minutes

Tom Yeah so, I don't know, I didn't want to get into it too much because he was a guy from the other team but one of the lads, the supporters on our side just turned around and said gees (client's name) you're the expert there (laughing). I said no I can't do any assessments, I'm only the expert on my own

Researcher Yes of course

Tom But people are beginning to get a bit more conscious of it, the fact that they were... the fact that the conversation was able to be had on the back of the match, the fact that it went that far whereas maybe two years ago it would have been “yeah go away out of that” (referring to match spectators)

Researcher Maybe not even been discussed, maybe not even a-

Tom Yeah it wouldn't

Researcher A footnote

Tom no, no “yerra sure it will be grand” (referring to match spectators)

Researcher Yeah

Tom “go on away onto the pitch” (referring to the match spectators)

Researcher Very much so yeah, so being in this space with you...one of my questions seems a little bit silly now having sat in the space with you...is how could this space be improved but sitting in this space with you and trying to tune into hearing exactly what you're hearing...for myself it's very echoey,

Tom Yeah

Researcher its very echoey, there's a lot going on with the bathroom heater, up and down the stairs and peoples voices, a little bit like that church they travel quite far even though I know that they're in the room at the very end of the hall I hear them pretty well up here

Tom Yeah

Researcher Is there anything that we could do to improve this room? This very room that we're in now, is there anything that could be done?

Tom Well for (ABI rehabilitation organisation) in general or for my particular issue?

Researcher Both I suppose, in (ABI rehabilitation organisation) in general if you thought there was something that we could do that we're not doing at the moment that could really help for example a sensory room if we were to incorporate a sensory room do you think that would be beneficial?

Tom Well there is lots of ways at looking at it, there is lots of issues, if you look at where the window is and then take the shiny surfaces and put them on one wall so that you don't have reflective surfaces and so that the window isn't reflecting, that's why I'm sitting this way

Researcher I understand

Tom The colour of the wall is perfect, if you put dark colours on the wall the sun will reflect more, the blinds, perfect because they're easy to turn around, the lights, you have two different lights

Researcher Yes, we do

Tom So again there are small things, there's...I'm not an expert on it but just in terms of your peripheral area there is lot of noise going on in my peripheral vision if it was all kept on one side, it doesn't bother me so much so if it was all kept on one side, you see the board here?

Researcher Yes

Tom So if it was all on one side so if I want to look at whatever's going on that it's all one one area so all this information (referring to the notice boards) is on one wall so that all the noise

is here (referring to one space) don't have your reflections on this wall, keep that so that all the light is just on one side

Researcher Yes

Tom Cover up all this stuff (referring to fuse box and servers) keep it as flat as possible, and the lights are easy to sort, furniture wise I wouldn't be an expert on furniture and obviously you're looking at constraints of budget as well so the rest of it I really don't know but in terms of sound there is only so much you can do, sound is a big budget issue,

Researcher Yeah

Tom a serious budget issue, in your new building...I presume, the other thing I would do is smaller because one to one those issues are easier to sort in smaller rooms, if how many people would it be necessary to do this for, if the rooms are smaller, it's easier to contain the noise but if the rooms need to be bigger it's much harder to contain the noise because bigger rooms, bigger sound

Researcher Yeah

Tom but containing sound, they are construction issues more than anything else something I used to do years ago...many years ago when I was in England, I worked in sound proofing for about four weeks. Yeah sound proofing has moved on a lot since then but it's not difficult but it's more to do with products and engineering more than anything else but you're not going to do it for this room it's your new building you're talking about, yeah, it's more products and it's very little to do with placement really, obviously your windows, keep your back walls so you don't have your shiny surfaces off your back walls, new buildings tend to have lots of windows

Researcher Yes

Tom so the wall in front of it doesn't have shiny surfaces so you don't have the windows reflecting onto you

Researcher That's a really good thing to know

Tom Yeah

Researcher I wouldn't have known that

Tom Right

Researcher So even to think and to keep that in mind and to even have, what I would hope from these interviews is to have like those, those really simple but very effective things that we could incorporate

Tom See some people won't have issues with light, so more people have issues with sound than with light so if your table is square...so people with issues with light can sit with their back to the sun and it's giving the other people then...can face the sun

Researcher Yes

Tom and if you have a square table then some people can sit right hand some people can sit square to the sun, if you have problem with the sun you can sit with your back to the sun so you have lots of people then who have options can sit left or right, it depends on how many people are sitting in the room

Researcher Yes

Tom you can only have so many seats, can you split the table so that you can people sitting square on so you're almost sitting triangle to the sun, so you have more people sitting because

sun is the issue, light is the issue but if you have the wrong light (referring to the lights in the room) it's to do with the UV, the wave length of the UV is a big issue, LED lights are a big issue

Researcher yeah

Tom We did a (refers to business) for a client in (place) and he sent me a link about how damaging LED lights can be, to do with the wave length of the LED lights, now I didn't read all of it, if I read 10% of it but the first 10% was interesting but he works for (names company) but typical (nationality) had done so much research on every little detail, where most people put LED lights into their kitchens now because looking for environmental reasons, low cost, he wasn't going for it, he wasn't buying it, he went for the old fashioned strip light because they cost more but they're better for your health

Researcher Yeah

Tom so I'll see if I can find that and dig it up

Researcher That would be great, that would be fantastic. (Name) I can't thank you enough for your time, it's been fantastic

Tom Ok

Researcher Thank you very very much

Interview 3 Transcript

Service User Rose (42) pseudonym

Researcher So I was just going to ask you to tell me a little bit about your brain injury if you don't mind (name)

Rose Yeah no it's fine, so my son who has broken his leg (referring to our conversation in before the interview started) is a competitive swimmer and we go to galas regularly and it was at own our club gala and I slipped, there is an angle on the slope of the deck, and I slipped on the slope and ended up giving myself the brain injury as a result of that. It was described to me as being kind of like shaken baby syndrome where my brain shook in my head

Researcher Ok

Rose I don't recall actually banging my head and I wasn't knocked unconscious or anything like that but just obviously the fall did the damage

Researcher Yes ok and what year was that?

Rose That was about two and a half years ago now, October 17...18 I don't remember...I don't remember

Researcher That's fine and were your senses altered after that? How were they altered?

Rose I wouldn't say I was always sound sensitive, but I would have been...like if the kids were acting up in the back of the car when they were younger I would have had to pull in you know to get them to stop

Researcher Yes

Rose because I just felt (gestures hands to head) I am (names profession) so I'm used to being around smallies

Researcher Oh yeah of course

Rose and being around noise and the whole lot where as now I can't focus at all if I'm in a noisy environment, I tend not to put myself into a noisy environment

Researcher Yeah

Rose and light sensitivity

Researcher are these lights ok would you prefer them off?

Rose No no they're fine, I know when I'm coming into, coming into somewhere like this but if I'm just thrown into a situation I just turn around and walk back out again

Researcher Of course

Rose I've learned now over the couple of years how to deal with it

Researcher and how does it impact then on your daily life, would you have to plan quite a bit

Rose Yes, be conscious of where I'm going, I've...so I own the school and I've had to employ another two girls to work in my position instead because by the time...so I work just two mornings a week now and by the time I'm finished all I can do is just curl up and get into bed for about an hour just to recharge the batteries

Researcher of course yeah understandably

Rose because there is so much going on in the classroom

Researcher it's a busy environment

Rose it's a busy environment, yes exactly, it's a busy environment and I never saw it being a busy environment but now that I have what I have it's a busy environment

Researcher of course so for you it's the noise and the light mainly, is that the two main or is there any other that it impacts?

Rose sensory wise?

Researcher Yeah

Rose I have no...I suppose speaking of senses I have no smell

Researcher Ok

Rose I have no taste because I severed my olfactory nerve in my fall so they're both gone so that's upsetting

Researcher yes of course

Rose Christmas time in particular you can't smell the tree, you can't taste the food when you're trying to cook Christmas dinner, just things like that and yeah senses wise that would be it

Researcher Those would be the big ones

Rose Yeah

Researcher and do you find then that you have strategies in place like taking the rest after work and things like that do you find that those strategies are helping in any way?

Rose 100% yeah 100% yeah and it wasn't until about a year after my fall that I was introduced to Headway and good old (names Headway staff member) advising about taking rest and you

know to charge your batteries, she explained to me the whole thing and it wasn't until then that I started going for my naps and things and yeah it makes a huge difference

Researcher That's great, so rest works for you then which is huge

Rose Definitely, I've scaled back unfortunately in my lifestyle, I would have been a very go getter type of person, always on the go, you know from the minute you wake up in the morning until you go to bed in the evening I'd never kind of take time out or anything like that

Researcher Yes

Rose So I've had to slow right down and limit what I'm doing, and I suppose make more time for me

Researcher Yes

Rose which is nice in a way you know, I would have always felt guilty if I wasn't working, conscious you know that I was working mornings only and then...so for me I was thinking that I was working mornings only but then I was also coming home and looking after the children, my own children and running a family and a house and what not and I would have felt guilty but now I don't feel guilty if I'm not going to work I've learned to accept...and adapt I suppose

Researcher and accept all that you're doing well I suppose in that sense

Rose Yeah

Researcher I'm sure that wasn't easy, you know, I'm sure it wasn't easy to get to that point

Rose No...no I suppose I'm still working on it a little bit

Researcher Yeah

Rose but it's...yeah it took me a while to not feel guilty about not working and about having to go for a nap in the middle of the afternoon when I knew that my husband was out working but hopefully we've reached a good place

Researcher That's great, that's really really great. Is there any noise or activity or place that make your symptoms worse or trigger your symptoms? Is there anything that would make you say no I'm definitely – a little bit like the loud noises- is there anything in particular? When I've been talking to people about this the one that keeps coming up is the dishwasher so just loading and unloading the dishwasher seems to be one for people that just comes up quite a bit

Rose Yeah the plates banging together and the cutlery going into the drawer yeah. We go to a restaurant quite often and it depends...where I will ask not to sit where they fill about twenty glasses with ice you know to have it ready for water to be poured into them, can't stand that, anything...we've just finished a huge restoration job on our house and in fairness to the builders they were great, you know they knew if I was on site that they had to stop all machinery

Researcher Yeah

Rose the diggers and stuff were fine but Kangal hammers, plasload guns, compressors like they knew not to start up the things when I was there. A noisy bar really gets to me, that really exhausts me

Researcher Yeah, understandably that's kind of a busy environment and a noisy environment I can imagine

Rose Yeah and then trying to concentrate on the conversation that you're having with somebody while trying to filter out all of that, that's going on in the background. What else would get to me?

Researcher Some people have been talking about...and each person is different like with each brain injury but people were kind of saying competing sounds and I think you touched on it there a small bit of you know if you're trying to filter out what's going on in the bar or the restaurant and just trying to concentrate, someone was giving an example a church or a coffee shop so all the sounds separately aren't so bad but when they're competing for you attention a small bit it can be a little bit overloading and overwhelming a small bit

Rose Yeah, I was trying to describe it to my husband and my kids, because I have a friend who has an autistic boy and she described it to me when he was very young, how he finds the sensory processing so difficult, and she was describing it as like being on an airplane and the air hostess is there trying to do her (gestures airline safety demonstration) you know what she does and you've got the engines, you've got people discussing where they're going to sit, you've got the air conditioning, you've got all of that going on and it's just so hard to block it all out

Researcher Yes

Rose and listen to the air hostess so it's a bit like that when you're in a bar or a restaurant trying to take away the competing sounds as you described them

Researcher Yes

Rose It is, it's exhausting to do that

Researcher I found one analogy that someone was talking about I don't know if it would be true for you as well, but they were saying of you closed your eyes and you knew that water was going to hit you, but you didn't know if it was going to be a spray, a bucket or a power hose you know

Rose Ok

Researcher is how they described it, so different frequencies, so a baby could be quite settled but then all of a sudden they could

Rose shriek

Researcher have a shriek and that's the power hose but then something over here like the ice cube machine that you described could very much be the bucket of water and there's always people eating, you know just cutlery moved across the table could be the spritz but it's all overpowering

Rose Yeah, that's good

Researcher and you don't know what's coming

Rose what's coming yeah

Researcher so that was a good way of putting it as well, but I like the plane analogy as well, you're trying to concentrate on the important stuff but there's so much..

Rose Yeah and when you think about it, it is true because you have the turbines, the engines they're going outside the window

Researcher Yeah of course

Rose You've got the air conditioning overhead, you've got the people, you have the clanging of the overhead lockers, you know it is, I thought her description was really good years ago

Researcher It was, it was really really good

Rose Letting us know

Researcher and you're nervous, you're nervous as well, so if you put yourself into a new environment, like a plane journey you could be nervous, you could be looking for something, and you're trying to focus on all of those things but that's a very good way of putting it

Rose Yeah, and just another sound sensitive of mine, people rubbing their hands off their jeans and things like that or the crackling of a crisp bag beside me

Researcher Things you wouldn't think of really

Rose Yeah

Researcher you know that initially even setting up the environment (gestures to building) you wouldn't factor that in you know that possibly the clothes and...

Rose Yes my husband has a habit of sitting down for the evening time and his two socks, he'd be rubbing his two socks off each other (gestures killing jokingly)

Researcher (Laughing) of course that's understandable, you've worked on your look to give him

Rose (laughing) he knows the look

Researcher Then in contrast what kind of environments or places help you to relax, like when you're tuning out, where's somewhere that if you thought I just need a day I just need to relax, is there somewhere that you can go?

Rose My cosy corner

Researcher You're cosy corner

Rose Yeah I love my cosy corner, as I say we've just done huge work to the house and this one corner at the front, the sun just pours in the front windows, I have a lovely blue velvet sofa and I just curl up on that and I just...(gestures relax)

Researcher That's you're spot

Rose That's my... you know the red spot in the home of the year

Researcher Yes I do, yes I love that

Rose that's my red spot

Researcher That's you're spot, that's a very good way of putting it

Rose that's my spot or just anywhere... you know put me sunning put me in the garden put me anywhere where I can just be passive thinking and not have loud noises around me and I'm...(gestures relaxed)

Researcher and is that what makes the space relaxing, the lack of loud noise? Is enough to give you that little bit of peace

Rose yeah, time where my brain isn't working overtime trying to filter out everything else, basically quiet time

Researcher Yes, quiet time absolutely, and the fatigue associated being in those busy environments like you said can be huge I'm sure cause your brain is working the entire time trying to filter those noises out and that must be exhausting at times so the rest is good. Do

you feel anxious on unfamiliar places? This question came out of... a few times people have said that they would avoid unfamiliar places, would you find that?

Rose I wouldn't avoid them if I had company with me that I was comfortable with

Researcher Yeah

Rose You know, my husband my family whatever, no I wouldn't be afraid of going to places I haven't been to before

Researcher You'd be ok that way, that's good, that's really good. So, looking at I suppose this space, not particularly this room but even in this room is there anything that you immediately dislike about this space or know immediately that's going to grate on me, even in this room here, when you walked in did you take it all in to think I'll sit in a specific seat that might be away from the window or anything or is there anything in this space that-

Rose Not intentionally but I would avoid sitting directly in front of a bright window certainly. The sound of the exit light (wincing) but you know we were talking when we came in, it's only since I've been sitting here that I've noticed it but no there's...(gestures)

Researcher Nothing too much, I know that there is lots of activity going on in the other space is that...

Rose That's ok, that's over there (gestures to where sound is coming from)

Researcher That's alright ok. Is there anything we could do to improve Headway spaces or to improve places in general in the community that you think would make- maybe small tweaks- that we could do that would make people's lives with sensory overload a little bit easier? Is there anything small that might make all the difference?

Rose I suppose I'm quite mild in my needs I suppose in comparison to what a lot of people must be, less acoustics

Researcher Yeah

Rose and maybe just the light sensitivity on the bright lights, I don't know

Researcher No That's all useful that's really good to know. So, if we incorporated a sensory room into Headway do you think that would be beneficial? Let's say in the new building if we tried to make a sensory space

Rose Yeah

Researcher Do you think it would be useful for sensory overload? Do you think people would use it?

Rose Oh definitely, yeah definitely

Researcher Yeah

Rose anywhere, for me, from my experience since I've had the accident, anywhere that is quiet and calm and...yeah

Researcher somewhere relaxing

Rose Yeah anywhere where you can just sit and you know watch your lava lamps or watch your bubbles in the water, you know things like that where you can just sit and just take it all in

Researcher Yeah that's great and it's great to know that when we're trying to incorporate new things into the building and trying to get funding for different spaces and for different

purposes, it's great to have the information that you can say yeah everybody...you know everybody in a survey or everybody that we asked said that they'd use it

Rose Yeah definitely

Researcher I suppose Headway is trying to be more...what's coming out from my research... is sensory informed

Rose Ok

Researcher So I think airports are doing it now where they're trying to kind of have as you described a quiet space

Rose Yeah

Researcher and we're trying to incorporate I suppose that sensory information into our spaces and we're seeing it in like that in music groups where some people just aren't suited to the music groups because it grates on them and that might be their trigger. Is there anything else that we could do to be sensory informed?

Rose just something you know put a carpet down that might stop the echoey sound, oh gosh Jenn I don't know

Researcher That's quite alright, if nothing comes to mind that's absolutely fine. The other questions are really more if you would add anything to this space or if you would take anything out, is there anything that hits you straight away? And it's quite alright if you think-

Rose I don't know what you would take out, it's all functioning isn't it?

Researcher Yeah I suppose when we're looking at sensory overload we're wondering is there a certain blindness that we have that we're thinking this room is absolutely fine and then for

somebody with sensory overload coming in they might say, for example one man said he wouldn't have any shiny surfaces because they're quite reflective

Rose Ok

Researcher That's just a small thing but if there's nothing for you that's learning in itself

Rose No shiny surfaces wouldn't get to me, I would be outing shiny surfaces into a sensory room so that young kids could be looking at their reflection and stuff

Researcher Yeah, it's interesting how it effects people in different ways with sensory overload. I'm looking at developing – those are all the questions so thank you so much for that- I'm looking at possibly...I'd just like to get your opinion on it, this is only in the beginning stages but it's an example of a sensory menu

Rose Yeah

Researcher So for example before somebody would come to maybe their needs assessment, their first meeting with Headway, where you sit down and you're asked a million questions about lots of – you probably went through a needs assessment (clients name) I imagine

Rose Yeah

Researcher I'm looking at this one (referring to sensory menu) just to see if we handed this out with let's say the consent forms and the medical forms if it would be useful piece so that we could get the space ready for somebody before they came into it so for example just asking if the windows open or closed, if they wanted the lights on, off or dimmed, sometimes people were saying that music helps them in the background

Rose Yeah

Researcher because it can, like a nice relaxing noise, it could help them out, some people want total silence which is absolutely fine as well so that's why that question is in there

Rose Yeah

Researcher and just asking if there's anything in particular so if I put on you know rock metal some people would be looking at me but some people have had suggestions where-

Rose Yeah, to me it would be nice just to have the background music just to have, just to make things more comfortable, you know so there is no awkward silences or something like that

Researcher Of course

Rose so that would be my...calming

Researcher Yeah I find that when I'm running groups sometimes if there is a little bit even you know a little bit of an awkward silence or maybe a comfortable silence but people are thinking it kind of takes the pressure off you know you're not listening to the ticking clock, as opposed to thinking you need to answer straight away, sometimes people need to think about-

Rose you need to think yeah

Researcher so the music might do that. I tried to think of temperature as well, I know that if somebody popped me into a hot room, I would probably pass out so trying to think of temperature but then likewise some people are cold creatures and like their heat

Rose Yeah, Yes

Researcher so that's why that question is in there and then the type of chair is in there because some people like a chair with arm rests where other people find it freer without one, people have even been saying for their breathing sometimes a chair is better if they can sit

back where arm chairs restrict that a little bit for them so that's why that question is in there. Then tactile some people like the stress ball, especially if it's a family meeting you know where it's a little bit stress or something else tactile might help. Is there anything that you would add to the sensory menu that maybe I've forgotten or overlooked that might be helpful in there? The last little bit was just tea or coffee

Rose I was just going to say maybe to have a jug of water or something, I was just going to say it...

Researcher and it's fine if there's nothing, if you think that...

Rose yeah the size of the room

Researcher Ok

Rose would some people prefer a smaller environment or a larger environment

Researcher That's a really good point, do they feel cosier, would they talk more, would they open up more in a smaller environment as opposed to a big purposeful room. Absolutely, yeah that makes a lot of sense

Rose like (names Headway staff member) office

Researcher Yes (names Headway staff member) office is lovely, you can relax in (names Headway staff member) office

Rose Yeah, I think you have it

Researcher Thank you

Rose when you think about the room as it is

Researcher I'm just going to make note of size of room because that's a really good point and I know what you mean, kind of you're creating your safety space as it is and it is more comfortable for people to talk in those cosier environments, you just feel like the rooms hugs you a small bit but it's not as big, that makes perfect sense

Rose yeah exactly

Researcher well thank you so much for your time

Rose no problem

Researcher thank you so much for coming in

Rose you're more than welcome I hope I was some use to you

Researcher you absolutely were, this was really really useful

Interview 4 Transcript

Service User Liam (72) Pseudonym

(Follow up interview post Covid-19 pandemic)

Researcher Thanks so much for agreeing to be involved again, so the first question as I was saying this is a little bit of an add to the study that you've already taken part in and it's kind of looking at the Covid-19 pandemic because I suppose how it's changed life for everybody but also how it's changed life in (name) services and the service that you get from (name of service). So, the first question asks can you please share what you enjoy most about attending services like (name of service)

Liam well it's amazing because it's only when we didn't...when we weren't there that we missed it so much, it's fantastic to be back in because it's lovely to come into a nice comfortable surroundings with very friendly people like yourself and we have a nice little chat and we have a look at the paper and the crossword I think that's fantastic, you would be looking forward to every single day you know

Researcher Well that's great to hear (name)

Liam It's tremendous. You know for the last six months all I've been doing is sitting down at home looking out the window at the rain

Researcher I know that's hard

Liam It would drive you crazy. It's lovely to come in here because there's always a great old sense of humour and an old laugh as well you know

Researcher Yeah

Liam and a nice cup of tea too

Researcher That's a very important part of the puzzle, isn't it?

Liam The thing is you're all for our good, and you know that and you're always kind of doing things to keep us going and improvements and sure that's fabulous altogether

Researcher Thank you for that feedback (name)

Liam That's fabulous altogether

Researcher Did you find during the lockdown, you were mentioning there about the six months looking out at the rain, did you find it got you down?

Liam Yerra, I did, I used to spend most of the day listening to the radio and sure that fella Joe Duffy used to come on and he'd depress you, all this stuff going on you know

Researcher Yeah

Liam Even though I suppose it's true, you know I like listening to music more than Joe Duffy

Researcher and how was lockdown overall for you? Did you find it hard or were you ok?

Liam I was ok really except I missed coming up and down to (service name) because it used to be great by day, like I had four days I think, and it was grand to head out in the morning, get the bus out at half past nine and go on my way at four o'clock on the bus and I'd be home at four o'clock, fabulous altogether

Researcher a change of scenery as well I suppose, out and about

Liam well that's it and the thing is we used to learn something every day. I love doing the countries, who were we doing the last day, Colombia I think

Researcher Oh excellent

Liam and that's a savage place altogether, Janey Mack

Researcher That's in (staff member's) group, isn't it?

Liam That's right yeah, that's a very good one

Researcher She does fantastic groups

Liam She does lovely pictures of all the places, it's fantastic

Researcher and like you say it's nice to learn something

Liam It is yeah, it is yeah

Researcher you'd get a bit of a boost from it

Liam Ah you would yeah, I keep all the coloured things at home, I'd be keeping them, and I look through them every so often

Researcher Excellent, so you keep a little book of them and all?

Liam Well I don't have a book, but I have them on the table

Researcher That's fantastic

Liam and it's great because I can put one up on Canada or Japan or somewhere

Researcher You can bring it out and refer back. So, when we're looking at this question (name) it's kind of the company, learning something new, the sense of humour in the group

Liam It is yeah, and another thing is ye're continuously trying to introduce new topics to kind of get the old brain turning over like you know

Researcher Yeah

Liam and that's good too

Researcher That is positive yeah,

Liam My brain doesn't turn over too fast anymore

Researcher You're selling yourself short (name) absolutely your brain is sharp as a tack. I'm just making sure our recording is behaving itself and it is so I'm just going to pop down to the next question (name). Thank you so much for your feedback on that one. The next question here asks-

*Brief discussion on highlighting the next question in large font and adapting the lighting so Liam could see it better

Researcher So it asks how has the Covid-19 pandemic changed (name of service) services? So how has it changed (name of service) for you here?

Liam Well I suppose the main change is the length of time, like I come for two hours a day now instead of a whole day but still the content of what ye do is still fantastic because it gives us an old g up every day to come in and even on the way home, sometimes if I'm on the bus I take out the pages ye give us, I'd say the bus driver doesn't know what to make of me (laughing) Ah no thinking back I'd say only the length of time

Researcher The length of time, so like you said you would have been coming in before from 10:15 until 3.30 in the day

Liam That's right

Researcher Where now because of the restrictions we can't spend longer than two hours

Liam Well that's fair enough too because the masks they'd be trying all sorts of things to keep safe

Researcher What about the size of the group?

Liam Well that's right we used to have 12 or 13 where now we're down to three or four

Researcher Yeah

Liam That was a big change because you'd miss some of the crowd we use to know like

*Briefly names and describes some other people using the service

Researcher So do you find that's a change, the size of the group as well, how are you finding that? You mentioned missing people there

Liam I find it strange like you know

Researcher Yeah

*Briefly describes other people in the group noting his friendships with others

Researcher So the length of time and the size of the groups

Liam Yeah but the thing is, I'm not giving out like

Researcher No, absolutely not, it's great to hear, it's great to hear the feedback

Liam That is the big change,

Researcher Yeah

Liam That I can see anyway

Researcher I know (name) that's coming from a place of real positive feedback in the sense that it's great to have these conversations

Liam Yeah

Researcher So that we can kind of see what's going well

Liam Just talk about it

Researcher Yeah just talk about it, exactly

Liam Like initially I came back for two days a week and then they added another day and then two or three weeks ago added a fourth day so I'm back Tuesday, Wednesday, Thursday Friday now and that's fantastic

Researcher Yeah so we're trying to...so before you would have come Tuesdays and Thursdays from 10.15am until 3.30pm

Liam That's right

Researcher Where now we're trying to give you four days, two hours each

Liam Fabulous

Researcher So you get eight hours as such but its

Liam and that's perfect

Researcher it's trying to match that, it's trying to juggle the system I suppose is a good way of putting it

Liam it's working great for me

Researcher which is good

Liam because you know after a week or two, getting into a routine

Researcher Yeah

Liam and the only thing is, herself now is giving out that she has to bring me up here four days a week instead of two or three

Researcher I understand that can be a struggle as well, the transport⁹

Liam You know it takes five or ten minutes to come up and five or ten minutes to head away again and that's twice a day, it's less than an hour a day, I don't know what in the name of Jesus Christ she's giving out about

Researcher She's finding that a change I suppose

Liam That's it, she's not used to getting out of bed early in the morning (laughing)

Researcher I suppose that's a change and I suppose with the weather that we're having being in the Winter months

Liam She got up this morning now about 10 o'clock, that's why I was a bit late, and she said Oh Christ it's lashing rain out

Researcher You would be very good to walk normally in the Spring and Summer months

Liam Well I'd prefer to walk really but not this morning

Researcher No, the weather was too bad this morning. So that's great (name). My next question asks what do you find most challenging about attending services during the pandemic? Is there anything that you find hard about getting here, like the transport might be one

Liam As we were saying while ago now, herself, she won't allow me use the bus and I have a free bus pass and that's soul destroying like because the bus stops outside our door, about 50 yards from the house

Researcher and is (name of wife) worried about you getting on the bus for Covid? Is she afraid that you're going to get Covid on the bus?

Liam I'd say her big problem is that she's always telling me that she's my carer and everything that is done for me she does is it and I think that's the big problem. If I go on the bus she'll be thinking that the bus driver is my carer (laughing) Jesus Christ almighty, I'll give her a clatter when I go home

Researcher Has she expressed any fears about maybe social distancing on the bus or anything like people not wearing their masks?

Liam You see on the bus now you can only sit on every second seat

Researcher Yes

Liam and every second row

Researcher Yes

Liam and I always bring my little blue mask and the bus driver always leaves me on because I have my (name of service) ID to show him and there's no problem with the bus

Researcher and that's ok, so the transport is doing ok for now

Liam It's herself now is...

Researcher finding it hard

Liam is beginning to worry about her ability to look after me I'd say

Researcher and do you find anything else challenging about attending at the moment?

Liam No I'm delighted

Researcher No

Liam It's like a holiday to me to go here for a couple of hours

Researcher Well that's lovely to hear

Liam It's great

Researcher and we so enjoy having you (name). So, we talked about this a little bit, the next question asks does the pandemic impact on your mood? Does it get you down, are you optimistic? What do you think of that question?

Liam Well I'll tell you I'm optimistic now that we'll be getting a vaccine in the New Year

Researcher That's kind of given people a boost hasn't it?

Liam Ah yeah, it's given us an old boost that it will be all gone in the New Year

Researcher You're hoping for that

Liam My eldest son (name) now and his wife and kids they live about 200 yards behind us at home and like presently I haven't seen the kids for about a month or two because they're not aloud out into the house

Researcher Of course, with level 5 restrictions

Liam With Level 5 and that's very kind of tough, it's tough on the kids more than me

Researcher You're missing the grandkids

Liam Ah yeah

Researcher and they're missing grandad of course

Liam Well I don't know about that

Researcher That is hard, that kind of disconnect within your own family especially when they're so close, so close yet so far

Liam Just out the back of the garden like

Researcher Yeah

Liam You can look out our kitchen window and you can see his house now in the back of the garden

Researcher Did that get you down?

Liam Ah no sure I'm delighted he's in the back of the garden

Researcher You're delighted that he's down there

Liam Ah it's great, because that's right listening to the radio now there recently and with the possibility of the vaccine the way we're going, that's very good

Researcher That's very positive

Liam and people have said a good three weeks now until Christmas

Researcher Yeah that gives everybody a lift

Liam It does

*Checks on recording

Researcher That's good to hear, I suppose the promise of a vaccine on the horizon has been everybody a little bit of a well needed boost hasn't it

Liam and I suppose the other thing that is important to me, but I'll just mention it. E have an old house down in (name and description of area) and there's a lady living next door (name) and her husband died 10 or 12 years ago and she's living alone now and she's (age) and her birthday was about a fortnight ago and I have a little gift ordered from the jewelry shop to take down to give her but I have no way of... like when (wife) collects me she takes me straight home and we won't let me take the bus so I can't go back up the village so I'm not able to collect the gift to put it in the post for her you know

Researcher Oh of course

Liam That's very annoying like you know

Researcher That's hard and is the jewelers open at the moment? It's probably-

Liam Oh it's open everyday

Researcher Oh is it

Liam I have gifts ordered as well every Christmas, I get gifts for all the women in the family so the mothers and the kids they get different things and the girl in the shop (name) she keeps tabs on what she gives me every Christmas, so she gives a little string of gifts that goes with the previous Christmas

Researcher Aw that's lovely

Liam That's fabulous like

Researcher I think at the moment, I'm not sure, you correct me if I'm wrong (name), but I think at the moment it's only essential services that are open

Liam Oh they might be closed

Researcher So I'd say they're closed for the moment

Liam You could be right there now

Researcher But coming on December 3rd or December 1st I should say

Liam They might be open again

Researcher We're going into Level 3, they might be open then

Liam I might be trying to sneak up the road to have a look, so I won't bother now

Researcher Yeah because in level 5 they'll be closed at the minute

Liam I didn't think of that, thanks for telling me that

Researcher Not at all

Liam That's a good one

Researcher My next question (name) is there anything you enjoy more about (name of service) now that the groups are... I suppose the pandemic has changed our lives so much in lots of ways but is there any kind of positive to the new way services are run?

Liam I think so, ye're very kind of supportive the minute we come in the door, to sit down and use the little spray and make a cup of tea and you know we're wearing the masks and all that sort of thing, that's fantastic because ye'll help us and ye're with us all the time you know

Researcher Yeah so, I suppose is that more kind of one to one?

Liam That's it

Researcher Yeah I understand, I suppose it has turned into more of an individualised service

Liam and you know it's great too because ye know you kind of know our names, I'd be calling people the wrong name all the time

Researcher That's ok

Liam But I remember (name and name)

Researcher But I understand, like I think people do get... I'm hearing what you're saying in the sense that I do observe people getting more one to one time with staff

Liam Yeah more like home you know

Researcher Yeah because I suppose in the bigger groups before it was... it was great-

Liam You used to have to go around the whole circle like you know

Researcher yeah and that was super in itself in another way but maybe people got lost in the group setting a little bit more or it was harder to give that one to one

Liam Yeah like that's brilliant, like this morning we're talking one to one

Researcher Yeah, it's just you and me

Liam Fabulous

Researcher That's great and it's positive, it's good to hear that we can pluck out the positives in it too

Liam Its fabulous altogether, it's great for the old confidence

Researcher Well that's good, that's lovely to hear

Liam Great for the old confidence

Researcher If we were to make a pros and cons list so (name) of kind of...what would it look like? So, a pros and cons list comparing before Covid and post Covid services

Liam Well I suppose the biggest thing would be the fact that we have a more of a one to one

Researcher That's a pro

Liam That's a very strong thing for me

Researcher OK

Liam We're talking to one another on a one to one...on a first name basis you know

Researcher Yes yeah

Liam That's fantastic like

Researcher It is, it's good

Liam See that wouldn't happen at home at all

Researcher I understand so is it the company?

Liam Yeah, it's the company and the chats

Researcher Yeah, and is there any cons then? What would our cons list look like?

Liam I don't know, I'm happy out anyway coming four days a week, it's fantastic, two hours a day, it's grand altogether

Researcher It's ok. Is there anything that you miss from before Covid came along?

Liam You'd miss some of the pals that we had before you know

Researcher Yeah and you mentioned that you miss your friends

Liam It was nice to have a chat with them as well

Researcher Of course yeah, that makes sense

Liam You'd get used to that because ye'd be keeping us up to date with what's happening with the friends as well you see

Researcher It's good, it's nice that we can be that link

Liam Ah it is yeah

Researcher What about then (name) another look at routine. Sometimes routine is kind of commonly reported that it's a big thing in ABI rehabilitation in the sense that people like a bit of routine and some people call it kind of their pillar you know

Liam That's true

Researcher That they can kind of-

Liam You latch onto it

Researcher Yeah you latch onto it, that's a very good way of putting it. Has the Covid-19 pandemic changed your weekly routine? Has it changed in any way?

Liam Well I suppose the only way I know at this stage that it has changed is that I get two hours a day rather than a whole day

Researcher Yeah

Liam but the thing is like I have changed my routine around it and like it's working out grand

Researcher and it's doing ok

Liam It's doing grand, like it takes a couple of weeks to change and get into routine

Researcher and adapt I suppose yeah

Liam and adapt yeah

Researcher How about life outside of (service name) then? Has it changed your routine, has it changed your weekly like what you would have done on a weekly basis, has it changed that in any way?

Liam Yerra I suppose, you know I have more time at home and if the weather was fine which it isn't, I'd spend more time in the garden but like for the last month or six weeks it's been very wet and windy and cold, you wouldn't go in the garden

Researcher It's been wintery for sure

Liam So I miss going in the garden because I have about a third of an acre and the grass hasn't been cut in about two months

Researcher Ok

Liam It's like silage. I was saying to my friend the other day (name) I think I'll have to go next door to the farmer and ask him for a few cows to eat the grass

Researcher (laughing) They'll give you a hand

Liam To eat the grass

Researcher and is that a Winter weather problem (name) or is that a pandemic problem?

Liam It's a weather problem

Researcher It's a weather problem so it doesn't have anything to do with the pandemic

Liam Oh no no no, I have plenty time, no weather

Researcher I understand

Liam Ah we'll get over it

Researcher You'll have to borrow those cows (name)

Liam Or somebody told me sheep are best

Researcher I think so, I've heard that previously as well

Liam Three or four sheep

Researcher Better than any lawn more

Liam You'd sell the sheep then after a couple of years

Researcher Oh my goodness

Liam I wouldn't do that either because I'd get friendly with them

Researcher I know, we'd get attached

Liam Ah you would yeah

Researcher The next question (name) asks has the COVID-19 pandemic and the need for PPE so personal protective equipment, the masks, your visor, has that challenged your senses in any way?

Liam Not really except that I forget to put them on sometimes and to being them you know

Researcher I understand

Liam So what I do now is I have two little porch sides at home so I have a mask on both of them so I can't forget it

Researcher That's probably a good plan so you kind of adapted to it so you just leave a mask in each corner

Liam It's great when I come here, I can take the mask and it's brilliant,

Researcher you like the visor

Liam it's lovely and warm

Researcher Two functions in one so

Liam I can see perfectly, the board or the is grand

Researcher I suppose this is something that we've tried to incorporate which seems to be working pretty well (referring to the interactive white board)

Liam Its fabulous

Researcher for people who struggle to hear us with the masks and things

Liam You're able to understand them much better

Researcher Yeah and how do you find keeping your distance and thing?

Liam I have no problem with that

Researcher That's ok, that's alright because I know we looked a little bit like Martians when we come into the room don't we with all our gear

Liam Well you get used to that

Researcher But you're finding it ok, you're adapting to that

(Liam talks about tea briefly)

Researcher My research seems to be pointing (name) it seems to be indicating that our senses so our vision and our hearing and our taste and our smell, they're all kind of tied to our overall sense of identity would you agree with that? what your thoughts on that?

Liam I suppose it is like, you know we do what suits us a lot,

Researcher Yeah

Liam and that's our identity, personal identity

Researcher Yes Yeah

Liam You know put on my shoes and whatever jumper I want to wear, and we do it to suit ourselves

Researcher Yeah and is that kind of tied to who you are then?

Liam Oh it is, you know the light affects me, as you know but the heat or the cold affects me too so sometimes, I wear a light jumper when it's warm and (inaudible for a moment) when it's warmer you know so I'm able to adapt to the situation around me

Researcher Yes, because some people have mentioned that when the lose...if one sense is impacted whether like light sensitivity like you wear the cap you know so that then becomes a little-

Liam Sometimes at home I'd walk out the door and I'd hi the light and say Jesus I have no cap, so I'd go back again

Researcher Yeah

Liam I'd be in the car with herself, and she'd be stating out, and I'd say Jesus I have no cap, she stops the car then and I'd have to go back

Researcher yes of course you need that

Liam There are certain things you're very dependent on

Researcher Yes, I understand, and those strategies have working for you

Liam Oh perfect, perfect

Researcher Good

Liam Because there's no panic, we can go around nice and easy and slowly because we don't have to be running any place

Researcher Is there any-I know you had those excellent strategies before the pandemic, is there any new strategies that you've put in place to make life a little bit easier?

Liam Well there is, one thing that hasn't happened me there in a good while, I suppose over the last 12 months is that when I'm eating particularly crusty bread, the crust goes the wrong way down my air pipe, and it gets blocked, and Jesus Christ I can choke

Researcher Ok

Liam But lucky enough now here they know it and they can give me a tap on the back, and it comes up and it's grand but once or twice at home there recently, I was eating something, and I panned out

Researcher Ok

Liam In the chair like, I panned out and when I came to again all I could remember was that there was something stuck in my throat

Researcher and have you talked to your GP about that?

Liam Oh I have yeah

(Liam talks about medical procedure and other medical information)

Researcher In your opinion (name) is there anything that (service name) or similar services like ourselves can do to improve services? Is there anything that we're not doing that would make services better? Is there anything that's missing as part of the services post pandemic?

Liam Well the only thing, I think I might have said it before but I don't know if ye can do anything about it like when we have a break we get up and walk around a bit because my old balance gets very bad and it takes me a couple of minutes when I get up to balance myself so at the break time or drinking a cup of tea I might just get up and walk out the door for a minute or two and come back in again you know

Researcher Ok that's good to know because I suppose-

Liam The balance will come back you see

Researcher Yes and you'd find that you need that minute to steady yourself

Liam Well that's right

Researcher and do you like to go for a walk just to get a bit of exercise and get moving

Liam Well especially the leg kind of goes on me

Researcher Yeah

Liam When I get up, I have to hold my hands out like that for a bit of balance, they call it Tai Chi but I haven't a clue what Tai Chi is, but it works for me like you know

Researcher Yes that's really good to know (name) because I suppose post pandemic- like before the pandemic would have been up and down and over to the tea trolley and in and

out of the hallways and everything and post pandemic you when you come in, you're directed to your seat and then the staff member gets your tea

Liam That's right

Researcher There's a lot more done for people now that would have been just purely out of-

Liam Being spoilt (laughing)

Researcher (laughing) purely out of protocol and sanitizing all of those things but it's really good to know that that you'd like to get off and maybe just safely walk the hallway or pop outside if the weather was...allowed for it that's really good to know that maybe you would just like to exercise the legs a little bit more because you already do get less exercise in here now than you would have before so that's something that maybe we could incorporate

Liam and something I'd love to know a bit more about, what is Tai Chi?

Researcher I'd have to look it up, but I think Tai Chi is a martial art

Liam Oh I see

Researcher as far as I understand and so I think I think you're right I think it does have to do with like your balance and your flexibility and all of that

Liam Ah Yeah, you'd hear an awful lot about it like

Researcher You would yeah, and I know other clients have brought it up in the past as well but what we might do is at the break we'll have a look at that and just get a little bit more information on it

Liam Fantastic yeah

(Briefly read through questions that have already been answered in the interview)

Researcher We mentioned this a little bit but we might just talk a little bit more about it it says the support of a peer group is often pinpointed as a key part of rehabilitation so like when we had the bigger groups here, has the the Covid-19 impacted on your peer group support and that could be in (service name) or outside in the community

Liam Well the thing is, about 12 months ago I joined the advocacy group

Researcher yes

Liam and that was fantastic

Researcher You enjoy that

Liam Because we learned something, your voice your choice

Researcher Yeah

Liam and that makes an awful difference to me because at home I I don't have any voice or I use not but now I'm able to look after myself a little bit better and maybe suggest I'm not going to do this as much as I used to

Researcher I understand

Liam It makes an awful difference

Researcher and have you been able to meet up with the advocacy group in the same way or are you doing it online a little bit more or...?

Liam Well with the advocacy group recently (name) now the meeting we had there recently with (name) was part of the advocacy group

Researcher It was, it was you're right, yeah

Liam and that was the first one (inaudible)

Researcher That was probably the first one since you got back to services

Liam That's right

Researcher Ok so that's good to know and how did it how was it doing it online?

Liam Ah it's great because there was a big screen, and I could see all the people and they were talking and their names were up and they spoke and we spoke and we were all happy out

Researcher Good, was it a good way to connect?

Liam It was fabulous

Researcher Good

Liam It was good to have (name) there because I said to (name) this morning I have a habit now when I start talking that I don't stop, she was laughing so I try not to take too much time

Researcher Not at all, that's what it's all about, is having your voice for sure. We're almost done there now (name) the last question is just says it seems possible that the way services are provided now after the Covid-19 pandemic might benefit some people for example as it were just mentioning services moving online, what are your thoughts on this?

Liam Well I'd love to have them online, but I don't know how to, I have an iPad at home, I'm barely able to turn it on

Researcher I think the latest plan in the next couple of weeks and certainly after Christmas is that we're going to try and run a group like that in services

Liam That would be fabulous

Researcher Just to get people a little bit more familiar with the laptops do you think I don't get everyone ready to know how to I either like I said I think that the the latest family now in the next couple of weeks and certainly after Christmas is that we're going to try and run groups like that in services just to get people a little bit more familiar with laptops and using the iPad

Liam 3 or 4 years ago we did the session on using the computers with (name) I think

Researcher Yes, could have been yeah

Liam It would be great to do that now with the laptop

Researcher Yeah, we might try that because with services moving online and things like that there are a few positives I suppose to take out and like you mentioned getting more one to one time is also a positive

Liam Yeah and if you're online you could talk to some of your buddies like (name) (talks briefly about friend) and especially with the iPad to send pictures, that would be lovely

Researcher Well (name) that brings us to the end of the research so thanks so much for your time and attention

Liam It's fabulous to have a chat

Interview 5 Transcript

Service User Joan (34) pseudonym

This interview was carried out to capture the impact of the Covid-19 impact on ABI rehabilitation services.

Researcher Super so as we were talking with (name) there she was saying that you haven't been able to to come to (service name) since Covid has that been the way since?

Joan Yeah yeah well you see I live in (place name) which is (location)

Researcher Of course yeah

Joan It's (describes location) and I have a vision impairment as well so I can't drive obviously so yeah public transport is my only kind of way of getting around and obviously with the Covid but I wouldn't be very comfortable getting on a bus so

Researcher Of course that's only natural of course

Joan Yeah

Researcher So has it been the full year since you've been in services?

Joan yeah

Researcher My goodness

Joan yeah

Researcher That must be difficult like obviously like you were talking about there like it's one thing it's great that you like the online groups but it's not the real thing you know in general

Joan No, you can't see everybody, you know you're not in the building and you're not you know you're in your own kind of ...my home as they say but it's not the same as when you're...in the building or in the (service name) or whatever

Researcher Of course how many days a week were you traveling up (name)

Joan I used to...we've be in... I used to go up five days a week

Researcher Oh wow so it was a big part like that was a big part of your routine obviously five days

Joan Yeah so it was just that was my kind of my weekly...

Researcher Outlet

Joan Yeah that was just my way of getting out of home

Researcher Of course and are you at home with parents with siblings or

Joan My parents yeah

Researcher That's tricky too with with Covid you know like it's hard being you know your your outlet is gone but also also living at home with your lovely parents probably be nervous of bringing anything to them as well of course

Joan Yeah yeah my Mom (age) and my Dad 's (age) or something so

Researcher and how are they getting on with it how are they doing?

Joan Yeah they're fine you know they're trying to just do the best they can really and by staying at home and my mother is big into her gardening

Researcher That's good

Joan So she'd be stuck out there most of the time my dad is retired so

Researcher and spring is coming so hopefully your Mom will be able to get out into the garden even more because this winter hasn't been easy on people with-

Joan No

Researcher Yeah

Joan and there's more... I think there's... is it today or tomorrow there is supposed to be another storm thing coming, I don't know, that's what they're saying anyway

Researcher I heard that too, kind of a wind warning or something coming

Joan Yeah Yeah

Researcher Today's a little bit gray alright so it might be kicking off later

Joan Yeah

Researcher We seem to be going from one weather warning to the next really

Joan You just don't know what to expect

Researcher Yeah and like some days are beautiful but other days are just muck

Joan Yeah you don't know what you could be you know there's some days there they're saying it's going to be lovely or something or it's going to be like I don't know whatever and then it's like you go out there and you're just like ok

Researcher They lied (laughing) I always I always joke that the weather people are like biggest chancers in the world because they lie way too long often

Joan Oh they do yeah it's crazy you're just going out there like what do I do what's you know what's this

Researcher So so five days a week going to (service name) like that that would have been a big part of your week, has Covid impacted on your routine so you know...with a new routine or or how have you been coping with it?

Joan Yeah well like I suppose I've been working out more which I wasn't really doing before I was quite heavy even last year really so I still am, I'm going to try to lose weight a bit more but yeah I suppose like I just you know I still used to get my buses on the bus every morning and it's just been to...that's gone now I see the bus because we live, the road where we live on the bus passes you know so I look and go oh there's the bus

Researcher Aw and how long would that journey have taken you (name)?

Joan About an hour and a half I think or an hour and 15 minutes something like that

Researcher Yeah a good long journey so and would you have another bus then from the bus station out?

Joan Yeah yeah yeah

Researcher I'm a bus user myself so I know that feeling of like looking for the bus and it has been nerve wracking getting on a bus now

Joan Oh I'd say so yeah

Researcher Yeah just even at the bus stop you know like I'd be wearing my mask all the time, but some people would wait until the last possible minute you know which I understand obviously

Joan Yeah

Researcher but yeah you know yes little bit nervy I think getting on because you're making sure your distance you know it's

Joan Yes yeah that's the thing you know I mean I'm gone so bad now my sister does be laughing at me sometimes she's my younger sister she's a (profession) but she would just be saying to me like don't do that (name) you know like I'd be going down to the beach and I'd with a mask with me you know to be on me down the beach

Researcher I know yeah

Joan and she'd like like (name) don't do that and I just I can't I just I don't know like if I'm out and I see people I just have to...I don't know put my mask and I don't know what happens to me I just seem to go into like a...I don't know...

Researcher Safety first I suppose

Joan Yeah you know she's like there's no need to do that and I'm just like...

Researcher I do I do something similar and I live in the city so if you go outside your door sometimes it's as busy as being in the middle of a supermarket you know

Joan Yeah

Researcher Because there's a lot of people lying on the street so I I I'm with you there I wear my mask everywhere too

Joan She's like there's no need to do that (name) I just feel more comfortable you know but she's like no there's no need to do that

Researcher and with the peer support, oftentimes clients will talk about the peer support that comes with attending (service name) like how you been finding it without that? Would you have friends down home that you could visit outdoors or like has that social- yeah

Joan Yeah no no

Researcher That's a loss in itself I think

Joan Yeah

Researcher The routine of getting up and out but also like you were saying like the people it's not the same as you know getting your energy from people as well and kind of meeting in person and having you know a laugh like that

Joan Yeah and then they know as well what you're...you know like there's morning there where I get up because I'm on (medication) because I have epilepsy as well but I'm on (medication) in the morning (medication) and I'd be inside in (name of service) and I'd be like I'm tired today and they would be like yeah I feel like that too or something you know whereas at home here if I say tired they'd be looking at me going what? You're tired? Why?

Researcher Of course that makes sense because somebody who can you know fully understand you know because they lived that experience themselves

Joan Yeah

Researcher That's quite as different from somebody who's who's saying what are you tired for who can empathise but not relate maybe

Joan Yeah that just look at you and go what?

Researcher and like thinking back to when you were attending (service name) what was it like what did you enjoy most about attending (service name)?

Joan Like I suppose like all the clients are great for you know we we always having a laugh and we always have you know just each other to kind of bump of off not bump off of but kind of just

Researcher Of Course

Joan Yeah and you know have our chats and stuff and we would have our good laughs you know if anybody heard us they would probably think we were a bit mad or something you know it's just nice to have that and you could say what you want and you know nobody would be looking at you as if to to say what did she say there he say or whatever

Researcher Of course

Joan The teachers as well like they're they're all so you know they're also they're for you and just even having the like (name) she's the...

Researcher (Profession)?

Joan Yes thank you, having her is great as well because she was so good just to kind of talk to and just to get things in my head kind of

Researcher Of course, (name) is a power house of a woman like she's just amazing

Joan Oh she's brilliant like

Researcher She is, we're very lucky to have her in (service name) we really are, because I know what you mean just her presence alone like where (name) could come into the room and just make everybody feel better just like by coming in

Joan Yes she's just she's lovely like you know

Researcher She does light up the place for sure

Joan Oh she would yeah, you know you see her coming and you're like hi (name)

Researcher Yeah exactly, if there's ever a training day that (name) is running, everybody's at that training day like everybody like (name) is running the training

Joan Yeah or (name) as well

Researcher Oh yeah oh (name) brings such a wonderful energy to the whole whole place

Joan Oh she's just comical like the stuff she comes up with sometimes I'm like sitting there going they're like I can't, it takes me a while to kind of understand she's saying but I just still have a laugh about it I'm like oh yeah

Researcher and that is wonderful, like you say meeting people like that can just just changes up your day you know it's just

Joan Yeah

Researcher When you meet somebody who's just full of energy like that or or just kind of yeah has that presence to to kind of make you smile you know and how like (name) was mentioning there that you've been starting online groups how is that going? Do you think you would like let's say service opened tomorrow would you like to do blended or would you like to get right back to the building or how how have you been finding it?

Joan No I've liked online, the online classes like you know it's nice just to kind of see people's faces and just to kind of being able to talk with them and have your little laughs

Researcher Yeah

Joan Just you know just kind of it's better than just being you know stuck here and you're like seeing the same faces all the time

Researcher Of Course

Joan Just something different and just kind of looking and going oh hi how are you you know

Researcher It's a connection I suppose yeah

Joan yeah

Researcher and you're still keeping in contact for sure and if like when lockdown hopefully hopefully lift I know that there's no date for that

Joan No

Researcher Do you think you'd like a mix of both online and in person or would you like to go back to your five days or would you like to do a bit of both or would you have a preference?

Joan I suppose a bit of both really you know I would prefer because just to kind of try to get myself used to kind of getting back into the building as well but at the same time kind of working on line you know at the same time

Researcher Yeah of course, because with the hour and a half bus journey I suppose were you up early to try to get it in and

Joan Yeah I was up around quarter to 6 in the morning

Researcher That's not the easiest way with fatigue and with epilepsy and everything like that that was a full commitment I'm sure

Joan Yeah, getting home then it could be... well the earliest I could get home would be about a quarter to 5 so

Researcher That's a good long day as well, that's almost a 12-hour day yeah by the time you're in so but no (name) you've answered all my questions so I can't thank you enough, would you have any questions or anything?

Joan sorry it's probably very fast so you're like what

Researcher Not at all this was absolutely brilliant it was really informative you answered everything, it's fab, I can't thank you enough all for participating because I know it's not it's not the easiest especially when we wouldn't know each other you know so thank you for doing that

Joan Yeah you're welcome, no problem

Interview 6 Transcript

Professional working in the ABI rehabilitation sector Lucy (25) Pseudonym

The researcher and Lucy began by discussing Lucy's professional role and how long she has been working in the ABI sector. Lucy explained that she is a rehabilitation officer, she does a mix of community and rehab centre-based work with service users. Lucy joined the organisation almost five years ago as a student and has been working in the Acquired Brain Injury rehabilitation sector for four years.

Researcher So as you know the study is exploring clients first-hand accounts of sensory overload, so in your experience, just in your day to day either out in the community or in the (name of organisation) building itself, what are the kind of sensory challenges that can crop up for clients in your experience?

Lucy Yeah so my first example would be out in the community with a client, so if we're ever in a shopping centre and it's quite busy especially around Christmas he won't be able to cope with the noise so if we're even chatting in a café he just cannot deal with people talking next to him or people just walking past and he just gets very irritated by it so even if we're trying to look at the iPad we might try to just sit down at a coffee table some days and we might look at his iPad for music or whatever and he just cannot concentrate with the background noise of people in and out, so that's a challenge for him.

Another thing would be if we're going for a walk even like, if an ambulance passes, he can't cope with the loud noise of the ambulance and has to cover his ears all the time too so that's another thing. In the community...I'm trying to think of something else, I suppose another client is in a wheelchair sensory overload for him would be the crowds as well, he gets a bit I

suppose embarrassed if people are looking at him, so he doesn't like to be in crowded areas either

Researcher Ok

Lucy and then in the building (referring to the ABI rehabilitation organisation) I found recently that if a particular client comes in, she requests that she has a chair with the arms because she absolutely does not like when there are no arms, she doesn't feel comfortable, she can concentrate better then so she needs the arm rest. Another one then in the building would be the light in there, sometimes a client might think it's just too bright so we might have to dim the lights a bit by turning one off and leave one on. Then, another one would be...I suppose obviously it depends on the group you do but if you're playing a video or music you have to be careful with how loud the music is for a particular client because he does not like when it's too loud, so you have to find the best kind of volume that suits everyone because obviously people then might not be able to hear it, if they have hearing issues, so you have to find a good balance between loud and I suppose quiet. I suppose another sensory in the building would be...especially in the Winter it can be very cold so, one particular client is always cold anyway throughout the year, especially Winter so try to make that she has a warm area, has maybe a blanket, is near the heater, because when she's very cold she just shakes and cannot really concentrate then in groups, so we have to make sure she's nice and warm and toasted. I think that's all I can think of for the moment yeah.

Researcher Those are fantastic examples and they're all so varied as well, you know like...to go from the client who can't concentrate in the community because of the background noise, to go from in house the temperature is a big one for sure, that definitely crops up for that client so it's a great range of examples, thank you so much.

Lucy No worries

Researcher We kind of answered question 3 and 4 there really which is great, so question 5 is just about the sensory menu which is at the end is we scroll down there but basically this came from when I was doing my lit review, I came across it, initially developed by an emergency department and they found people coming in, obviously high distressed state, but they found having the sensory menu really helped just calm down the people and just kind of gave them a really good experience from the off so I liked the idea of a sensory menu because I suppose when we're setting up...whether it's an IGP meeting or a keyworker session or any other meeting like that, like at the moment we kind of do a one size fits all you know

Lucy Yeah

Researcher So everybody comes into the same room, into the same environment and like you said before, when we're in a group setting, we have to find the balance, you know even with the level of noise and things like that but when it's just the person and their family member coming in I wonder if we could tweak that a little bit more and tailor that a little bit more, so the idea behind the sensory menu is to...sorry Lucy were you going to say something there?

Lucy No sorry you're grand

Researcher The idea behind it is to basically give the clients the opportunity to choose how they would like their environment set up, so just they can say...I was actually thinking of even myself if I was going into a doctors practice or anything like that, if it was too hot I'd be on the floor I would be passed out you know so I would just need an airy room and maybe the lights off and things like that. So, if we just have a very quick look through the sensory menu, I've done this with the clients, and they've come back with some really good suggestions. So the

first one was the room size which I wouldn't have thought of before, it's a really good suggestion from one of the participants, and with these things we not always realise, especially in the current building, we might not be able to provide this, this may need to be something done in the new building with some planning but if we could even hit a couple of the markers so the participant was saying the room size that some people might need because of their needs, they might need a large activity room, they might like the space, but she was saying that some people might like a small compact room, they might open up more and they might feel differently to a large purposeful room. So that's why that one is in there, so room size, I'm just thinking of our own building we'd have maybe the choice of two but as you know any given day that could be, pre Covid times could be a very busy building

Lucy Yeah exactly yeah, the room makes a difference yeah for sure, because our room is ok but when there's a lot of people in it, it can be a bit overwhelming for sure

Researcher Yeah for sure. The windows open or closed is one thing that came out as well. So maybe just the heat of the room.

Lucy Yeah

Researcher The lights on, off or dimmed. Now I know at the minute in our building we don't have a dimmer switch, but I was thinking even a dimming lamp might make a difference, you know you can pick those up for fairly cheap, that if the lights were affecting someone in a keyworker session that we could have them on, off or dimmed.

Lucy Yeah it would be great to have a dimmer setting in our new building too because sometimes it can be too bright and then it's too dark so it would be handy to have the in between yeah

Researcher I think it would too. Some clients liked the idea of having music on and some clients I'm sure would hate nothing more than to have music on in the background, it might annoy some people where it might sooth others, so that's why I've included that one in there and just an example, I was thinking first off if I put classical music on for some people they might absolutely love it and others would be like what's on? Like where is my Christy Moore? We need to put on somebody else so that's why I've included the options there. The heating, you mentioned that one, the temperature for some clients, they really need a nice blow heater and a blanket, where other clients then would be far too hot you know

Lucy Yeah

Researcher Then you already mentioned about the type of chair which is great, some like the armrests and some don't. The tactile items, so like a stress ball or maybe a weighted blanket or something like that might suit some clients and that's why there's "are there any other tactile items you would like to be available". Tea or coffee, I know a cup of tea definitely puts me at ease so maybe if a client was coming in for like a multi d meeting or an IGP or something, it might just be good to have, I know we always have water on the table, but it might be nice to have a pot of tea or a pot of coffee as well.

Lucy (laughing) I suppose

Researcher (laughing) or a pot of hot chocolate for yourself

Lucy Yeah

Researcher Then there is just space at the end for "is there anything else that would aid your sensory needs" because I'm sure it's not all inclusive, I'm sure clients would say oh you forgot

x y or z which would be great because there would be space to put it in but is there anything there as we're reading through it that you think should be included or changed?

Lucy I think everything there is actually really good because even for me I always find for example if I'm going for a doctor's appointment, even for literally a very small thing, you're a bit nervous and tense so I could imagine how the clients and the families feel you know going into needs assessments or an IGP meeting, so you want to be as comfortable as you can and I think, I definitely think the armrests make me feel comfortable anyway so I think that's a really good one and I definitely like having the window open a bit too just for a bit of air

Researcher Yeah

Lucy and the lights not too bright because I think with my glasses, they just reflect off of them quite badly, so I think the clients there, got really good examples there yeah.

Researcher Fab, that's great, yeah it could be an interesting way... I'd like to do it pre IGP or something, you know to see how it would go, but I think they might respond well to it, the feedback has been good on it so far anyway which is promising

Lucy Yeah that's really good yeah. Sometimes places can be too big too bright, too hot especially when you're nervous about going to an appointment like that like yeah

Researcher Yeah exactly. So, question 6 then is, when I was talking to the clients, during my interviews they spoke about basically the various ways their Acquired Brain Injury and sensory overload has changed their lives, so some people spoke about the impact it has had on their profession, some people spoke about the impact it's had on their hobbies and their ability to be alone, you know and just have some alone time. The relationships were a big one and the roles in the family unit, so for some clients having an ABI seems to have impacted on their

overall sense of identity and I know this has cropped up definitely in my career in (ABI rehabilitation organisation) of clients, some clients feel removed from the person that they were pre injury. Have you experienced this through your work? Through your clients?

Lucy Yeah I suppose from the clients I've worked with, you could definitely, especially when you meet the family members, say for example like a client, a male client with his daughter maybe or his son, the daughter or the son becomes the parent then you know like, you'd be ringing them to see how they're doing and they're all worried and they're just about their parent so I think the roles are kind of reversed there, that's I think a huge one because the client then just feels a bit I suppose oh my kids are worried about me and they're looking after me when it should be the other way around you know

Researcher There's been a shift yeah

Lucy Yeah there's been a huge shift yeah exactly. Another one, relationships, like a client I work with in the community, before his injury would have had a number of friends and then like 20 years later, he always says Oh I haven't seen them in about 10 or 12 years, so like you know he loses that kind of friendship, you know I suppose they move on in their lives and they have families and friends whereas he doesn't have any of that, you know he's not a married or he doesn't have family so I suppose then he kind of feels a bit like Oh they haven't spoken to me in 12 years I don't know why you know so there's a bit of confusion around that, and then when it comes to their professions one client I work with has very, 6 to 8 hours a week, kind of doesn't understand why you know he can't have the 35 hour week or whatever it is but it's because of his fatigue, to manage it so it's kind of, I suppose it's a bit confusing and it's a bit kind of...I suppose, I can't think of the word but you feel I suppose, I don't know

undervalued or something I don't know, that kind word because his hours have been reduced
I suppose

Researcher Yeah

Lucy and anything else there, hobbies, I suppose yeah hobbies would be a big one because of mobility issues they can't go for long walks or hikes anymore or even gardening, if you have you know, I know a client I work with in a rollator would find gardening difficult now because of his leg you know he couldn't bend it or you know walk too far so he used to love gardening so he'd find that hard now so he had to, when he's doing the gardening he has to be like...he has to have plants that are on the window sill instead of going down to the ground and digging up stuff

Researcher Of course

Lucy So that's kind of changed his hobbies differently. I suppose another client then used to be painting, a painter so he is also in a rollator wheelchair too so he kind of rollates, he walks with a rollator but he uses a wheelchair a lot too because he gets quite tired so he would love to go back painting walls and stuff, but it would be just physically too much for him because of his fatigue and I suppose his mobility issues. Yeah, that's kind of it really. I suppose like there is definitely a huge change in peoples relationships, with their friends especially, I suppose the family will always be there for a lot of the clients, the friends kind of become, I suppose a bit distant over the years you know. Yeah I think that's it. That's all I can think of anyway

Researcher Those are some great examples thanks so much, they're so relevant as well like I can see across the range like, you could see in all different ways how people's lives have

changed you know due to their...whether it is their profession or their relationships or which, there's definitely been...it's not just the injury itself I suppose it's what comes after as well so thank you so much for all those examples. So question 7 then is kind of about clients getting isolated basically, so sensory overload appears to be isolating for some clients so possibly coming back to the identity question as well of the one before but they experience the rehabilitative environment differently so some of their triggers can be quite individualised as well, like having the interviews with the clients I realised that there wasn't, while their symptoms of sensory overload were equally intense they weren't the same so there were different things that they found very difficult following their diagnosis of sensory overload so it can be quite isolating for them because like with some of our clients inside they can kind of go Oh like I'm feeling really fatigued at the moment and when somebody else says Oh I've got that as well or I had that in the first few months or whatever there's kind of that bonding but for sensory overload it seems to be a little bit isolating because nobody else has experienced the same symptoms as you have so that got me thinking about our clients and their own needs and their individual needs and the idea that they can get isolated in the group a little bit so have you observed this? Have you observed clients being a little bit isolated due to their individual needs whatever they may be, sensory or not?

Lucy Yeah, a client we work with has aphasia and she has an iPad I suppose to help her with her communication but obviously it's still a lot of learning for her but especially in groups if...I just remember doing a quiz a couple of years ago and they were in teams, the groups, so she kind of found it hard then to answer the questions because the other clients...I suppose they weren't...they couldn't really be like what's the answer? Because they just knew she couldn't say it so I think she felt a little bit you know Oh ok I'm just sitting here and they're just

answering the questions and they're not asking me because I can't really say it you know so that can be quite isolating then for the client.

Researcher Yeah

Lucy I suppose another thing would be...let me think now...isolating, that's all I can think of at the moment if that's alright

Researcher No absolutely that's a really really good example. So, the big question of the moment, how has it been working through the Covid-19 pandemic?

Lucy Do you have three hours?

Researcher I do (laughing) yeah, take it away

Lucy Take it away. It has been I suppose quite stressful, but I understand then, I always think ok it's stressful but we're not in the ICU wards too like I think ok it's not the end of the world but it has been stressful of course because I find myself it's quite, you know working from home can be quite lonesome sometimes and then when you're in the office then you're on literally like what's the word, eggshells, you're just trying to watch and sanitise everything you touch

Researcher Yeah

Lucy and then when you're with clients especially I just find...yeah yeah to be fair it is quite stressful because the clients might not be very you know aware of Oh I just coughed and I just touched the table you know what I mean so we can't...yeah it has been stressful because you're watching everything that you're doing and you're watching everything that the clients are doing and you want to make sure everyone is safe so yeah it can be quite stressful alright, yeah I suppose...yeah stressful I can't think of another word really

Researcher No that's the perfect word for it, that's the perfect description

Lucy It has been a lot like, it has been a crazy 12 months yeah

Researcher It certainly certainly has, and I suppose like that it has thrown up so many different challenges both for people professionally and personally. So, if you don't mind me asking, what have you found most challenging in the Covid-19 times, that could be professionally or personally if you don't mind me asking but

Lucy Yeah

Researcher what have been the really difficult parts of working through it, like I know definitely the stress is certainly there but if there's anything you could pick out in particular?

Lucy I'll start with professionally, what I found challenging, I think when we're not in the office as much I definitely feel you know, it's been quite...I suppose it's been lonely too because you're working from home a lot too, you would miss the team and you would miss the colleagues and you would miss all the clients too, so I think that's been a huge challenge for me. I used to always thrive on the atmosphere inside the office, you know the team having great fun and meeting the clients and you would be having you know jokes and stuff so you would definitely miss that kind of energy in the office

Researcher Yeah

Lucy and then I suppose professionally too I suppose we're all quite stressed and yeah I suppose that's been really hard and then personally what I found challenging in the Covid-19, obviously miss all my family and miss all my friends a lot but personally I find it very hard, I suppose at any age really but at my age I thrive on like planning stuff whether it's like planning a trip or meeting a friend for a coffee or lunch, having something to look forward to, for me I

find that very hard because it's been a long few months of just sitting around and you're just working from home and you're just like oh the weekend is here and you just have nothing to like countdown to like you know so I find definitely for me I have to have something to look forward to, something to plan and you know kind of get you by really because it's very hard to be sitting around and not have...you know things to look forward to as much, I am looking forward to the future but like whenever that will be you know what I mean, you know the new, the old future like where you could do things but if that answers your question

Researcher No that's perfect, I completely understand as well because there is no end in sight it's really hard too...you know if you were told ok for three months you can't go anywhere but you know once that three-month marker hits life is back to life as we knew it you know

Lucy Oh you could cope better, like grand yeah, no bother, but just so many lockdowns you're like oh right...still you know, it's very hard like

Researcher It is and it's the unknown as well isn't it

Lucy Yeah

Researcher It's kind of the...because there is no end in sight, we've never been through this before so nobody...event the experts can't predict you know how it's going to go

Lucy Yeah exactly

Researcher I find that personally it's the uncertainty of it as well, of being like...but nobody knows, you know like, with a lot of things in life even when they're uncertain there's kind of an element of oh but this has come before, or this is what happened so it's a little bit predictable but in this it's kind of like nobody knows

Lucy Nobody knows yeah and I'm looking forward to planning stuff again

Researcher Yeah for sure, and you mentioned the energy in the office and things like that, I think that was a huge part of our role and even without knowing it possibly, a huge part of our debrief as well, you know, didn't know it at the time but yeah

Lucy Yeah definitely yeah

Researcher That was big, so how has the Covid-19 pandemic impacted on the clients service in your experience?

Lucy Its impacted hugely, like we were lucky enough that in August we got to go back and have you know our Day Service open again but obviously it was certainly a huge transformation, because obviously we had less hours with the clients and we had less clients in the building so even though they were all very happy to go back, you could definitely tell that they were missing each other, you could have one client going how's so an so because that client might be in the next day, you know on his day, and I suppose it impacted the service too, because you know we are thankfully giving them a service but like they used to have five hours a day whereas it's been reduced to two hours maybe twice a week or three times a week so like obviously that's been cut down a lot too so it's great that they're out but you know not for long if you know what I mean, even like community work, I used to work with a client for five hours a week and that's gone down now to two so that's a huge thing, like I know it's only a couple of hours difference but it is huge because it's only so much you can do in two hours too I suppose so yeah like I'm so glad we can do a service and we're doing it in a safe way but unfortunately the consequences are like you know less time with the clients and less time with the clients with each other, you know they might not get a lot of chance to catch up as well but I think that is definitely huge because their days you know their waking

up and their going to the services for two hours and they're home again so it goes by fast in fairness so I think that's a huge thing

Researcher Yeah, yeah I completely agree, it has been, and then of course we has clients understandably weighing up whether it was worth coming in for the two hours, you know I suppose balancing the cost of the taxi or the cost of the transport in, it always seemed worth it for a five hour service to them but they understandably had to weigh that up as well, of like I'm almost in before I'm back out again you know

Lucy Yeah and I suppose you're right too about the taxi like I know one our clients didn't come in because of the expense of the taxi whereas if it was five hours you'd be like oh that's worth it but for two it's not because the taxi would probably have to park outside for the two hours, by the time you know the service is kind of finished

Researcher Yeah, it wasn't, yeah that couldn't kind of go far before they would have to be turning around again depending on where they were coming from, yeah that makes a lot of sense, yeah the loss of the clients being like how is so and so or where is so and so, I heard that question a lot when we went back, where is whoever and you think that was kind of sad to hear because they were so used to obviously seeing those people and then all of a sudden they were separated you know

Lucy Yeah

Researcher Obviously given the times we're in we're masked up to our eyes and gloved up to our eyes and lots of PPE, how do you think that impacted on the clients, did you see an impact? Was there an impact? The need for us to where PPE and them I suppose as well

Lucy Yeah an impact, yeah I suppose when we first started I found they definitely...a lot of the clients especially in our groups, they could not deal with the mask on for that length of time and you could definitely think oh I can't breathe in this or I don't like this but eventually as time went by I think they got very used to it, used to wearing the masks and they got really good at like you know sanitising and then from my client in the community, I've been working with him since June, we stopped in March but we obviously went back then in June to do our one to one work but that was a huge transformation because obviously we were so used to like you know being in the car together you know whereas then we're out for a walk like two metres apart so it was a huge you know transformation but he found it quite...fairly hard to wear the mask at first, like complaining that he couldn't breathe but to be fair eventually he did get quite used to alright and safety protocols I suppose at the start too people are kind forgetful of the two metres but then, once you talk to clients and go look remember the social distance they get really used to it, I suppose the more you kind of say no two metres they get used to it, it's all learning,

Researcher Yeah

Lucy Learning the new things really, I think they've done very well all the clients but definitely like I guarantee when we go back there might be issues again like oh I don't like this because they might not have worn a mask in a long time now you know

Researcher Of Course

Lucy Getting used to it I think

Researcher Until it becomes a habit and becomes the norm and it was so far from the norm we knew I think it was a big leap understandably for everybody, clients and staff alike that it

was very strange to be down in the room with a mask on, visors on, gloves on and all the rest. Yeah you're right they did remarkably well, fantastically, adapted well to it like they do everything, they adapt you know but yeah the PPE, I know that you got the clear mask, cause the next question is about like how do we cater for...I don't expect you to have the answer but how do you think we cater for clients who experience sensory challenges, like some clients come to mind, they would struggle with... might have always been lip reading maybe didn't realise, we didn't realise how much they were doing it and perhaps they didn't realise how much they were depending on it, but I know that you got like the clear mask and things like that to cater for those clients, that's a tough one, how we go about that, how we design an environment I suppose to cater for clients with sensory challenges with the need of PPE you know

Lucy Yeah, no exactly, because I know we don't encourage the visors now anymore but at the time we didn't know but I got the clear mask because I found it was very helpful for obviously our clients with aphasia so like one of our clients, I know for sure would be lip reading and would understand you better when you're lips are moving and I know another client might have you know hearing issues too so I was kind of conscious of that too because they could hear better without the mask because the mask could be quite muffled of course whereas the clear visor you could hear them, you could hear a person, a bit better you know. What else have I done? I suppose what I do as well, I don't know if it would help these clients but when I was doing my group I was doing countries of the world and used to bring handouts to the clients so we would read the handouts together so I didn't want them to be...I didn't want me reading from my sheet and they would be like what is she saying? So I said look I'll give them handouts so they can follow me as well, they can follow what I'm reading and I think that helped too because like at the start when I first did the countries they were like oh sorry

what? what? and I had to keep moving my mask or like you know take it off for literally two seconds to be like oh I said this you know so I was like I'll just do handouts instead and that worked better but I'm not sure if I'm going off the topic there

Researcher No you're not, no not at all, those are great examples, I know what you mean about the...I started using the whiteboard a lot just getting the...or the interactive white board I should say, I always use the board an awful lot, the actual physical board but what I found with that I'd have to get too close to a client in order to bring it out so I just didn't do it but I just bring up like a word document and just make the writing really big and then the clients who would have been lip reading and things like that seem to respond well to those kind of things and like you said following reading the handout was big because it was in front of them then and they weren't struggling to hear you

Lucy that helped definitely yeah

Researcher I think all of those things hopefully help, they certainly seem to get a response from the clients you know which was good and then I suppose the next question is just about key strategies that the clients use themselves so those are the kind of things that we were using but have you seen them, any clients use anything to alleviate their sensory challenges like that you've seen working well for them? That could be pre Covid or post Covid really that's just a general question but this question kind of stemmed out of when I was talking to one of the clients in the interviews, he was saying...I would have always thought that it was just part of his fashion choice, but he always wears a cap, and he was saying that he does that to avoid the glare from the light so he was like this is why I always wear a cap because it protects my eyes. Have you seen any clients do anything like that or kind of employ strategies?

Lucy Yeah, that was a good one there yeah, probably thinking of that too because I remember that client because of the light.

Researcher which is something I didn't realise for a long time that he was doing

Lucy Yeah I didn't either, that makes sense

Researcher that's why

Lucy I suppose one of our clients would sit nearer to the staff because of his hearing issues

Researcher Yeah

Lucy so he'll sit nearer because he might not be able to hear if he's at the back of the room

Researcher Yeah, he chooses his seat doesn't he

Lucy Someone who might be... you know bad eyesight sit nearer to the board too to make sure they have a better view of what's going on, yeah that makes sense doesn't it

Researcher Yeah it does, completely. We kind of touched on this one a small bit already but like the...I suppose all of our clients say the support of a peer group is often the big one you know and is kind of key and like we often say how we facilitate the group, but the clients are the big draw obviously, that peer support is next to none. How has separating the groups and I suppose it was necessary, absolutely necessary to separate the groups but how has that impacted on the client peer group? I suppose we've already kind of touched on that in terms of clients looking for others and you know

Lucy Yeah definitely, I can't count how many times a client has said oh how's so and so because they would have been used to seeing them in their days but obviously we had to separate them, but I suppose another thing too, client peer group, you could say we had to

put them in groups where their needs are best met so...how has it impacted on the peer group, I think I've just answered early really...sorry

Researcher Yeah no not at all

Lucy asking for each other really and stuff like that yeah

Researcher yeah asking for each other was a big one wasn't it

Lucy Yeah definitely

Researcher I know that we were talking about it in the last team meeting about maybe getting those...like I was thinking pen pals but what ~ was suggesting was actually one up from that was the three-way phone call that might be something that might answer that in the future

Lucy That would be great, I would love that

Researcher Yeah that would be a great option, and then like that got me thinking about our own professional and personal peer groups, like how has that impacted on your own peer groups, I think you might have answered that a little bit earlier as well but

Lucy my own personal is it

Researcher Yeah

Lucy Yeah, it's been very challenging year because some of my friends might have different views to be on how to handle the Covid so like yeah it's been very tense because...especially over Christmas one of my friends wanted to meet for a few drinks with other friends but I was like I'm just not comfortable and then I didn't go and you would feel like oh God I missed out but then I just knew that I would not be comfortable going into a setting with friends I hadn't seen in months that I didn't probably need to see any way you know so it's definitely impacted

my friendships definitely because I know some people are going to meet other friends now, even during a level 5 and I don't agree with that and then you're like oh I'm going crazy, yeah it's been definitely challenging, and professional...has it affected I suppose yeah it has affected us professionally because we don't see each other as much and I thought we always definitely thrived on the team work whereas now we don't see anyone really so yeah it's been different but yeah am I making sense about the personal thing?

Researcher Makes perfect sense

Lucy There has been a few intense texts going no I'm not going because I do not want to spread this virus

Researcher I know

Lucy so yeah it definitely is a hard one because you'd miss all your friends of course but you don't want to meet up with them for the sake of two hours in a bar, restaurant and then to get a call to say oh yeah, I'm a close contact you know, yeah it's been very stressful to manage all that

Researcher Yeah, absolutely, it's the fear, and like you say of course you ache to see people but then it's the fear of contracting or transmitting the virus itself and yeah there's lots tied up in that because there's the guilt and the want, the guilt of not going, wanting to see people but then also not wanting, obviously not wanting to flout the rules or anything like that but it's all...yeah there's a lot to unpack there isn't there

Lucy Yeah, I can definitely tell that I've had a few fights, not fights but disagreements with friends in the last twelve months and you feel so bad because like if this never happened you would just be meeting them as normal anyway so it's just weird to think like how you were

meeting normally all these years to all of a sudden going no, I'm not meeting you anymore because I don't know who you're meeting as well you know

Researcher I know, there's that trust as well of like, you know you trust your friends and obviously you trust your family and everything but at the end of the day you just don't know who they've seen so that's certainly a hard one and you mentioned earlier as well about the energy in the office and things like professionally, peer group, like I know we were talking recently about celebrating things in the office like that peer support has been lost and it was a sad one when we were talking about oh God yeah if these were normal times we would be in having a big celebration in the office as normal you know

Lucy even Christmas time was weird there was no Christmas like you know atmosphere, party, you know everyone, we just didn't see each other so I felt like that really went by so fast so that was missed, I always used to find the last day of work so happy and exciting where this year I was like oh yeah it's Christmas holidays tomorrow but there's no one here to celebrate with

Researcher I know, it didn't feel the same did it, no it didn't. So, we're almost there thank you so much for your time

Lucy No worries

Researcher So the second last question is just about...so basically my study is looking at how do we tailor down the rehabilitative environment, how do we make it serve each client as much as possible...and that seems to alleviate sensory overload a small bit, but do you find it easier or harder to tailor the environment now like with our...let's say our group of four when we were client facing, did you find it easier or harder to tailor the group. I suppose when I was

thinking about the question I was thinking maybe easier because there's less people but harder as well because you have less feedback, what has been your experience?

Lucy Yeah, a bit of both , so I definitely found that I enjoyed the group towards the end before Christmas because the four clients I had worked with were all...had huge interest in the group I was facilitating so it made my group much easier and fun because they had so many questions and I suppose when it was just four of them they could ask as many questions as they wanted and we had all the time in the world you know compared to the sixteen where if they were asking me a question every two minutes I would not be able to finish the group you know but then on other days it would be very hard to facilitate because you might have someone that isn't...doesn't really want to talk or is a bit shy and then yeah it can be very hard to find a group that suits, it just depends on the group really I suppose because you would have people who don't have an interest in the topic that you're on about and then you'll have people that do and yeah it was easy and hard so it depends on the day really and it depends on who's there so if that makes sense

Researcher No it does

Lucy I just found my Friday groups a lot easier because they had all had interest in the group and had all questions where Wednesday there was definitely... I suppose people with aphasia or maybe just a shy person, they just didn't...they would enjoy the group but they wouldn't ask as many questions so then you'd be trying to fill the time a bit then you know

Researcher Yeah, it was definitely a double-edged sword on that one, sometimes it was easier if you had that interest and then other groups were harder of course yeah

Lucy For one particular client I found that she definitely thrived more in the group of sixteen because there were always a bit of jokes going around and stuff whereas when it was a quieter group and a smaller group she was definitely a bit more quieter because her other friends or clients from the group or from different groups weren't there so I just felt she thrived better in the bigger group because she could be herself a bit more whereas when it was a bit more personal I think she was like oh God everyone is looking at me now

Researcher Yeah, yeah I get that and I think that was different for each client because I know that one client said God this is like...I used to get lost in the big group before and I didn't know who I was coming into, I just kind of put the head down and come in, I wouldn't want to ask a question because there was too many people in the room but then I know exactly what you're saying as well on the flip side other people thrived off that big group atmosphere and having a lot of friends and maybe the focus not being so much on them, where when you're one of four there's nowhere to hide and that can create I'm sure a little bit of nerves as well if you're thinking like oh God there's...I'm just one of four here that's a much smaller group especially when we went from sixteen to four

Lucy Yeah, it's huge

Researcher The final question is, for sensory overload in a strangely interesting way it seems possible that services provided this way post Covid might be a benefit just in particular...so the clients at the moment who would have been commuting into services that weren't necessarily then serving them all that well because they might be triggering for them, might trigger their fatigue, the environment might not be the ideal environment for them so at the moment now they can access sessions online from the comfort of their own home kind of in their own sensory informed space, their own space that they've set up themselves just the

way they like it, so travelling to the environments that were triggering for them has been eliminated, what do you think? do you think the new way of delivering service helps or hinders clients? And I suppose what you were saying on the last question it might depend on the client you know

Lucy Yeah definitely, I'm thinking of a client for example that might have fatigue issues that maybe this service might suit them better because I know some clients travel for like maybe forty minutes or an hour away and by the time they get into services they are tired then for the day, so like if they can get up at a comfortable time and then log on and have a group online it might suit them better for the fatigue you know, so I think that would be helpful for someone like that, that might like that but I don't know I think a lot of them would like to be in a group setting because I suppose it's nice to have social contact and to meet other people because when you're at home all day you know it can be isolating and lonesome. I can see how it could be helpful for some clients because maybe they just don't want to be with other people, they might not want to, they might not get along with some of the other clients and they just may prefer to do everything online maybe, if that makes sense

Researcher Yeah, I think it depends, it depends on the client for sure but I suppose what the Covid-19 era has done is that it sped up things that might have possibly taken another ten years to get off the ground, in the sense that if you had said to us pre 2020 like you know a lot of services will be online, clients will be able to access from their own home, that would have been...now I know with our clients and digital literacy and access to Wi-Fi and things like that, that hasn't been the case for them but to think that we'd all be having team meetings from our own homes like that would have been alien before you know

Lucy Never

Researcher Where I think it sped up those kinds of things, and maybe for those clients who were travelling like that, long distances to come in, for maybe even for a psychology group of an hour it might benefit them but then I know exactly what you're saying on the other end as well it's good to socialise and it's good to meet and it could be isolating on the other foot as well

Lucy Yeah, yeah

Researcher (name) thank you so much for your time I'm just going to stop the recording

Lucy Oh cool

Interview 7 Transcript

Professional working in the Acquired Brain Injury Rehabilitation Sector Ellie (33) pseudonym

Researcher So as you know the study is exploring clients first-hand experience of sensory overload and I know that's not something that we crop up in the DRS role a whole pile but in your experience and observations what are the kind of sensory challenges that crop up for clients?

Ellie So I think you kind of hit the nail on the head there a little bit, I feel like I've seen some, but I'm a little bit nervous that maybe I might have missed some over the years, I'm just going back over it but I suppose the main ones that I've experienced is sensitivity to noise, loud music, loud conversations, singing, some clients have had a reaction to that. Likewise with hearing, clients with hearing difficulties and repositioning themselves in a room that works better for them so in that case that client has been very well able to self-advocate for himself you know to reposition himself around but I'm just thinking now has there been clients in the past that maybe weren't able to self-advocate and you know I'd be a little bit nervous that I've almost missed something because the two that spring to my mind are 4u6nh4u6nh hearing and fluorescent lights, or like loud noises but I'm thinking, obviously there's more senses so I'm just trying to go back along but I think I've had limited experience with it but I suppose maybe I need to educate myself a little bit better on sensory overload

Researcher Ok great yeah, no it isn't something that necessarily crops up a whole pile or maybe like you say it's the awareness of it as well and like that knowledge is power in the sense that the more we know about it maybe the more we can look out for it as well. In the same way as absent seizures, when you know what you're looking for as well and know what to ask you know

Ellie Yeah, that's it, knowing the questions and knowing the client because like I said earlier we have a client centred approach to our care with our clients but then I'm like we really need to take into account their sensory needs and you know outside of like the big two that I can think off the top of my head, I'm thinking like we need to be better focused and focused in on our clients sensory needs

Researcher Yeah that's exactly it, like that it's like until it's kind of on your radar of things that it can fall into the background a little bit until it sits firmly on your radar and you're like oh wait a second you know this is... it's a little bit like our clients when they say that they're their injury is a little bit of invisible if it's not physical you know, the senses might fall under that category a small bit that until you see a problem cropping up for the person you don't really think about it so hopefully studies like this will shed a little light on that

So, we talked about like their sensory challenges that can present and in your experience like what are the kind of environmental barriers that can cause difficulty for them either in the building itself or in the community?

Ellie I suppose a little bit of both really, like it just made me think about how rehabilitative or actual physical building is you know just from things like stepping into the building and I'm trying to step into the building with fresh eyes now and if I came in the front door there's just a lot of you know safety signs and warning signs and which is fine and I understand the need behind having you know the fire safety and the the emergency escape plan and all that's all that's important to keep someone physically safe but I suppose it looks very clinical and I just I worry that maybe we might be re traumatising them by coming into an environment you know that that's just a little bit too clinical like I know we do our best to try and you know make sure we have our art projects up and we we put up photos and things around the room and you know we try to make it their room as opposed to just a rehabilitation room but I suppose I do worry about the signs being a little bit too clinical and and just wanted not not wanting to re traumatise them by by bringing that in you know ideally I'd like to get rid of the signs but I understand the safety reasons behind having them up so that's kind of and one of the barriers and as well as that I think I mentioned it briefly earlier but it's just awareness like you know I'm in ABI five years and I have openly admit I've limited experience with sensory overload at the extent where like I don't know have I fully taken in my clients sensory needs throughout the last five years and just looking back and you know have I missed something or was there client who maybe didn't advocate for themselves because for whatever variety different reasons and like was something overlooked and like you know I think the barrier, the biggest barrier is lack of awareness and lack of understanding the knowledge around that so if if staff who were trained in in in this area are a little bit limited on their knowledge on it then how can we best support our clients if we're the trained staff to do that and we're... are we missing something so I suppose from my point we think the biggest barrier will be lack of

education and awareness and we just need a lot more training on sensory issues and sensory overload because then we can inform best practice if we're best informed ourselves

Researcher I think that's an excellent point and a huge point because yeah if we're not in tune with it ourselves then we're definitely not setting up the...you know almost in a small way unintentionally setting up our clients to fail a small bit by making their environment work against them as opposed to kind of be a tool an extra tool in their toolbox you know of rehab because we're just we're not in in tune with it and we're not you know we're not looking out for it so I think hopefully yeah the more the awareness grows than that we that it becomes commonplace and I think you mentioned that earlier of like you know until we're really just until it becomes the norm of just like oh can we check their you know their sensory needs or does the client...even asking the question does the client have any sensory needs that isn't something that rolls off the tongue you know even when we're talking about a new client

Ellie It definitely needs to become new practice though doesn't it just to to really factor in sensory need of a of a person coming into the service needs to be...it just needs to be one ...it needs to be a checklist question really like doesn't it

Researcher yeah it kind of needs to be it needs to be in the mix in the same way that we would say like you know just trying to to forward plan what might be the best day that they could come in just given space or anything that we'd say like oh you know is the person in a wheelchair or you know does the person have any swallow difficulty or you know help feeding or or or drinking or anything like that and then hopefully it would become you know just commonplace to be like oh and what are their sensory needs you know

Ellie Yeah because I think we're... I think we kind of pride ourselves on being client centered and I I really do think we are client centered with our clients but at the same time then are

we fully client centered if we're not sensory aware you know and I just think like I think you mentioned it that like it just needs to become part of a regular conversation does it to normalize it's like OK just you know such a such a client have any sensory needs that we need to be aware of, does she need to have a blanket does you know it's all these questions that will become commonplace but they just need to be commonplace because they're just as important as a client's physical safety if it's going to trigger them and we're not aware of it

Researcher that's exactly it exactly, so on the back of that I have developed a sensory menu and the aim of the menu is to give clients just that the opportunity to kind of choose how they would like the rehab environment setup so that it's tailored to their personal needs and preferences prior to the meeting or the key worker session or whatever it might be so it might just scroll down if you don't mind just have a look through that what how this came about so it's just on page 5 I think

Ellie Yeah just there now

Researcher Perfect, so the idea behind this this was this this isn't my baby this is me borrowing from the wonderful idea of other researchers and adapting it but so it came from an emergency department, staff originally developed it and the idea of it behind it so the theory behind it basically and they found that obviously people coming into emergency department just high stress environment and you know the they might need to communicate what's going on for them and there might be children involved you know in the sense that if something is wrong with their parents they you know might be the middle of the night and they have to come in and how much was that environment working for them or against them and they were finding that they needed an example of basically kind of just a checklist or a menu item that everybody could kind of choose from to decide on what things like the most therapeutic

at maybe the highest stress time in are one of the highest stress times in a person's life so I thought that could I could develop that in the sense of the minute that somebody is coming in for our initial assessment the needs assessment which is high stress anyway because they can't visualise the building they don't know who they're meeting all of those things are already stacked against them so could the environment then be one thing that is working for them you know?

Ellie Yeah

Researcher So even for like that, that's the initial assessment but even for things like keyworker sessions or IGP meetings like there's there can be high stress and those conversations can be lovely some days and those conversations can be hard other days depending on what needs to be addressed so if the environment at least is soothing to begin with than maybe you're starting on a better footing possibly

Ellie I think that I'm like because when we're initially assessing our client list we have to send out paperwork and that's just part of the process but like I feel could be intimidating going through all the paperwork and it's like you're going to an unknown like you said just that you're going into unknown what is so like you don't want to re-traumatised there's already enough things inviting fear about coming to the building without there being something that traumatises them you know

Researcher that's exactly it and and I know we were kind of talking about the example earlier like going into a dentist or doctor's office and if they weren't stacked against you you're just not going to to you know somebody could come out to the doctor or dentist could come up with the wrong impression of you in the sense of thinking oh like she's definitely somebody that I have to watch because she's a fainter or something more seriously wrong when it could

just be the temperature of the room or you know the brightness of the lights or whatever it might be and so if if the environment could be something that's kind of basically working for the client and isn't another kind of hurdle to jump over on that particularly stressful time or stressful day or stressful meeting hopefully would be something that would suit them and be therapeutic so I've asked the clients that I have interviewed I've asked them to have a look over this and but if you think of anything or if you think of anything that needs to be changed we might just go through the points and here and if anything jumps out at you just say so the the room size came from a client who was saying that a large activity room can be quite intimidating because it can be a large purposeful room and you feel like you kind of need to almost fill the space when all you want is a small cozy compact room to open up and have a conversation

Ellie yeah, I was just going to say no I'm just starting to think and I always try to put myself in every situation if I'm asking that something something I always think how would I feel if I was coming to meeting to those I don't know people I don't know to have conversation I don't want to happen there's a lot of fear around that and I just remember we had an IGP meeting and we had it in the day service room and I remember having to come through first one and he was so nervous but then there's lovely meeting room with just behind that room it would be cosier it would have been warmer with a little candle, it would be a better environment for our first initial like IGP meeting so I think room size is a very important factor

Researcher That's exactly it and like you say maybe lighting a candle and maybe you know even having a pot of tea or you know just kind of setting it up in the sense of and like you were saying maybe taking that clinical side of it that could be re-traumatizing out of it but

room size was one and that came up which I thought was a great suggestion because again it's not something that I would have first thought of you know

Ellie Like even things like you have here windows open or closed and it just makes me think of the service that we have at the moment, and we have doors that open up wide, we don't have windows in the room

Researcher No we don't, I know

Ellie I know that can't be helped I know that's just the environment that we have we have and we have to try to adapt it as much as possible but to me like I I love having the windows open and the fresh air coming in, and having the doors open takes away privacy but having a window open it's nicer, it just feels more homily and I know we can only work in the environment that we have and just be mindful of it as possible you know to have some fresh air coming in somewhere you know it's just it's a little thing but it's a big thing

Researcher That's exactly it and and you mentioned it earlier which I thought was a really good way of putting it, about looking at the building with fresh eyes. It wasn't until I went around the building armed with this knowledge now that the clients have given me by sharing their their first time experiences but it wasn't until I was doing that I was walking around the building noticing things like that that would have probably again I would have noticed but maybe passed under the radar little bit, we don't have windows in the services room, even in the meeting rooms that we do the the windows are quite limited you know they're opening and like even the the best room let's say the top room for meetings has a nice big window but if you wanted to open the window like the space that you can open that window was limited by the shutter door you know so yeah it's all those kinds of things and hopefully the idea is that when we're, I know that could be a long way off yet but when we're designing (new

centre) that the clients would be involved in designing sensory informed spaces because they're like they're the experts you know like I could walk around the building without sensory overload and without sensory challenges and needs and only only see it through my own eyes where it's nothing like having having the expert on hand to say like these are actually the problems that that I can see straight off you know

Ellie Absolutely utilising our clients and their and their needs and their sensory needs because it's it's all about them and their rehabilitated practice so like if they say oh the lighting is too bright or there's no windows or whatever issues they may bring up that's imperative that we bring that to the to the planning of a new building because it needs to them it needs to be guided by them, it's for them

Researcher That's exactly it and and through my research there's...I know we kind of touched on it a lot at work but there's there's a real move to like where you know the the clients are the experts and the mentors and we're just learning from them you know and so to kind of shift that focus a little bit yeah exactly and and with the the new building to to treat the client as the expert I suppose in in their own condition you know

Ellie Because we can be as empathetic and I know we are, but we can be as empathetic as we as we possibly can be and and listen to our clients as much as we can but like at the end of the day we're not experiencing sensory overload, like I can read about it I can talk to them about it but I don't actually know what it's like for them so if we don't use their experiences and their information like what are we doing

Researcher That's exactly it, we can, I think that you hit the nail on the head there we can absolutely empathise, we can absolutely try to to appreciate it and and... but we'll never fully

understand that, we'll never fully understand their lived experiences you know so so better off to learn from them I think from directly from them you know

Ellie Yeah like ignoring their advice would be ignoring the experts like you know

Researcher That's exactly yes that's exactly it

Ellie You know "oh it's fine I know better" it's like you don't know better, you're not experiencing it and until you experience it your opinion is valid but I think the clients who are experiencing sensory overload opinion is paramount really to be honest

Researcher Exactly like we can have suggestions but like they have the the hard lived experience you know they they actually the on the ground experience you know, we can read the book on it, but they've actually lived it you know

Ellie Exactly yeah so we need to listen to them, 100%, so we can guide better practice for ourselves and even even for like for future clients coming in like you know if we're listening to the clients who are experiencing sensory overload now like have that in your head like ok I actually didn't know about tactile sensory overload or whatever the case may be, be like ok let's use that information we have now that we didn't have beforehand, that we got from our clients and use that into future practice

Researcher That's exactly it, arming ourselves with that information I think will hopefully be huge down the line as well as as well as now I think planning for the future will be really good as well hopefully you know that it will inform best practice

Ellie Yeah I think so

Researcher The lights, I know at the moment we can't dim them, but the idea would be that we could have them on off or that we would hopefully either could bring in lamps that would

be able to be dimmed for the building at the moment or that God be with the days that we have a new building, that we would have like a dimmer switch involved just so that it could be at the right level for them

Ellie The lights, the dimmer lights would be very good idea, it just sorry it just got me thinking there if we have you know I don't know how we would negotiate it and maybe it's a conversation for future down the line us but like what if we have clients who had different aversions to light, like one who only likes it bright and one who likes it low I suppose that's a different conversation but it's just it's good to have options it's going to have the dimmer as oppose to having just the on off switch because that's not going to really benefit anybody who is experiencing it

Researcher That's exactly it and hopefully you would find in in a in a group setting maybe a happier medium with a dimmer switch then then just that then just having on or off and then maybe planning going forward like I know Covid has been so awful in so many ways but in in one way what it has done is is made us look at the smaller groups and and maybe matching clients either by friendship or you know just by by need and maybe down the line you know if we were looking at even smaller groups that you could say oh like these three clients have similar sensory needs so that we could really set up the environment to to really respond to those you know

Ellie That's true yeah

Researcher That might be something but down down the line, the music one came up because I suppose I I thought first hand that I didn't know if music would be triggering for some clients or soothing for others and that seemed to very much be the experience that some clients would like music off where some clients would love a little bit of background music and and

then some clients would like you know soft like maybe Enya esque music you know something that's kind of not not too jarring or anything but then like some clients wanted Christy Moore on in the background because it's what they love you know so it really depended on the client

Ellie I suppose having that knowledge in itself is a is a tool you know as in like we could go in like let's say if Covid lifted a little bit and we went in and we had four clients and let's say we didn't consider music at all for whatever reason and one's Enya esque and one is no music and one is Christy Moore or whatever like knowing that their that's their their approach we could be like OK if so and so is going to... you know so we can plan it and make it work for them as best as possible but not knowing it is a barrier

Researcher Yes that's exactly it and even even for like an IGP meetings you know to I know it's never something that we've done before but even like I think it would take that clinical side out of it and that kind of I don't know like really stressful environment out I know if I went in somewhere and there was music that I particularly like playing, music can have that wonderful effect you know of relaxing you or energizing you or you know so hopefully having if it was let's just stick with our Christy Moore example if it was on low in the background and the clients you know if we had a big pot of tea on the table would that change the conversation maybe and maybe ease clients in you know

Ellie If you're talking like again I always try to put myself in it, if it was me and I came in and let's say they had, I like Christy Moore like he's a good singer, if they had Christy Moore on and a pot tea I know myself I'd be more relaxed you know

Researcher Yeah

Ellie Let's just, from a personal point of view I'd be like ok I like the music, cup of tea, this is actually.. it almost kind of sets up your mind to how a conversation is going to go whereas if it was clinical and nothing you'd be more tense or something but if it's more relaxed atmosphere that would kind of set up for a better meeting I think

Researcher I think we'd be starting off on a on a better footing possibly

Ellie I think so

Researcher I think we we talked about this on a small bit already but the heating on or off could be a big one, like some clients are called creatures like that they might want to blow heater or near the rad or a blanket where somebody else then will be roasting and will want to be positioned by the door you know

Ellie Yeah I've experienced this with...in (service) with a bit of a to and fro with this one because we had one lady who absolutely would sit on the rad and she just loves he said she needs the heat for her she's like she's a cold creature but then in direct contrast with gentleman who if the fan heater is on too long he generally just he gets very very warm he thinks he's going to pass out, he just can't cope with heat of it and the lady is always very kind to like you know oblige if he needs to turn it off like it's just trying to get the balance but like I know that that client can overheat and I know that that lady needs the heat so like you position them in the room where it has impacts them least as as possible while they both get what they need you know

Researcher Yes

Ellie But it's just keep an eye on it as well because you don't want anyone to overheat but you don't want anyone cold either so it's just again having the knowledge as opposed to not having knowledge is, like you need it, it just informs the best practice possible having it

Researcher That's exactly it and and it made me think of things like could we you know get the blanket and maybe a hot water bottle as opposed to the blow heater you know if they were going to be sharing a space you know I don't know if that would be the most effective solution but you know so that the client could stay at his own temperature but that the lady wouldn't be cold you know but I think it's until we have these conversations and throw these things out that those kind of suggestions or thinking a small bit outside the box might work as well

Ellie Yeah I think that suggestion actually would work in that situation but again it's just it's so important to know it's like if let's say if a new staff member or student came in next week and things were all ok with Covid and you know when you're doing induction you know there's a lot of information to throw out someone so you almost try not to overload a student or a new staff member but like if something like that slipped through the cracks of like oh the gentleman loves heat and the lady doesn't or the opposite way around sorry like that information could be lost and it's just you know and the group might not go the way and the group might not be comfortable like you know it's just knowing the information is basically it's so important to have, to have the best group possible you know

Researcher I I think so too like we were saying even in if we were having one of our morning meetings you know pre Covid that we'd say like ok so who's coming into us today ok here are four clients or or more I know that there we'd be dealing with 16 pre Covid but like let's just say we're dealing with six or whatever you know I'm thinking like ok so you know three have

indicated that they have sensory needs and then yeah planning it so that it's part of the conversation I suppose is... would be really really good and the type of chairs came up because obviously some people love a chair with armrests and it helps them to get up and into the chair and then other clients were saying that they prefer it without it because it actually helps them breathe better

Ellie Oh wow

Researcher Which I didn't know yeah because they can sit back and not have the arm chair or the arms on the chair I should say that they can sit back more fully into the chair and it it opens up their airway which I did not know until-

Ellie That's new to me, I wouldn't even consider that I would've thought like the sides of the chair is just for like maybe people who have some difficulty standing up and they just need a little like they physically need a bit of a like a like a barrier to push themselves up which I've seen with some of our clients, but I never thought of it in terms of breathing better

Researcher Yeah

Ellie That never occurred to me

Researcher It it didn't occur to me either, I'm right there with you gal

Ellie That is brand new information

Researcher The tactile items are one that like I know we've talked about weighted blankets and so I just kind of put in like a stress ball or any other tactile item I might play around with this question a little bit more, I might put in a few more options

Ellie Yeah

Researcher but there's kind of, the space is there for any other tactile issues that the person would like available and maybe just investing in that a small bit that we could you know sometimes funding comes through that we're almost you know wondering what would that be good for that might be one of those things

Ellie Yeah

Researcher and then we were talking about maybe the tea or coffee during the session or anything else like I know we have clients who we just like water or we just like green tea or the staff member yesterday was joking that like a vat of hot chocolate would be like her preference you know it's like and then there's just at the end there is is there anything else that would aid your sensory needs just in case there's something on this these few pages that I haven't even thought of that could be a huge huge help to them

Ellie I think it's important that section as well because as much as we were trying to learn about it and study it and whatever like I think there is always say that could surprise us like oh ok I didn't know that whatever could help with that you know it's like we're like we're saying earlier we're learning from experts so like having that other box you know like we're alternative beverage or alternative tactile item or any alternative I think that's very important to have it in there so we can you can learn from our clients and be like ok didn't consider that's add that to the list you know it's very important

Researcher I agree I think that's true I think it puts the client back firmly in the driver seat where they belong, you know of like is there anything else that I'm missing as a passenger to this show you know is there anything that that I am just completely forgetting or blind to that that you would outrightly be like this would actually help me

Ellie yeah definitely I think even those...like it's good to have those questions too but it's also good to have the open ended ones too like ok this actually just works for me because like we were saying earlier like someone with sensory overload like people experience it differently and nobody will experience the same brain injury the same, no one is going experience the same sensory overload all the same you know so why would the questions, I think it's imperative that you have that question at the end you know

Researcher That is perfect so if if we are all good there I will move on to question six if there is anything else on the screen you just let me know so question six is kind of just about the role of identity, it kind of cropped up in my research so during the interviews with clients they spoke about the various ways their ABI and their sensory overload has changed their lives and I know that this is something that we would crop up for our clients but they spoke about the impact it had on their professions their hobbies their relationships and and the roles in the family unit as well so for some clients having an ABI seems to have impacted on their overall sense of identity, have you experienced this through your work?

Ellie Oh absolutely I think like, just as you asked the question I think I think I went through every one of the clients I work with like I think every... I know every client experiences and an ABI completely different and that's very important to note but at the same time like they're all going to be grieving a loss of something you know whether it's a loss of I can no longer drive because I have seizures or you know I am no longer 100% in control o my finances but I have you know a majority control but like there's still that little little question you know or like even things like hobbies like you know clients who are big into gardening but maybe they can't do it as much or they need assistance in doing that or you know people who love to read but their eyesight has been damaged like there's so many different variables that like have

affected and impacted their identity so I think it's just very important to name it like you know I can't read as well as I I once read, I wonder if I do anything about that you know could we look into an audio book could we look into...you know I think knowing what's impacted the clients and their identity and you know and what's important to them and seeing if we can try and brainstorm and get some some basically try your best to kind of adapt I suppose but I think every client is experiencing a loss and a grief of their former self in some way big or small you know and I think that's unique I think that's unique to brain injury because you're saying goodbye to little part of who you once were but it's just adapting and trying to get it back in in a different way

Researcher Yes I completely agree and I didn't realise until doing this research how much I suppose I I would have had a low awareness to it but again not a big awareness to it in the sense that how much our senses they are tied to our overall sense of identity which isn't something that I would have of course heard the clients down through the years talk about how their ABI has changed that but in terms of senses like a client was sharing that like she lost her sense of taste and smell, which she was saying in the grand scheme of things initially upon hearing it you might think like ok like that's awful but it's not you know it's not the worse symptom in the world and she was saying it's amazing that like for somebody who ran a really busy household with her children and who took great joy in planning and and and cooking big meals she's like I can't taste them anymore and she was like you know I I would always like you know check the taste of the stew or check the taste or whatever and you know as you're going along cooking or how does that taste the best she's like I can't actually that's not something that I can do anymore, she was saying even like you know like we we think of the big ones like Christmas Day and things like that but just a general family meal but but for Christmas Day she's like you can't like be like how's the stuffing does it need more onions you

know she's was saying like that, the smell of a fir tree at Christmas time you know things that like yeah it's just things that we would all take for granted and when you like and she was right initially upon hearing like you lose your taste and smell your thinking like ok well at least it's not your vision or you know but she's like it's actually...you don't realise it until again you're living it you know

Ellie and it's I think what you were saying there about things we take for granted like to me now if I was told you can't drive anymore that would have a huge impact on my identity like I love going for drives I I love going for walks I love being active and if somebody told me tomorrow you can no longer drive because you're having seizures I really think that would affect my identity as a whole and like and as you were saying there like on paper like like on paper might seem like maybe not the worst like oh look at least your mobile at least you have your vision at least you have your... all these senses and you're doing great but like it would really impact on my on my identity so I think if you look at every client that we work with they're all missing something they're all grieving a loss of life that they had and I know a lot of them and I know that they adapt and they're the strongest people we know they've come back from from from a lot but like they're still missing a part of themselves you know like be it speech difficulties or aphasia or whatever you know everything every single one of our clients is missing something that they had before and all we can do our best to support them and try and think of strategies and help them with that but a loss of identity I think would be huge huge like even if it's a certain part of your identity it's still a loss you know so I think even acknowledging and owning that is very important and then trying to build a strategy that could maybe help them in some way to regain their loss of self you know

Researcher I think that's huge yeah I think that's like yeah like I couldn't have put it better myself that's like yeah it's a huge point I think and like you said even with the driving and I know that one crops up a lot for our clients I was even thinking for myself like like playing the piano when I cut my hand last year and I was I was playing the piano maybe two months you know but I couldn't play the piano for like six weeks afterwards you know and and I was new to this you know I couldn't imagine if it was something lifelong that I loved or even loved for for a year or more and and and thankfully I got that that strength back in the finger and you know like it was it wasn't nearly as serious as as as anything that the clients have gone through but you think like God I really got attached to that quite quickly you know that that was kind of interwoven in my identity without knowing knowing it as just some somebody who plays the piano like something you know a pastime like that I enjoy you know

Ellie and yeah I suppose we're all such creatures habits we all have our own routine and like even even with Covid we've all adapted to a new routine like ok in the morning I'll do this now and it's different but like we like I think as humans we like having our own routine and knowing what we're doing with the day what we're doing with our lives like day to day and if someone took a huge part of that way I think it would really impact anybody you know I think we really have an impact

Researcher Yeah I think so too I very much think so too and with with sensory overload I suppose it appears to be isolating for some clients because they experience the environment so differently to other people so a little bit like going into the building with fresh eyes when they when they go into an environment that's working against them and and maybe others are are blind to that without intentionally being blind to it but just don't experience that the same way and some of their triggers can be quite individualised I think we were touching on

these a little bit earlier but like things that I would have never never imagined things like exit signs you know emitting a noise and you know hands rubbing off jeans things like the echoing in the building and so there it seems to be a little bit isolating because they don't they can't turn around as easily to somebody and say have you experienced this and and you know how do you how do you deal with it and is there any strategies that have proved helpful but I know that we don't work a whole pile with in (specific service) with sensory overload but have you observed clients maybe being a little bit isolated due to their individual needs when I was thinking about this question and (client initials) came to mind in the sense that he always seemed that little bit disconnected from the group and I don't know if it was his individual needs or maybe he just didn't connect with people in the group but he was somebody that came to mind when I was thinking of clients being maybe a little bit isolated

Ellie Yeah I think if you look at (client initials) is a very good example of that actually I'm thinking like was it sensory you know because I know what you're saying like you it's always a little disconnected from the group that he was in and but I'm trying to think, if you think of all the clients there's probably something that we could be missing in a lot of them, like I was thinking of one client in particular and when I first started working with him I was unaware of his sensory issues with loud music and or just music being played but yeah loud music and I would always put up music like on the tea break or the lunch break and like I'm thinking like jeeppers if I had known that he had a he had an issue with loud music or music in general I would have I wouldn't have thought of doing that you know but it's just...likewise like was he isolated in that did he experience that for a long time in isolation and he must of thought sure everyone else is grand and they're all singing away was started it must just be me you know and like that could be very lonely if you're like in a room with people who were you know who have gone through brain injury different types of brain injury of course but have still gone

through a similar circumstance but then they're experiencing this one this one trigger that nobody else seems to be experiencing so in one way I think it's very lonely because you're with people who you should have, like not should have but your with people who have experienced similar similar loss like I know it's all different but they experience similar circumstance we yet the symptoms are different so it's almost like being in a support group but like not really having that support as well, so I think that's why as well I know I keep banging on about awareness for each client and their sensory needs I think it's just as important as their physical safety because otherwise we are just going to be retraumatising them and isolating them so I think it's just like knowledge is power at the end of the day when it comes to this

Researcher Yes I completely agree like you say like with with as sensory needs are come more to the forefront and as we're more aware of them and and factor them in more and they're just on on our radar that hopefully even for clients who may not you know be able to fully communicate what they're experiencing if at least we're all somewhat on the same page about at least if we're not on different universes you know us being completely unaware of it and the client experiencing it but maybe not certain how to communicate it or like you said maybe thinks it's just them so I just have to get on with this nobody else seems to be experiencing this this way and hopefully that would move in the right direction where we would become more inclusive of sensory needs and just just yeah like awareness is definitely a big one of the big barriers to that

Ellie Yeah absolutely it's just again we we we preach about being client centred but we need to actually back that up with being sensory informed because that's part of being centered

you know we can't be you can't be service that claims to be client centered when you...we're missing a big factor you know we're missing a big part of the puzzle with sensory overload

Researcher Yeah part of the puzzle is a good way to put it. The big fun question at the moment (name) is how has it been working through the Covid-19 pandemic?

Ellie It's been... it's been a transition (laughing)

Researcher (laughing) Has it been a joy?

Ellie It has been the joy that keeps on giving oh my goodness, how's it being worked working through the Covid pandemic, oh crikey there's a question in itself

Researcher As people have said to me do you have three hours

Ellie I don't know where to begin like I mean I'm like ok I'll take you back to March last year, so so so much to take in like are we talking about the clients in in regard to their sensory issues or are we talking about in general

Researcher No in general just how has it been, your own lived experience how has it been working through this like crazy crazy time

Ellie Oh I think it's like I think we we adapted as well as we could but looking back now, if I look back at last year it was so stressful it was a really really stressful time and I think personally for everybody because everybody obviously is concerned and there was very scary moments and I think we're in a scary moment right now with the peak like with the numbers and everything but like when you look back over the last year my biggest stress was probably with work and making sure that our clients were safe

Researcher Yeah

Ellie Like you know should we open the doors or is it safe at Level 3 and you know I think we're in a bit of a strange one where our clients fell into an unusual bracket in with regards to (service) and (service) being in essential services but they weren't essential services the first lockdown but they were the second and third so I think with that that brought a lot of problems in itself because they...if we say that we're safe to open then we'll open but like is it safe though there was like a bit of a grey area a bit of a blurred line and I think basically trying to keep our clients was the biggest stress of my life last year and coming into January because like it was just...we didn't fit into any real bracket, we were essential but we weren't essential and I just found it very stressful trying to trying to advocate for our clients and making sure that we're keeping them as safe as possible and while also when they were in with us from August to January and you know trying to adapt the environment that was a huge huge part of the process like you know these were used to large groups like up to 15, 16, 17 people to like 4 and all the safety procedures will they wear the masks will they sanitize and can we force them to do that, can they social distance there were so my questions so much to take into account and I think in the end we adapted very well to it we had a maximum of 4 people for two hours a day twice a day but jeepers when you look back at like pre Covid it's just absolutely it's it's worlds apart from the service that we have but I think it's good and bad there's been pros and cons to that having smaller service but just in general it was very stressful, it was a very stressful year

Researcher It certainly was it really really was

Ellie For everybody involved it was hard here

Researcher Yeah it was and and like that like I think you already answered it possibly but like it's I suppose it's thrown up so many challenges for everyone like across the globe but both

professionally and personally so like if you don't mind me asking and as I say I think you already answered this but what we found most challenging like either personally or professionally like just in general nothing to do with with senses as such but-

Ellie Just in general

Researcher Yeah

Ellie I think professionally honestly I was very concerned for our client group, our client group were just like you to check list of the most vulnerable people who could be affecting potentially in a very bad situation if they were to get Covid I think our clients collectively as a whole not necessarily individually but as a whole they tick all the most wonderful boxes

Researcher Yeah

Ellie You know we have a lot of over 70s, we have a lot of people with diabetes and you know with maybe obesity, over 70, they just...a lot of people in nursing homes and how the nursing homes got very badly hit you know not every nursing home of course but like you would worry so so much about the clients and you know professionally for me is keeping them safe you know like I know there's logistics and a lot of how are we going to open services what's it going to look like and that was stressful as well but for me personally I think the most stressed I've been was in January when we opened and we were looming into 7000 cases a day and I just didn't feel that they were safe to come back and thankfully level 5 came in the nick of time where we could actually not open but to just keep them safe is basically the biggest professional stress of my life this year and personally I suppose you're separated from everybody you love really like aren't you and I suppose it's a weird comfort but not a comfort that everyone is experiencing that as well like you know everyone is missing somebody I suppose is what I'm trying to say you know so like I know we'll come out of it and I know the

vaccine is coming and you know it's going to take some time maybe the bones of another 12 months but I suppose just missing people like I think or missing hugs you know I think everyone is in the same boat there they want to give someone a hug that they haven't seen in a year or family and friends like so I suppose it's it's lonely but it's also not lonely in the sense that people are going through it as well not that you would wish it on anybody else but like safety in numbers or something

Researcher Yeah, no I completely get it

Ellie Like I don't want you to miss your family but I'm like ok name gets it you know

Researcher No I do at least because we're all so isolated but there's something about not being isolated alone I know that that's like a what do they call that, that's like a total contradiction of a sentence

Ellie An oxymoron

Researcher Yeah an oxymoron thank you but yeah there's something about the whole world being on pause at the moment and nobody seeing anybody that you feel like well at least I'm not the only one you know there there is that that that small unity in in shared misery which is awful

Ellie That's exactly it though like I'm like it's weird to say but I'm like OK I'm at home for lets say the seven millionth night in a row and I'm bored but if I if I test anybody they're doing the exact same thing and they're bored, they're not having fun

Researcher Exactly exactly it's kind of at least yeah at least there's nobody out there that's like at least you're not watching it from a lens that like life is carrying on as normal but but your your life is on pause you know and you're not seeing the people you love at least it's kind

of like a collective we're all missing people were all you know on our 7 hundredth million episode of Netflix like we're all at least that's yeah the collective is is the one thing that I think is keeping us all a small bit sane

Ellie I think it is the only thing keeping us sane, we're like ok, we're literally all in it together we'll be fine we'll get out of it but like if you're at home and you're going through that and you see people out partying, like off doing all the fun things you're like oh it would just grate, it would just get under your skin like but at least we're all a little bit miserable together

Researcher That makes perfect sense, I get that when you when you said hugs I felt like I felt that in my heart when you're like, so everybody wants to hug somebody I'm like oh they do they really do

Ellie But look we'll get there

Researcher We will no we will

Ellie Collective misery for now **Researcher** Collective misery for now exactly just yeah, if you say it in a happy tone it's OK right collective misery

Ellie Of course yeah, everything's great

Researcher Right, I think we may have touched on it but how... in your experience how is it the Covid-19 pandemic impacted on the client service experience? Like do you think it changed it like for good for better for worse like what what do you think was the biggest impact?

Ellie Do you know what I found interesting was like I feel like we could be very busy day to day pre Covid you know and like I know we tried our best to link in with family members but in fact we... a couple of calls a week or a couple calls a year for like you know outings and

things like that you know and Christmas and just things that we need to get done but I find I built up a bit of a relationship, a lot stronger relationship with clients and clients next of kin

Researcher That's a really good point yeah

Ellie So like you know for example there is one client and her next kin...his next of kin sorry and traditionally she would be very difficult to get a hold of and if you get her you'd have a 10 second conversation and you'd be lucky to get that because she's...she's just a busy lady and there's no there's no negativity around that it's just it was traditionally very hard to get through to this person but now we have a bit of a relationship where we could stay on the phone for half an hour or I can call up and see her her brother and I've done that twice so like in one way it strengthened relationships and next of kin and even with clients you know because I know we have one to one with clients but like I'd ring a few clients twice a week at the moment and I feel like we've a nice relationship you know it's it's I think it's impacted positively on the client key worker relationships

Researcher Yeah I think that's a really good point

Ellie and like I think we've got a little closer to the next of kin which is just such an important thing to do you know I know we have a...we're client centered and we work on our relationships and we gain from that but like they're next of kin is an extension of them so like it's like another part of the puzzle so like if you're... if you can connect a little bit better with that person that's only going to work to yours and the clients advantage you know

Researcher Yeah definitely because you're right we would have only probably seen them maybe at an IGP depending on who attended you know but yeah it's kind of it's it's

definitely...possibly for them as well but definitely for us but like more more much more of a face to a name you know and and and and definitely strengthen that which is which is huge

Ellie and as well as that two of my clients have come back and said that they much prefer...because like we were saying earlier the group size could be anything up to like 16 or 17 they were busier... not busier days but they were fuller days like client size but like the smaller groups two of my clients have both come to me and said that they way way prefer it that they feel like they're getting a proper service, one client in particular even mentioned that you know his confidence is up a little bit with it because he'd be a little reluctant to...I'm paraphrasing now but he'd be reluctant to take somebody else's voice in the room like he would be aware of like OK so and so hasn't said anything in a while I won't answer because I think it's her turn or like you know he kind of hold himself back a bit more whereas with the group sizes being anything from two or three or four at present before this lockdown he was more relaxed he enjoyed it more and the same with one of my other clients he just he said he just got a better service so there's there's a lot of negative Covid a lot of separation there was big gap there where they got no face to face service throughout the first lockdown but you know we've gained from...a lot of knowledge from our clients through the phone calls and even to the packs that we've been sending out we're like OK so and so does not like crosswords jeepers I used to give them a crossword when I was in (service) and they used to do it but now I know they actually don't like that you know so I suppose it's just I was talking talking a lot more and gaining more information I suppose and I think certain groups size suits certain people better so it's hasn't all been negative for the clients

Researcher Yeah I completely agree I know that some clients have mentioned that it could be daunting to come into such a big group size and we certainly did have big group sizes you

know and that they kind of... like one client mentioned feeling a little bit lost in it you know just saying like coming into such a big group of people you kind of you sit down you get your spot and you might feel a little bit lost in it where now when you're one of four you you kind of yeah you kind of have have I don't know more of a one to one service or more of a like that now I'm paraphrasing but he was basically saying like you kind of have more time with everybody you know because it's it's a lot smaller which like you say there's so much so much negative about Covid but these tiny silver linings that we can grasp as well are good and like that the communication has definitely upped hugely

Ellie Yeah I just think it's important not to focus too much because it's been a hard year for everybody, but I think we'll take the positives where we can get them, and you know if communication has improved and client and key worker and their family members that's always a positive and we take that into next year into this year you know

Researcher That's definitely it, I know the the necessity for PPE and safety protocols impacted on some clients, like how... do you think that it impaired some clients' senses? I know some people struggled with it

Ellie One client in particular I know at the start he used to wear a visor and that was at the time where visors were seen as ok and then we had to transition to masks when the WHO came out and said that the visors aren't... don't provide the proper protection and I know that that particular client struggled with that but he said he found it too hard to breathe and I understand that they're uncomfortable but that was a little bit tricky to try and negotiate that with that particular client and some clients have to be reminded quite often to put their masks back on and but when reminded they took it well and they did put it back on so there's just a few little teething problems around wearing the PPE but overall as a majority I think the

clients adapted very very well, very very respectful of the PPE and even the sanitising and I think they responded very well to it to be honest just a few hiccups but look it's completely new to us as well so we're still learning as well you know

Researcher Exactly they adapted so well to something that was so new and so strange and I think like even I know some clients struggled with us wearing like staff members wearing PPE but I think that that also like kind of got our thinking caps on a small bit in the sense of like I know that I started using the whiteboard a lot lot more and just for like the client who may have been lip reading who I wasn't aware was lipreading as much and maybe he wasn't aware how much he was depending on it but then we got into a system of using the whiteboard that worked really well for him

Ellie Yeah

Researcher So it kind of in one way it got my thinking cap on of like how best to do this you know so it again kind of forced us to kind of reroute and look at things in a different way which was kind of no harm because you found that well I found that that he he definitely responded very well to that you know

Ellie Oh I think so too and again I I feel like I'm droning on a bit about it but it's just knowledge is power like we knew that that particular client had very bad hearing difficulties and he would have always positioned himself closer to the room but like you were saying I don't think we realised how much he relied on lip reading

Researcher Yeah

Ellie Like it actually shocked me how much he relied on lipreading so the use of the whiteboard became a tool and I think he really really really appreciated it like and I think his I

think his service has improved so from pre Covid to being in the room of 16 people to maybe not having his...maybe not hearing all the information because he's not getting everything that is said around him whereas if he's getting the instructor at the top of the room he can lip read he can get it but he might miss things where when the group size is smaller for him and he can see the whiteboards I think he's improved, it's improved for him basically which is a huge improvement but like now we know that we can take that back to post Covid whenever that is

Researcher Yes I I completely agree like I was...it was funny one day we were putting absolutely everything up on the board and we were having a great old chat and he was really engaged and then another client asked a question but she asked a question that was like totally unrelated to the topic at hand so we kind of forgot for a second and started answering her question and I thought it was brilliant because the client straight away like put his hand up like you haven't put it on the board and I was like I'm so sorry like I lost the the run of like you know we were talking about the topic talking about the topic and then it was like so far left from the topic that she asked us like I think she asked us like who here watches the chase or something you know and we couldn't have been further from that topic which is absolutely fine but it was just like we all forgot ourselves for a second and started answering her question but I thought it was so wonderful that he advocated for himself and was like you didn't put it on the board I was like I'm so sorry I did not you know I was so caught up with the question but but that he felt comfortable enough to do that because the group was small enough that it was like it was real like laugh out loud moment for everybody because we were like of course we forgot to put it on the board

Ellie It's funny because I don't think he would have done that pre Covid

Researcher No I don't think so either I think it would have been it would've been hard to do pre Covid you know, there's so many... so many physically people in the room but so many voices and you know it could have yeah it could have gotten swallowed up in the grand big group of things where he was much more comfortable to do that in the smaller setting

Ellie Yeah, so I think environment has helped that particular client and a few other clients I have worked with as well, so I think it's actually you know been a positive change

Researcher I think we've kind of already answered our question 12 about like how can the rehabilitative environment be designed to cater for clients who experience sensory challenges and I think it might be those kind of things do you think so too? About like maybe using the board a little bit more or just factoring those things in?

Ellie Yeah as in like for that particular client that absolutely works for him and that has like 100 percent improved his service but again I suppose thinking more of an individual size... like more on an individual level you know like you know, basically taking everybody's sensory issues into account and make it more individual so like basically using the knowledge we know about him or her and bringing that into the group and what can we do to to help that so the whiteboard is a classic example of that but we need to do it for all our clients who are experiencing sensory overload for it to work

Researcher Yes yeah yeah that's an excellent point yeah exactly it needs to be it needs to basically serve the clients that are in the group at that given time, it definitely won't be- and I think we unintentionally maybe in previous years fell into the one size fits all in terms of that's just all we knew you know we went into the same group we went into you know with the same lighting with the same whatever but it is about drilling down to that more individualised service

Ellie Definitely yeah it's important to take forward, going back after Covid or even in the middle of Covid, try our best to adapt to it with or without Covid you know

Researcher Yes I think so too, armed with that knowledge for sure. When I was talking to clients there were some key strategies that they are actually using to alleviate sensory challenges that I didn't actually know was a strategy so I think we were talking about our man with our peak cap who I just thought was completely a wardrobe choice but he's actually doing it to avoid glare so have you observed when you're working with clients like pre or post Covid any strategies that they use to maybe help their sensory challenges or alleviate their sensory challenges or is it something maybe it's something that has never popped up for you but...

Ellie I haven't given it too much thought beforehand but like just thought this conversation I'm just thinking back of like you know that we had a client who used to be very very very cold so we always used to give him a blanket and another client who also felt the cold we would put the rad on for her and give another client you know question a cushion for their back, their back needed a bit of support and you know positioning certain clients like well that client we spoke earlier with the white board he would always self-advocate and position himself to the board so he could help with his sensory issues so I suppose it's... I suppose I'm going to look at it now with a different lens like going forward now having this discussion around sensory because I'm trying to go through all the times that I would have worked with but I suppose those are the examples that spring to mind but I know we spoke about the gentleman who wore the cap he did that for the glare but we never knew that so I'm like I suppose I want to get more information now on on the clients that we work with and just see is there anything I'm missing

Researcher Yeah think I think that's great and and I think we were touching on it earlier of like you know as we're planning the day ahead just like you know in the same way we would plan anything for a client coming that you know like let's just say something that springs to mind is printing things slightly bigger because we know that somebody needs you know is better on a, A3 sheet as opposed to an A4 sheet that we would just as equally be like oh so and so needs you know a blanket or so and so needs a cushion or yeah it's definitely it's definitely just putting it on on the radar and making that part and parcel of the service which which could be great

Ellie I think that's a good point point so I think we we naturally do it for a lot of our clients anyway like you were saying there like the A3 I know exactly like I'd be like oh so and so has difficulties with his vision and and it's something that you do naturally because you think ok that just helps himself or whatever but to have it in kind of black and white and written down for the staff and just be like ok make sure big print for this client you know it's just having more of like a checklist like the thing with checklists is they become and in a good way they become routine so like you're going to have to check this like you can almost look down the line and you'd be like ok so and so needs this and so and so needs that and are...do we have have everything ready, it'll become more routine and more natural but I think just have it as a checklist would be no harm

Researcher Yeah that when it becomes kind of commonplace like that

Ellie Yeah

Researcher That could really work. The support then of a peer group, I know our clients always talk about it as kind of a key part of their rehabilitation and like in your experience or in your view how has it impacted on the client peer group not having... I suppose we've talked about

the benefits of not having those big groups but how has Covid kind of impacted on the peer group level of support

Ellie I suppose like our clients are the best at peer support so like they'll still always support each other and like when we reopened services In August everyone was very happy to see each other which is great but in saying that like because we're limited to the group sizes like again with we're all missing people everybody is missing somebody like so we try to pair our groups as best as possible to you know compatibility and friendship and you know things like that but you're always going to have clients who are going to miss their friends like they're missing their friends as well you know , while I think the peer support is still very strong, I think our clients are very good at that I just think they'd like to see their people they're missing you know but their support has stayed the same but I think they just like to see the people that they that they miss you know

Researcher Yeah

Ellie But they're thankfully they're still there to support each other

Researcher The question that came up a good bit when we opened in August I found was where is so and so you know yeah where is (name) where is (name) and they're looking like you said for their friends you know that I found that was sad you know because and understandable you know but then like you say they were wonderful to adapt to it as well and even when we're talking on the phones and they're asking for each other and you know the the thing that (name) was talking about in the team meeting last week about maybe connecting them on I know we were talking about maybe pen pals

Ellie Yeah

Researcher But maybe connecting them on calls all of those things hopefully will help with that as well and those could be really good initiatives you know to connect people again

Ellie Yeah I think that would be a great idea because like we said our clients are just the best in the world for adapting like when you look at the stuff that we've... everyone has gone through this year, and they just adapted like so so well like they're just the best but then like they're just missing their friends and it's understandable you know

Researcher Yeah and on on your own like in your professional and personal peer groups has Covid-19 had had an impact as well I suppose like we're saying it's impacted on everybody but how has it impacted on your own peer groups?

Ellie I suppose from a professional level we're so used to be in a hustle bustle office positive environment like of course there's ups and downs to every professional career and relationships but in general we'd be very in each other's lives and like you know someone comes back from an outing or someone comes back from a day in (place) or (place) how's your day? how's it going? tell me everything like we're very involved in each other's professional lives in a very supportive way and I think since Covid and of course we need to have the support bubbles and you know limit the amount of people in the office I think we've lost a little bit of that at the moment I'm fully certain we'll get it back when we're back together but I think we've lost our...not our edge because that's not, that's a little bit too harsh but I think we were such a community, we were such a strong unit that I think we just miss each other and we miss seeing each other like unless we're covering for somebody we don't really see a whole lot of people

Researcher Yeah

Ellie So from a professional point that's what's impacting me. On a personal I suppose again like I was saying earlier you just miss your friends like you know there's times that where you could go for social distanced walks you know but you know it depends on what stage of the pandemic you're in but now we're in a 5K limit so you know again you're just missing your friends, you want to go for a walk, you want to go for a coffee even if it's at a distance and you're sitting in the cold you'd take it over that but at the moment I suppose you're limited with the 5K so yeah I guess we're just missing people like we're missing our community you know we're still a community we're just online

Researcher Yeah exactly and I do completely know what you're talking about that I I think before we didn't realise how much we informally debriefed constantly

Ellie Totally

Researcher Like like you were saying we were always so good we were very much very much connected in that way of like you're so right even as you were saying it I I could imagine the pink office of like how was your day? how did you get on? how was so and so? you know like that was part and parcel the minute the door opened and somebody new walked in you know you and you would kind of you know generally where they had been and you know who they had met and and stuff and so or generally what their day had kind of looked like and that informal debrief was kind of like cut you know which like probably took the biggest cut but probably wasn't something that we were even aware of that that the benefit of

Ellie 100 percent, because you could come back from a bad day and just be like oh this was crap and this happened and this didn't work and like oh whatever but just sit down and have a cup of tea and just be like oh my God so glad that day is over or just like I think you said it best like it was an informal debrief but it's like the professional colleagues and the

professional relationship we had with each other I think it was just when you think it now when we come home from work and when you come home from a day in the office and I it's like oh how was work yeah yeah grand

Researcher Yeah

Ellie Because nobody at home knows what your day in work is like except the people you're in work with but then you're limited with people you see in works so you don't have that debrief anymore which I actually hadn't thought about until just now really even if you're like we have some people who like... well I know like one person is meeting one client at the moment but we don't see her after whereas before we'd be like go on tell me about your day, how did it go

Researcher Yeah

Ellie But we don't do that anymore, not really

Researcher No no we don't and it's it's something that was just kind of interwoven into the into the the team that has kind of been been yeah very very all of a sudden swiped you know swiped away and probably had like definitely had a wonderful effect when we were in there but it's something that now like you say you come home and and like you know whether partner or housemate or whoever it might be they don't know what's gone on you know

Ellie No

Researcher So you do kind of fall to the default of of yeah it was fine like no matter what happened yeah it was fine

Ellie Because you find yourself kind of explaining you would be like but yeah but this person you know and then this happened and then they're like oh yeah that's ok and I'm like that's

not ok you don't get it in the kindest way possible you'd be like if I was in the office the girls would be like oh in get you, I have you girl and like that in itself is so reassuring because you feel like you're not going crazy

Researcher I know, I completely understand thank God for voice notes (name) what would I do?

Ellie Oh my God I think they saved us

Researcher So we're we're almost there, we've talked a lot about tailoring the environment which is fantastic and kind of drilling down to it to really having a tailor made environment for each client that comes in and that that seems to be at the crux of sensory overload is if you can make it as individualised as possible, in in general terms not like even even not just specifically thinking about sensory overload but when we went back in August did you find it easier or harder to tailor the environment post Covid?

Ellie I suppose kind of a bit of both as in hard in the sense that like we were so oh God I remember it, we were so hyper aware of safety that like like to the point where it needed to be but it was also to a stressful point where right down to the ok if that person uses a spoon that's going straight in below the you know it wasn't like down to the tiny

Researcher Hyper aware yeah

Ellie It was just like you know yeah you're really really really hyper aware of everything and you know if so and so touched a cup that cup is going away and that table is sanitized but like don't use the same cloth use a wipe you know it was just hyper aware of so it's harder in that sense you know to kind of adapt to it, post Covid was it harder... yeah to be honest I think it was harder I know I started out saying was it easier or harder to tailor the environment but I

think like when we went back and we had a we had another lockdown in in October, November and that went away but this is going... like when we go back in after this lockdown I think we're better geared and better prepared for it like I was speaking to even (name) about this yesterday like it won't be as big a shock as the last one like when we went back in August I just remember us all be very stressed and very...are the clients going to be safe and just right down to the position of the room, the 2 metre distancing like we were basically enforcing everything so like the buck stopped with us basically so if we messed up from my point of view you know I know I would have felt it, if I didn't do the spoons right, if I I didn't do this right, I went home I was like oh God are my clients safe you know

Researcher Yes

Ellie Whereas if we're going back, when we go back next, I don't know when, I feel a little bit more relaxed and a little bit more safe in the knowledge knowing that like OK the strategies are in place and our clients are comfortable with that so yeah so it was yeah it was hard to be honest it's hard to tailor it but it's easier now in the sense that it's set up for us to go back

Researcher Yeah I think, so I I would completely agree I found I found the environment itself was like like that we were hypersensitive, and it was a harsher environment because we were sanitised to within into our lives

Ellie Yeah

Researcher What what I found a little bit easier was probably what we were already discussing was the group size made it easier to kind of tailor make a group in the sense of like with the one thing that comes to mind is like my music group like instead of you getting a choice one out of 16 weeks you got a choice once a month you know which was...now I know we didn't

have all that many months between August and January but it was something that that tailoring in that aspect was easier but exactly like you say I think we were watching ourselves and watching every single thing that the clients did to make sure that that spoon didn't go you know went straight into the dishwasher and that cup went straight into the dishwasher so it was definitely a yeah it was it was tough old mix wasn't it

Ellie It definitely was but actually you just triggered something but like when you say easier like just think of two gentlemen that I briefly referenced earlier like they're more confident now to come to us and say and oh I didn't like this but I do like that so I'm more confident in their ability to self-advocate for what they want like if one of them turned around to me and said like when we go back like I just don't want to do a cognitive group today I'd be like ok that's fine what would work best for you. Like I'm more confident in their confidence if that makes sense

Researcher Yeah no no completely yeah and I think that like I think you said it very well earlier like that communication like that communication line has definitely been strengthened you know I think there's there's the awareness of... I think they were like we always knew the clients and they always knew us quite well but there's there's that's definitely that line of communication I think has been reinforced you know of like yeah I can tell (name) anything you know I can go to her and tell her that I like this I don't like this and and we're going to have a conversation about it like you know

Ellie I think in the past our clients were afraid to like...and I still think it's still there but you know at the end of like a couple of weeks like guys did are ye enjoying this group or is there anything ye don't like, like there's no offense if you don't like x y and z about it like we'll

change it, we'll adapt because it's your service and you can guarantee it like everyone is like no no love it but in their heads they would be like I actually hate the word wheel

Researcher Yeah

Ellie and it's palpable like you know some of them are holding back and that's fine too like if I'm asked in a group, if I was in training and they were like oh anything you don't like I wouldn't say anything, I say it on an individual or smaller scale because that's where I'm more comfortable with so I get it completely but I think with the smaller groups I think that they would be more confident to say do you mind if we don't do that because it's not... I don't really like it I'd be like oh right let's do this instead...in a good way

Researcher That's exactly it like in the training there the other day like I think if we were in a very small group where we could have had a laugh and like if we were asked for that feedback like we could have been like your man on the meditation wasn't the best you know like there was no way in hell I was doing that in a group of like however many 25 people at all you know just wasn't yeah so so yeah that's a really good point and you'll be happy to know it's the final question so if you had your party popper ready just then it would you know

Ellie Nah, this is grand, nice chat

Researcher In a strange way as we were talking about silver Linings with Covid and everything else it does seem possible that kind of how the services are provided now might benefit some clients definitely not all clients but some clients and particularly people with sensory overload just because they can like the clients would have spoken before about the commute the commute alone too (service) would have wiped them out fatigue wise so when they got to to their sessions they would have actually had to have a little bit of a sleep beforehand just be

ready for it so now they can access the sessions from their own home in their own space, you know it's not a triggering environment because they set it up themselves so in a weird way developing the remote service that I suppose Corvid made us do probably 1000 times faster than we would have ever done before like even when I think of like us all now logging into a team meeting later today all from our homes are all remotely anyway that would have never ever happened before so in a strange and interesting way it seems possible that the way services are provided now might actually benefit some clients, what do you think? do you think the new way of delivering services helps, hinders clients, bit of a mix what's your opinion on it?

Ellie I think it's quite positive actually I'm thinking of a once client in particular you know springs to mind, like this particular client I think he got a lot out of groups but I think he found the groups very challenging as well and he'd get a little bit lost in them and it was a small group and I just think like I think he enjoyed the company and I think he enjoyed the groups but when I ring him on the phone now I could be on the phone to him from anything up to 20 or 25 minutes and I don't know that doesn't sound huge

Researcher It is huge for that client

Ellie It is it is huge for that client and like to the point where like when I first start making calls and I know he had issues with his phone for a while so I had a little bit of a gap in communication with him but I could start conversation let's just say about the rugby this weekend and he would he nearly lead it you know like I like I try and keep conversation going as long as possible but the effort is a lot less than what it would have be let's say if I rang him this time last year

Researcher Yeah

Ellie So you know in one way it's it's really strengthened our relationship and his ability to kind of hold the conversation longer and to...but it in a really meaningful way as well so not just like talking about weather is great and everything but he really opened up you know so I think it's it's just strengthened relationships a lot and I know our clients aren't really geared or ready for online computers and meetings just yet some of them are nearly there but not we were kind of cut a little bit short in our preparation but the phone calls I think have helped our clients a lot like you know we've almost got a little routine and we've got our own little routine of like you know if I'm 20 minutes late ringing one client he'll always joke about it oh I didn't think you were going to ring me at all today

Researcher Yeah

Ellie So you know I just think it's it's strengthened relationships you know a little bit and it's just when we go back to our setting that we're used to I think we'll have a better bond with our clients because we're used to speaking to them one to one like some clients are getting calls twice a week not all but some are getting twice a week calls and that's like two keyworker sessions in a week really if you think of it you know

Researcher Absolutely and the quality of that engagement like we would have seen the gentleman you were talking about who like we would have seen him from 10 until 3 once a week so like a five hour service and like to think now that you're getting 25 minutes or 20 minutes of like quality engaged time you know and and conversations that he's possibly even leading now as well like that's huge given the man that we knew you know that, would we have had 20 minutes of fully engaged conversation that he was leading before in a 5 hour time slot I don't think we would have you know we would have had glimpses and a little bit of interaction for sure and he would have you know he would have given little little engages

for certain and it was never a lack of of you know interest on his part or anything like that you never felt like it was a it was a lack of interest it was just more of a lack of engagement overall you know

Ellie it's almost for him into like a quality over quantity services yeah like don't get me wrong I think he'd love to go back and I think he wants to go back and he wants to see people and have a bit of normal because there's other issues of course you know not seen as many people he used to and I think the phone calls I think I'd nearly keep the phone calls going

Researcher Yeah

Ellie Even one phone call a week like if we went back to (service location) now next week on a Wednesday I think I'd still give him a call on a Friday just to see wish him a good weekend to see how he's doing because I think I think he gets a lot out of it you know

Researcher Yeah

Ellie and this particular client would have very bad vision problems like very bad so like I think when he's in group I think he likes being there he likes the environment but like he it kind of holds him back a little bit so I think getting more conversation will benefit him you know

Researcher Yeah

Ellie More active relations simulation you know so it's just yeah I think I think it really just refocused and the person-centered care just to really add in the sensory because a huge, huge part of it that we're just we're not too focused on at the moment I think it just needs to be more more included

Researcher (name) thank you so much for all your input and for taking the time I'm just going stop the recording

Interview 8 Transcript

Professional Working in the Acquired Brain Injury Rehabilitation Sector Ciara (35) pseudonym

Researcher We were talking about of sensory overload, and we were just talking about the kinds of sensory challenges you would see crop up for clients

Ciara Yeah will I go ahead?

Researcher yeah sure go ahead thank you so much

Ciara yeah so like that, interestingly it's something that hasn't you know come up an awful lot you know when I've been working with clients in the services in particular that I'm working on which is actually where I notice it more is on the in the needs assessments when people would mention things to me like I suppose to do with the sounds you know there's very loud sounds in a room next to where we do, or used to do the I needs assessments and a number of clients have often flagged with us or I know in our own service a client would speak about the texture of the chair that they're sitting on and places where there is arms or not and those kind of things and it really impacts on their ability to participate in the group and I think even from what you sent on to me it definitely raised my own awareness of sensory overload and sensory issues and I would definitely feel it actually is an area that you know doesn't get the same amount of focus as perhaps physical difficulties or cognitive difficulties and that's through no fault of anything really I suppose it's just all down to awareness and perhaps you know initially after somebody has an injury you know which is the physical at the cognitive that directly impact their day-to-day and perhaps the sensory overload you know only becomes apparent over time when it keeps happening and so I you know I suppose like I say I wouldn't say it hasn't been there at all it's possibly been to a level my lack of awareness or equally the clients lack of awareness around this the sensory issues yeah

Researcher yeah for sure and I thought you made a great point about like their their simple simple enough fixes you know like the getting the proper chair for the client and things so it's it's a simple fix but it's all you know it's it's their dominant focus until that happens because it's a huge thing for them you know a simple fix for for us to accommodate but a huge focus for them because it's it seems to be a little bit all-consuming you know when the chair isn't right or obviously when the senses are triggered as well and then we were looking at the sensory menu we had gone through that just about through the different bits and pieces we're kind of looking at like room size and the the the type of chair and like the the presence or the absence of music, was there anything else that you would have added or anything to that I'm just going to have it in front of me here and quickly go down through I think we were talking about kind of temperature for windows open and even the heating on

Ciara Yeah yeah absolutely I like that is something that will come up for some of our clients from time to time it would be to do its temperature as well it does bring its challenges in the sense that you might have a group of eight and it might be one person out of eight saying that the temperature is you know affecting them and I think that's where it's really important even to have the menu like this so that when we're going into a group and a client is there that just because it's only one client that we can accommodate them and you know that we look at it in advance and you know maybe is it that that particular person you know that we encourage them you know even if we had blankets you know I know with Covid at the moment you wouldn't be thinking of these things understandably but that like you know you had a designated blanket for that person if we can put on the heating behind seven other people don't want it on but you know I know I've mentioned already but I think it's really important that you know that this is just you know similar to a cognitive challenge that the client just expresses that they have needs around it and that it can be accommodated really easy and

that as an organisation we have things in place to make this happen very easily by staff for for the client and it shouldn't be seen that you know this is an extra burden or an extra job for the staff and the client should understand that you know we want to know you know any needs they have and I think that's what the sensory menu that you have developed does you know to open conversation

Researcher Thank you so much (name) I would love that I would love if it became part and parcel of the service you know as easily as we would grab a cushion for a client who has back problem and tuck it under their chair we would grab whatever you know we would grab the lamp for a person who's coming in with sensitivity to the lights or you know just have like that's like a blanket or a tactile item or something that they might respond better to and I would love that I would love it just kind of became part of of you know who do we have in today, oh so and so is in today I'll just grab whatever they need you know. I was I was talking to other team members as well they were saying it might which I would be great but it might help clients vocalise what's going on for them because they were saying some clients do understand what's going on, I think you touched on that as well that's some clients do understand what's going on but others might not know exactly what's going on and it might help them if they're used to verbalising it in services and it being accommodated. We can't control what happens at the community but it might it might strengthen their voice a little bit to be like no this is actually a need that I have

Ciara Absolutely you know and even on that I think that will have an even further impact in the community because you know I think then the client could see in the community you know they could verbalise this challenge they have but they could also give the solution you know they could say you know look all I need is for you to dim the lights during this therapy

session you know or what during during my GP physician I just asked them to dim the light and I think then for people even in the community you know like sometimes I think people's concern comes from not knowing what to do or how to help and if the solution is there you know it's it's fine it's not it's not a big deal at all and yes so I think yeah I can see a huge potential in the organisation and again to you know support links independence in the community again as well

Researcher I think as well when you were tuning into these things like (name) was discussing recently she was saying when you're actually tuned in you know like when I walked around the building and tried to put my sensory hat on I missed so much, you know the things that I thought were obvious that I thought I could solve weren't the things at all that bothered the clients with sensory overload you know it I was looking at the big one so the lights and things like that which all played played a part for sure for sure like one lovely lady was saying like it's it's the sound from the exit sign that is it's emitting a sound and I would have never thought of that you know and I was thinking there's one of those in every every building you know probably 10 in in in our building alone in (place) you know outside every door you know there's there's so many that it wasn't those things at all and (name) was saying that when you tune into it and and like it it becomes part and parcel you begin to notice things a lot more she said your you're kind of your sensitivity to it or or how tuned didn't you write to us and I suppose how where you are but like you were saying awareness that she was giving the example of like a delivery person came in and they said like oh there's this new whatever it was fridge or something that he was like doesn't admit any noise, it's perfect and he brought it in and she was like oh God it makes so much noise you know and and he was like it doesn't make any noise and she was like it does you know when your ear is is trained to to listen out for it you know

Ciara yeah I don't think actually it'll be you know it's almost a fantastic opportunity when you're doing this research you know given that the building the new building hasn't commenced you know it should be just fantastic to think that we could implement some of those changes you know before the building even started you know so then like going forward when a client comes in you know they can actually get the most out of there their rehabilitation time

Researcher I was thinking that would be wonderful in the sense of like put put the client in the expert seat because they are the expert on that and let let the building be designed for clients by clients but especially with with things that are you know can be quite individualised and very triggering for clients in different ways but if a client with sensory overload can design the sensory rooms or the sensory spaces or the space in general but especially you know how it would be sensory soothing as opposed to sensory triggering I think that would be great because the the clients were apparently when they were asking about the new building to all the staff they were saying will there be a place that we can sleep and will there like will there be a place of complete darkness that we can just go into and completely just you know block out every kind of stimulus and will they be available and they were thinking they absolutely should be available you know that would be part of the plan because I sat with a lovely gentleman who an interview with me and he was saying even the shiny surfaces he was like those could all be on one wall that I can just put my back to that wall and not even look at it where he's like you have shiny like a board and this board he was like I'm surrounded, you know the sun hits it, the light hits it that whatever the fluorescent lights and I'm I'm completely then triggered you know where I can just put my back to it and it's it's not affecting my session anymore you know which is

Ciara yeah and like I thought that was really nice what you said there about I suppose rather than being sensory triggering just be sensory soothing and I think even a really important way to look at these things is that yeah like this is to support everyone and to help everyone you know like even for example we'll say if there's a a wheelchair accessible ramp going into a supermarket actually a person that's you know just maybe on crutches and you know has a temporary disability you know you know is helped by that being there, a person that's pushing a buggy is helped by that being there so like it's it's a lot more about just doing these general things they'll actually support all of society you know I don't think it should be necessarily has to be you know because XY and Z has sensory issues now that we need to do this it it actually helps the whole of society by making these changes and and like I don't know on a personal level like you know I just find myself even going into a supermarket when it's really busy and loud or even if it's say for example clothes shopping you know my favourite time to do clothes shopping would be at 12:00 o'clock at night if they would open up yeah it's not really because then I think you know it's quieter so you know there's not that hustle and bustle and you know and like that's just you know I don't have a brain injury and that's you know that's still how I feel about it so I think it's just him encompass everybody you know it really can

Researcher For certain, I completely agree even you know when you're... and it's not sensory overload but you know after a busy day at work and you kind of, I know myself that I would seek silence, you know I wouldn't turn on the radio or anything you know I just I just want silence for for maybe 1/2 an hour an hour ideally but maybe 1/2 hour would be gold you know where you just think like just need to quiet at the minute you know so so yeah that's that's just after a busy day that's not even every day you know so yeah I get that but yeah going into I would be exactly the same doing clothes shopping or any kind of shopping when it's like really really really quiet you know yeah

Ciara Yeah

Researcher We were talking about that like it kind of came up for the clients in a lot of the interviews how sensory overload was and and the it was really tied to their identity, it seemed really ties to their identity the senses and and losing or overloading the senses seemed tied because the three clients that I interviewed weren't able to get back to their profession in the same capacity or some had to give up altogether and different things were were happening for them like if they were always the cook of the family and they lost their sense of smell and taste they were saying I don't know for tastes good or bad are you know and then kind of the rituals of like around Christmas time or the traditions around Christmas time of like getting the tree and the real tree and smelling that kind of that being the start of the festive season for you and things. I think it seemed linked to it and and I thought you made a great point and when you were talking about how it's hard that this person is like getting used to their identity then being pulled in opposite directions as well

Ciara yeah yeah and that's very much so. I suppose I know I mentioned it just yeah like you clients would often say they're adjusting their new strengths and their their new challenges and you know going through their life with that and then they might meet a friend in the street and they're asking them to come to the pub or to come and play the soccer match and and then like you know the client is almost saying that they have to explain to them that you know when I'm not you know you know I can or can't do that anymore I do or I don't enjoy it anymore and then like clients would say you that they are trying to dip back into that and then you know that's where the struggles and challenges crop up again whereas you know yeah and it is it's a huge thing around identity and like that I suppose other people are just completely unaware of that change that's going on for that person and the adjusting they're

doing and the person would be finding their feet and then even a family member like that you know that they haven't seen in years might suggest that they they do something or you know go somewhere and it's just I suppose it's a reminder of the changes that have taken place and yeah it's definitely a drag from to and fro I can you know I quite commonly hear that from clients that it's really an area that you know I think a lot of clients can relate to really

Researcher Yeah and they're adapting to that all of the time you know they're they're always in that kind of to and fro is a good way of putting it because the clients kind of talked about themselves before and now but still there was still under completely understandably the yearning for the before you know which is, which is hard you know

Ciara Yeah

Researcher and then especially if others are kind of trying to pull you in that direction as well your heart is going in that direction but no you can't do that you can't go back people are kind of saying be the person you were you know it's just not yeah it must be very very difficult

Ciara Very very like I say down through the years it's really something you know working with clients it has more definitely come up from more clients than it hasn't but I think it's important to flag too you know that you know I've worked with a number of clients where it hasn't come up you know

Researcher Yeah

Ciara you know and it's it's really important to note that as well but I suppose for clients that it does come up for it's a huge challenge and it's it's you know it's emotionally draining really because I suppose clients would say that they feel that they're reminded of things they could do and now they can't do so even if they're progressing I suppose they're just kind of brought

back to those thoughts again so they have to work extra hard, they have to work hard to progress and they have to work hard to manage those thoughts that might be brought up for them you know every time they meet somebody so that's it's a challenging challenging area really yeah

Researcher Yeah, speaking of challenges so how has it been working through Covid I know we were touching on this last week

Ciara Yeah yeah so I suppose again like in the service I'm in I suppose each lockdown has brought a different way of delivering services so I suppose the first time we were just on the phone and making contact with people and sending out resource packs and again really I think that one it was strange but because it was all so new everyone was kind of going with the flow and even when you be having conversations with people the topic of Covid was so new everybody was interested in talking about it whereas that dialogue has certainly changed you know even now Covid is the last thing people want to talk about on the phone you know it really is but I suppose just to dip back a second I suppose then we went back into services then and things were as such as they ever were you know besides the fact that we had less numbers in the building and people were wearing masks so I suppose there's advantages and disadvantages to that in the sense that because group numbers were smaller we were definitely able to tailor the groups and support people's individual needs at a much greater level and that's certainly been an advantage. I suppose a disadvantage then as wearing the masks you know as something that some clients have felt very uncomfortable doing and you know it has affected whether they've come into services or not and equally I suppose you know I'd have a few clients that would need to travel from (locations) and because they would have needed to get two buses I suppose they had a fear around contracting the virus and you

know becoming unwell and so that meant they weren't coming to services so you know I suppose my role changed greatly as well because you know you're you're trying to deliver a service in a new way and then I suppose the most...professionally the most stressful time for me I would feel was after Christmas this time round and a lot of that was because we went fully online with the clients and this is something that needs to be done really really quickly and you know for some of my clients they would never... they don't even have an email address you know so everything and certainly don't have a laptop so everything was very new so I suppose on a professional level that was probably the most stressful time for our team that I've definitely seen and as well I think after Christmas it was a bit you know it was hard for people to see the light at the end of the tunnel you know I think people thought maybe we're making progress and then they felt we're taking a back step again so yeah like I would I would definitely say if it's changed and there's been ups and downs and there's definitely some positives to take from that I think the blended learning approach will support some clients greatly you know clients who are traveling distances, you know have difficulties with fatigue equally for others it has meant a level of isolation and you know something that they feel they can't get from not being in in person or that you just get from a one to one with the person so it's been it's certainly... and I suppose just to flag as well you know it has certainly shown how resilient people are you know it's phenomenal this is huge and people you know as such have have gone with this and taken the bad with the good and so it's been it's been a journey to say the very least

[Researcher](#) It certainly has, aw (name) thank you so much I'm just going to stop the recording

Interview 9 Transcript

Professionals working in the Acquired Brain Injury Rehabilitation Sector (Group Interview)

Sarah (44), Sinead (40), Fiona (37) (pseudonyms)

Researcher I'm looking at the client sensory needs and I'm looking at sensory overload and how do we kind of incorporate that in to (name) services and is there tweaks that we can make to the environment itself and into the settings itself of the (name) building that might make it easier for people with with sensory challenges so that's what I'm kind of that's kind of the direction that I'm coming at it from and so like just to start off I should say first does anybody have any questions from the off or will I just go right ahead into it or?

Sarah Rock on

Researcher Ok so the the first question really is just kind of what sensory challenges that you might see present for clients and what might crop up for them or or that you might find that present a bit for clients just the kind of sensory challenges they might come across?

Sarah I think light and noise are probably the two big ones (name)

Researcher Yeah

Sarah and very prominent and not only does it affect their one to one work but it also affects their group work so many of the clients really enjoy the the peer support but because of the number of people in the room it means more noise and that they have to make kind of a tradeoff for the benefit of the service versus their sensory overload and sometimes when we're talking about light even the journey to (service name) and we would have a number of clients who would say particularly if it was a sunny day and it was bright light that the light coming through the trees maybe as they drive up the road is very difficult for them so it is

regularly happened that even before a client comes to start their service that they are quite sick because of the sensory experience getting to (service)

Researcher Yes

Sarah So light and noise, strip lighting in particular

Fiona Yeah

Sarah Which you know we have and is common in supermarkets

Researcher Yes

Sarah and office blocks, so I would always ask clients now do you want me to turn on the light leave off the light I have a lamp in my office that I have on unless we need extra light which is obviously easier during the summer

Researcher Yes

Sarah but noise even because of the the building and the various different services we might for instance be working with a client and the (service) could be going on outside

Fiona Yeah

Sarah which used to coincide with one of the groups so they're obviously using tools having a great time, it's noisy and then the clients inside are struggling with the noise coming from outside and that can be a tradeoff too then you know I can see Fiona* and Sinead* nodding because we're saying do we open the window to leave in the air

Fiona Exactly

Sarah Because of fatigue and it's getting too hot

Researcher Yeah of course

Sarah and then if we open the window then we're magnifying the noise from outside. So, what you're doing is really important because this stuff really impacts services every day

Sinead and I would have even said Sarah* do you know the way, I'm just thinking of a few clients who even the clock ticking (researcher) would have been enough to... to so sensitive to it which is interesting and yet the other side of it is some clients found that comforting the kind of the consistency of a of a ticking clock but most would say yeah that would have been another check in as well would you like me to take the the clock down and so I suppose not to

Fiona It seems really apparent in the neuros well I don't know about you guys but in the neuros when they're trying to concentrate on the assessments that's when they asked me to to like or they'll say oh the clock is driving me bananas versus you know when you are kind of it that seems to be where it's really apparent when I'm working with them, but I don't know what it's like in your services

Sinead when you're talking about the buildings as well (researcher) I'm just remembering flashbacks to you know the needs assessments and there's some of the hand dryers are really loud and just because of the sound in the building and the way it travels but even for me without an acquired brain injury it was interesting I could even sense the frustration you know of trying to be heard

Researcher 100 percent

Sinead So I can imagine when you're trying to feel heard and concentrate on the words you know and with that behind you so yeah in terms of sound

Researcher 100 percent

Sarah I do think we're probably more sensitive to

Sinead Yeah

Sarah sensory noise now working in the area just a real practical example, recently enough they were going moving the server and from the hall into a room and I said yeah that's fine as long as it doesn't make any noise and he was like no no it's really quiet it doesn't make any noise and I was saying ok because sometimes the hard drives the clients will...they'll tell you that the fridge is humming

Fiona Yeah

Sarah or they'll...they can hear the hard drive so I was...went into the room and I was like that's really loud, he was like that's not making any noise, I was like that's loud we can't use this room to work with clients and have that in the background so from a man coming from IT he didn't hear it he said it was really silent and for me the minute I walked into the room I was saying that's totally not compatible with working with the person an acquired brain injury in this space and space is a premium. Space is another thing so light, sound, temperature, keeping temperature regulated and space is a big thing

Researcher It's so interesting to hear you talk about it as well like you're so right when you tune into it it's almost you know you have to consciously tune out of it again when I was sitting with the clients and we were talking about the different things that that might be triggering for them or it might be it be just like really really tying into their their their sensory needs they were saying it's not even the the obvious ones that you would pick out like they were saying if you actually tune into the (service name) building it's a very echoey building which I would

have always known kind of in the background of my head that you could always hear what's going on in the (service name) room or you know especially the hand dryers and things like that but they were saying you can actually hear every noise if you tune into it you know and they were saying I can't tune that out said they were they were saying it's not even there were saying some of the localised sounds were ok so they were saying even though the hand dryer is really annoying it's not the worst sound the worst sound in the front room was people walking up and down the stairs because they they were saying I can I can that's really grating you know they could really hear that so it was kind of interesting to sit and share the space with them and and tune into that and and realise if I couldn't turn this back out again how how just overwhelming that might be

Sarah some of the clients...sorry

Sinead sorry sorry no I think as well I found in (service name) and because you're asking people to be vulnerable in that space and I think that's where sometimes they they're disjointed or the disconnect or the conflict of interest really (researcher) in terms of sound so you could hear people outside laughing and joyous and happy and yet you're in somebody's depth of pain

Researcher Yeah

Sinead and it's that part I would agree with you there as well (Sarah*) it was me as well as being very sensitive to that and nearly sometimes oversensitive that's the other side of it we're so biased that sometimes the client can switch off from that you know but I suppose yeah because like that you know you say one brain injury you see one brain injury and isn't that's the uniqueness of it like or you know what was sensory overload for some in a group setting was was perfectly fine for others and it's that part that it's the struggle

Researcher Yeah and I think I think it's the individualised nature of it you know that you can't say... and I know that's the nature of brain injury you can't say that what will will overwhelm one person will be absolutely fine for another and triggering...something else would be a trigger for somebody somebody else

Sarah I think what you're doing is really sorry

Sinead Sorry I cut across you there

Sarah No not at all, this is the joy of online work because there is a delay all the time. I think what you're doing is really important and now is really timely because with the new building there is a really good opportunity to negate some of those things that have just they're just a legacy of acquiring buildings that you know we do our best with but aren't purpose built so there's a real opportunity now to change those things for people and the level of sensitivity you know I was in a group once where one gentleman was saying what is that noise and I mean it was so quiet and he could hear the battery dying in another group members hearing aid

Fiona Wow

Researcher Oh my goodness

Sarah you know the low kind of beep to alert them that they needed to change their battery so even you know what we're sensitive to which is why it's so important to ask, you know we know the gross lights and the music and the temperature and space but we don't know the specifics for each person and the level of which they're filter isn't working you know and clients aren't aware of it you know I get anger management referrals and sometimes it's sensory overload irritability

Fiona Yeah

Researcher Yeah very much so

Sarah So they're being referred to (service name) for it so they're not even aware you know a lady who for instance rang me really upset one day because she had ran out Tesco, she was crying she was in her car she didn't know what had happened she'd ran out of Tesco, left her shopping there and it was total flooding sensory flooding the lights the music the divided attention you know the notoriously difficult trolleys that always end up going in the wrong direction loads of people and really bright stimulation you know rows and rows of the products for some of our clients things like movement so being in a car and having just that movement of passing fields or power cables can make them really really sick

Researcher Yeah and like it like you say it sometimes it's it's the things that you would never think of like one lady was saying...I was trying to...trying to set up the meeting room trying to have my my sensory hat on and it was it was none of the things that I thought and it was all of the things that I would have never factored in which was huge learning for me but she was saying it's not actually anything to do with the the sound in the building it's actually the sound coming from the exit sign she could hear the buzz coming from the exit sign over the door and she was saying that's really I'm finding that really grating now at the minute you know at the minute

Fiona Wow

Sinead Or you know what it was lovely to see (researcher) you're going through the senses in terms of smell I remember the the client's cooking and even though some of them wouldn't be or wouldn't have as sensitive as smell as they previously had pre injury it was still brought

them joy because it was the association of smells and the past or you know yeah I said that satisfaction as well of doing the job well so even with the smells and think, I remember actually in (service name) I'd light candle and just to set the space and most people would like that even for the light so even if they they couldn't smell it was just that sense but I actually do remember then so here's where you go, another client asked me to to blow it out they hated the smell they they found it really...I wouldn't say toxic but just overpowering you know so I think you're right there (Sarah*) you touched on before it's actually about asking and it's about their awareness of their own because sometimes they might even realise the level of sensory sensitivity they have and it's not until you start enquiring that they start making sense of it going...

[Sarah](#) or that it's related to their brain injury

[Sinead](#) Yeah or their mood or

[Sarah](#) They're missing that you know particularly young younger clients maybe with children would find themselves saying you know my my relationship with my my kids and I I'm going to say wife here because it's often that you know the male with the brain injury that we're working with that and what it transpires that the young children make a lot of noise so they're really struggling with being in that space so it's impacting their ability to parent but their perceptions of themselves as a loving father as well so it's above and beyond you know kind of making sure the room is ok sometimes people don't even understand the impact on their actual functioning and their relationships. Noise and young children or even with the grandparents that we're working with who love their children their grandchildren dearly but just the noise that they make and the unexpected noise

Researcher Yes

Sarah I think that's another factor, the noise that the clients can predict it's kind of ok but the sudden shrieking or dogs barking is another one clients will report something that's unexpected and comes out of the blue they can find very very difficult and then you know obviously people will come up with solutions like well why don't you try noise cancelling earphones which are fine if you're engaged in a solitary activity but the whole point for instance of a peer support group is that you're coming because you're enjoying the company of others and then sitting there having to wear earphones until you speak and taking them off for a small while and putting them back on again is counterproductive

Researcher Absolutely, absolutely and I think you touched on it there as well (Sarah*) what seemed to come through for the clients was that how the senses are tied to their it seemed to come through that it was almost tied to their identity you know that the sensory overload had such an impact on their professions and their ability to to enjoy things with their family in that kind of family space and and all the lovely normally lovely chaos that can come with that especially if there's kids involved and things like that it kind of it seemed to impact on that like one client was saying like (Sinead*) when you were talking about smell as well and and she was saying if I asked you you know which sense you would be ok with losing you probably say oh you know if I had to lose one I would probably lose my sense of smell and she said but I've lost my sense of smell and even to try and cook a meal for your family or for anybody you can't taste it you don't know is it you know it does it need salt does it need seasoning does it need anything and and then you begin to doubt yourself of like this isn't going to be any good and she was talking about even at Christmas been able to smell things like a real high sensory time you know being able to see things but also being able to smell things and all the food and a fir tree and you know she was saying that that that all has impacted on on her ability to even enjoy the festive season you know

Sarah and we would have had clients who have been quite distressed and conscious of whether they smell which had led to excessive washing because of the fear that they were smelling because they couldn't smell themselves and so when you kind of get stuck on that or ruminate on that, that in itself then can become a difficulty where the clients focuses on while I can't smell myself so what if I do smell bad and people aren't saying it to me so...and things like you know another client would say that smell of kind of fresh cut grass you know around kind of March April you know the seasons are changing and there's a bit of a pep in your step with the days are getting longer so you know it's a continuum from missing things like that but absolutely right up to your favorite perfume or you know the things that that you find soothing or comforting, smelling your child you know

Researcher Of course yeah

Sarah another client who who doesn't know about nappies so they don't know just on a really practical basis if if their child needs a nappy change so that leads to over checking and then being very conscious particularly out with people

Fiona Yeah

Sarah so yeah it permeates all aspects of people's being. One of the clients called it... said that that overload was like an assault on their brain which I think is you know is a very profound way of saying they're walking around the world and sometimes it feels like their brain is being assaulted

Sinead and their bodies you know even with the landing with the movement, the touch is you know having aphasia or hemiparesis on top of that and so you've lost that sense of the feeling of or even feeling grounded

Sarah Yeah

Sinead Yeah and if you're on about the building you know it's wanting to provide... I'm saying seating that we think might be more comfortable but in terms of function then that's the hard balance isn't it for everyone and to make it as accessible and as comfortable at the same time

Fiona and then I suppose the clients that they can't tell us

Sarah Yeah

Fiona you know like where do you... where do you even start then like is somebody in a nursing home with behavioral challenges is that down to something as simple as people continuously turning on the light above their beds

Sarah Yeah

Fiona you know and they can't tell us like that's actually awful to think that because you know you'd presume that you know if they have enough impairment that they'd be in a nursing home or nonverbal you know that that they would have significant sensory issues

Researcher and I think we're seeing that in in (service name) at the moment with one particular gentleman that it seems like sound and he's he's living in a nursing home and they are, they're treating it as challenging behavior and like I've I've just been in contact with this keyworker just to say I really from my experience of working with that man I really think it's that he's experiencing sensory overload and she completely agrees and she's trying to get that across then to to the nursing home that are just saying no no you know it's you know any noises is they they were trying to think like oh it's it's it's even when something is not loud he's reacting to it and we were saying yeah that's that's exactly the sound doesn't have to be loud for is to to...

Fiona Grate

Researcher Yeah exactly

Sinead and you know where that becomes dangerous (researcher) is when clients are interpreted as having challenging behavior and there's something official written up

Sarah Yeah

Sinead and then they go on, I've seen this with with services then where you know you're at the forefront of their anger because they have felt unheard or misheard for trying to be honest with you and and you know and explaining like that the sensory overload but if there's not a level of professional awareness around that or trying to I suppose get the bigger picture for that it can be really damaging to the person's recovery you know

Researcher Yeah and and I was thinking that even in terms of needs assessments like if they're coming into I was just trying to think of an example in my head that if somebody was coming into an environment that was too hot or too bright or too noisy that or it was just particularly triggering for them that are we setting them on the back foot already you know would there... would... the environment is kind of working against them as opposed to working for them like I I know myself if I went into a really hot dental practice or you know if I was going to get a filling or something I'd probably pass out I'm terrible with heat and they probably think you know problem patient over here you know but

Sarah Yeah

Researcher I I was thinking of that in terms of a needs assessment you know if afterwards they were saying oh I don't know if that person would would be able to sit in a group setting

but is it, is it because of the environment is is working against them or is that at least a factor in in their needs you know

Sarah I think anybody you know when you're talking about environment anyone who spent any time in hospital either visiting or and I guess I'm equating that around nursing homes which is often where people are inappropriately placed after brain injury as we know it's really loud and busy and noisy and it's really bright and there's so much activity your sleep is disturbed it's very hard to concentrate and we've all had that experience but if that's where you're living with and the expectation is that somehow you can adapt to that that's very difficult without you know your own real personal space and I know people have the bed space but like a living space you know and they negative effect on cognition I've definitely had that experience where sometimes you know if there's sensory overload in your head is so full and someone is talking to you that it's much harder to process what they're saying just at the basic level you're thinking ok can you give me 2 seconds there I just have to... you know we often say I need to clear my head

All Yeah yeah

Sarah I'll go for a walk and I clear my head and I'll come back to it but if you don't have that opportunity

Fiona Yeah

Researcher How do you...I know even throw fatigue into it then you know

Sarah Yeah

Researcher and you're you know trying to explain what's going on and and maybe you you don't know even the full extent of why am I you know why am I feeling so overloaded you

know and and yeah and that poor gentleman in the nursing home at moment like that I I'm not sure that he knows how to express exactly what's going on you know that he's in he's in that awful situation where where people around him don't seem to understand what he's going through and he might not have the full just be equipped with the full information of what he's actually experiencing him

Fiona and I suppose like that when you when you actually think about it - but like the lighting in a hospital slash nursing home the sounds the clattering you know and it's not a calm but also the smells like there's a very distinctive clinical smell from a nursing home or from like I remember working in in residential care and it was such a learning curve because you know when you're on night duty you have to clean down everything and and you know I guess with with you know there were some hygiene issues in so everything was Dettol and you know it's a really distinctive smell and one of the verbal ladies was able to say you know that smell reminds me of the institution

Sarah Yeah

Fiona but she could verbalise it you know so the other four were unable to verbalise it so when you think of... you have everything all of...you have the sounds, the smells, the lights,

Sarah Yeah

Fiona everything kind of in like a melting pot

Researcher Very much so

Sarah Yeah and that divided attention you know the clients will always say I can't do it I can't have a conversation with you if there's a radio on in the background. Think about every house in the country, the television, there's more than one television on you know now we're all

gone online which is another kind of complicating factor I think and you know divided splitting your attention between two things so I think it's much harder in one sense for clients because they have to attend to you know look at us here today you know there's pictures on the screen I'm talking you have to kind of pay attention to who's talking next but in a room you kind of get a rhythm of people and you have a felt sense of that it's harder on a computer for some of the clients but divided attention like fatigue and sensory overload are irrevocably linked if you're working really hard to tune in to what somebody saying to you and to tune out the bits that are irrelevant that your brain or longer does for you that's going to come at a cost and that cost is cognitive fatigue so you're back in that vicious circle then so you have high levels of fatigue you're functioning deteriorates further you may get more irritable with the people that you live with or your loved ones and you're in that vicious circle you know

Researcher Yeah that's a that's a really good way of putting it is a vicious cycle for sure. The the sensory menu, while basic came out of an emergency department actually they they started developing it because they saw like that people coming in in a high stress situation and straight away they were getting overloaded and it was leading to communication issues because they couldn't communicate what was going on for them or or what maybe was going on for a loved one and there was lots of children involved and they thought what can we do to just try to calm the situation down a little bit that the small environmental changes that we could make that might just make this a more pleasant experience it will never be a good experience coming into an emergency department but is there tweaks that we could make that that will will change that and slightly for the better so that got me me thinking about coming into a needs assessment or coming into a keyworker session or or anything that the client is coming in for

Sinead Or on a totally biased level the music there,

Sarah Yeah

Sinead because I would have heard clients in (service name) refer to still having the memory of the music that was in the background when they were in either in the acute or community rehab setting and and how important the the music was to them and and just for my own masters looking at the impact of music actually was emotionally more so about their associations with with happier times you know gone by so there's something very poignant about music for people and so that was just a totally personal level as well as professional I love to see the music there (researcher) (referring to sensory menu)

Researcher Aw thanks so much (Sinead*) I tried to think of the I suppose going around and your trying to to put your sensory hat on but again in saying that there was nothing like sitting with the clients and asking them to to have a think over the the menu and and they were looking at which I know is something that (Sinead*) you were good enough to look over the sensory menu for me a couple of months back and and we were saying the the size of the room maybe isn't something that we can factor in right now but they were saying that some rooms hug you and encourage you to open up and they were saying others are big and purposeful and you feel like you have to fill it and that can be really really just it can it can be triggering in itself because you're thinking what do I say here? and is what I said big enough to fill this space and where the smaller rooms actually feel cosier and kind of feel like you can open up and you can fill them much easier which I thought was an interesting take on that

Sarah and I think it's important to ask (researcher) even if at the moment it's not conducive all of the time to service delivery because we are so caught for space but that doesn't mean that we shouldn't ask and we shouldn't think about that and I think what the real benefits of

your project is while we're all very aware of it I'll speak about myself here if something is obvious or I see somebody wincing or you know I'm aware that they have a difficulty beforehand you kind of take that in your stride and and integrate it but it's those pieces that where it's not as salient that you might not necessarily ask so formalising this I guess what I'm trying to say is formalising this into standard practice is a really good idea

Fiona Yeah

Sinead I think it's really important, good because you know I don't think we go a day by in (service name) without becoming aware or being made aware of a sensory either issue or challenge so so it makes sense as well doesn't it for the organisation in terms of moving forward. I'm even thinking too you know in terms of rooms how...and listen it might be again to ask the clients you know how the color of the walls do you know we've one room that's lilac I don't know just it feels I don't know warmer but then again maybe it depends on your perception of of color you know

Sarah and even we would use you know blankets and sometimes oils and maybe fluffy cushions in face to face groups and at the start people we'd leave them under the chairs and people are like oh yeah no no I don't need that and then you see us maybe sessions go on that people would reach under the chair and they'd be holding their cushion or stroking it or wrapping themselves in a blanket and so it's so important, think about your own life I often think about going into a yoga studio and the instant kind of relief when you smell the incense

Researcher Yeah

Sarah If that's your thing and you know it's kind of dim there's very gentle music and it it absolutely soothes your your your central nervous system

Researcher Yeah

Sarah and that's what we should be aiming for is that the clients come into the building and it has a soothing effect on them as opposed to adding additional factors that they have to manage in order get the most out of their their their services in fact one of and it's not related I guess to the severity of brain injury in one of the recent groups we run the clients were talking about you know our new building the dream new builds and one of their questions was will there be a sensory room? will there will there be a somewhere where a-a) people can go to sleep if fatigue over overtakes them... is there going to be somewhere dark to go and so it's very much in the forefront of people's minds

Researcher and and I think you touched on it there so well in the sense of like it's it's about putting the client in the experts seat you know like we can we can empathise but we can't fully understand what it what it's like to have sensory overload so so when we hopefully we we are getting the new building and you know that's all in the they but even in the design stage I would love to to bring it back to clients and say well what you know what are the biggest factors for you like one gentleman was saying which I thought was really interesting and he was saying if you put all the shiny surfaces on one wall that will suit me a lot better because I can just position myself so I'm not anywhere... nothings hitting off that wall that the lights not hitting off at the sunlight is not hitting off of it because otherwise if I'm surrounded by shiny surfaces boards or whatever it might be or notice boards and it's just too clouded and it's just too cluttered then I can't sit in that space for very long without without being overloaded so he was saying at least that way I might be able to sit in a group setting you know I just turn my back to the wall

Sarah Yeah which I wouldn't necessarily have thought of that without without him saying that

Researcher No

Sarah another one of the other suggestions in one of the groups was that just like in the hospitals before you know if you were going to X ray they'd say follow the yellow line to X ray follow the green line to hematology follow the blue line to outpatients they were suggesting that on the floor we would have a similar similar situation in the new building where we would have colored strips that might bring you to for instance the kitchen or outside or the group room so that for people who spatial awareness isn't you know great after their injury that again that could be something that they could be relieved of by simple environmental kind of modification so you could say just follow the blue line and it'll take you there they don't have to think about it

Researcher That would be great yeah it's it's it's kind of about handing over the the weight of having to carry all of that isn't it

Sarah Yes

Researcher It's just kind of freeing up your mind for other things if if the environment is working with you as opposed to maybe against you a lot of the time

Sarah Sorry I was just going to say it's not their homes yeah you know they desperately want integrate often with friends and family and you know be social and go to that wedding or be at that christening and there becomes a point where they have to make a trade off you know and often people will try to fight it you know they'll say you know it's really important for me to be there for my granddaughters christening and then I spent the next three days in bed with a splitting headache nauseous, unable to function and so it is so important because we have an opportunity I guess to tailor the environment more but for our clients the world isn't

conducive to sensory sensitivity and they find themselves all day every day in situations where they have to make that tradeoff for themselves

Sinead I suppose I was just thinking there where I think even the building in where... our new building will be... but I think it's been amazing to see how that's evolved into kind externally into kind of a sensory area between the garage and the (service name) and you know places where people can touch and do things and feel satisfaction so it's really important to terms of knowing the sensory needs so people can achieve their potential as well you know to to give back basically so I've just seen that I suppose where it went from a blank canvas and how it's really helped the recovery like you know so always learning absolutely (researcher) experts by experience because I suppose what we take for granted sometimes we absolutely need to be reminded of everyday you know

Researcher Yeah for certain I would love the sensory menu or something like it to become just part and place of the centre

Sarah Yes

Researcher as easy as we would pick up a cushion for somebody with a back problem and pop it on their chair before they come in I'd love to just be like oh well I'll have a look at their sensory menu and has anything changed or you know is anything particularly working for you or working against you and just I'd love it to be part of the conversation all the time you know that's... that we're kind of factoring in their sensory needs as much as we're factoring in physical needs or you know that yeah it just becomes kind of commonplace so you know yeah

Sarah and formal part of the intake procedures

Researcher Yeah because I feel like in the needs assessment which of course we need like we give them so much formal you know sheets and sign this and you know we need this back and everything I'd love if the sensory menu was something for them you know that they could be thinking oh well hang on a second this is this is actually for me and for my benefit for when I come in they're actually thinking of me you know they're not which I know that they're probably not thinking of you know they're just making me sign on the dotted line so much but it might be something I don't know if that would give it just a little bit of of a human side of like ok

Fiona It also might at that point the INA be the first time that somebody has acknowledged that this is an issue for them but it might be the first time that they they're awareness has even been brought to this idea that oh hang on a second they're asking if I have sensitivity to light well actually I really do but I haven't actually kind of you know consciously thought about that as part of my recovery I knew it was annoying me but I didn't kind of connect it

Researcher Yes

Fiona But you know

Researcher Very much so yeah but like one staff member was saying it's it's a third of a page on the the needs assessment you know, sensory needs are like a third of a page, and we asked so many questions at the assessment that it's you know it's quickly boom boom boom dine you know

Fiona Yeah

Researcher you know it might be like you say it might be then just taking a moment to think like oh yeah hang on a second now what what might benefit you know what might help. (Siren outside) Sorry city centre living

Sarah Well there you go isn't that a good example because the buildings under flight paths as well not that that matters anymore because there's no planes but it used to cause some difficulties we used to run groups where people and I know you're (Fiona*) you're nodding because I can think of a particular one where the the planes were going overhead which was very disturbing for a client and then the volume of a clip we were showing so most of the room couldn't hear it but I think it was maybe less the volume and maybe the tone of the recording was excruciating for a particular client and then on the same day do you remember the fire alarm went off?

Fiona Yeah yeah

Sarah Because obviously you need you need drills and she suffered so much like she she ran out of the building I actually ran out of the building with her because I knew it was going to really trigger her and she really... so she came in for a service and she just really struggled that day

Fiona It was like we hit her

Sarah It really was between the the clip that we showed none of which was intentional

Fiona Yeah

Sarah but just the coincidence with the fire alarm and it was just too much she she her daughter actually came and collected her I think that day

Researcher and and that's just it like you were you were touching on that earlier like we can't control what happens out in the community unfortunately as as much as we would like to but can we somehow tailor the environment that it's it's working for them at least when they're you know they're going to access the service they've done the hard job of getting there so can can we kind of work with them as opposed to being another place that is is triggering for them

Sinead and I do think it's our duty of care (researcher) to set the intention at least, you know the big difference in the acute setting that's expected but in a community rehabilitation I think it's very important that you know that people feel cared for in in a rehabilitative way you know and as opposed to more clinical and I know forms are very important process in the info taking but I do think for sure thing and you can have the space

Sarah Yeah

Sinead To show compassion I think and that's it at the end of the day you know to say and we are aware and I think you pointed it out too (researcher) it's something that the clients can take away for them for themselves so even if they don't take up services it's something that we have shown them to be aware of in their lives you know

Fiona and you know just from this morning I'm kind of thinking now so at the moment what we're doing is we are asking if people are IT literate and we're asking have they got broadband so that we can do the INA with them, we're not asking are they you know like I mean blue light is is a problem for people who don't have a brain injury so you know so maybe that needs to be something we look at you know like is working on a screen ok for you sensory you know do we need to factor that in alongside IT literacy and broadband

Researcher Yeah that it becomes part of conversation

Fiona yeah

Researcher and then hopefully through services like hopefully through through expressing their needs in a service like ourselves they might take those those... that that confidence out you know to say I'm going to an appointment next week or going to you know a family gathering next week... hopefully that will those will happen again.. but what can I you know what can I bring with me or what can I ask for in that I would hope that that would down the road you know and give them the the ability to be able to do that and if they didn't have that already you know that how can I get the the space to work for me a little bit better?

Sarah Yeah

Researcher If they were in the habit of doing it maybe you know they might it might be very good at advocating for themselves already but even being like OK I know that's that's there are small tweaks that can be made you know

Sinead I just wanted to add there I think it's just as important to for the families and you know because we do cater for clients and families that you know in terms of sensory needs because I know sometimes the services for families can happen externally or I just think it's just as important that we we care for them in the same kind of I suppose the same sense in that they're aware of their sensory needs too when they become flooded as the carer you know and so yeah it's just something I think even in terms of the family education just to bring it to their own awareness for their own needs to do you know even something small (Sarah*) and (Fiona*) like the compassion focused therapy, the three circles so that being a sense of how do I get to my green soothing circle because you know I I'm constantly here fighting or advocating for the right of my family member you know

Sarah and there's definitely a point where you just habituate to it and I'm sure it happens with families as well I if I go walking I can't walk near main road where there's cars whizzing by while I I can walk of course again that's a ridiculous thing to say I find it really really irritating the noise and it's because I spend the vast majority of my day with people with acquired brain injury often with a dampened down sensory environment there have been numerous times where I've stood at the door of particular shops and gone can't go in there today too many people, too noisy, too bright, when I come home from work in the evening I need crave quietness for a little while which doesn't happen but ideally it would I like walking in woods and beaches where there is less noise and so I think my own sensitivity to it is definitely increased and I can imagine then if you're you're at home in a family situation and that's what people do, you know keep the noise down Daddy has headaches or you know that over time that you habituate that too yourself and might find it difficult to go out maybe for a family get together for instance

Researcher Yes very much so yeah yeah absolutely, it becomes habit for sure. We found over in (service name) I wonder if the same happened for ye when when we reopened back in August obviously we had all the PPE and everything like that but it was creating sensory challenges for the clients that hadn't cropped up before or maybe that we weren't aware how how much the clients maybe had been lip reading or reading our facial expressions and it was something that posed a new kind of sensory challenge that they were saying understandably clients were saying I need you to take off your mask you know we were saying we can't take off our mask you know it was it was that real a new challenge did you find that or was that your experience or did you have any any experience like that?

Sinead For sure I'm just thinking of the two of my therapeutic clients who due to aphasia (researcher) it really wasn't realistic or practical or helpful or beneficial to them or to to me in terms of resources we were looking for an organisation so absolutely warranted one to one with all the protective the protection you know that we could afford and given the restrictions so for sure especially for the clients with communication challenges absolutely and you know what I have to say I have absolute respect for them for being able to name it to say this won't work for me because again it was both the awareness of going you know thank you and unless I can do it this way we're going to have to press pause here you know

Fiona Yeah

Sinead and so for that yes and then I'm just thinking for two of the clients with the neuro psychological assessments (Sarah*) where some of them (Researcher) are like they're either timed tasks or it's very much you have to observe while doing

Sarah Yeah

Sinead Some of that is not conducive to online like a lot of it is and it's great that we've been able to do that and there is always space where the the one-to-one physical necessity is there yet

All Yeah

Sinead For sure so yeah that they would have been the examples I'm thinking of straight off the bat because you couldn't interpret any findings (researcher) unless we had a true sense of this is their ability in this snapshot of time

All yeah yeah

Sinead So there's the aphasia and the cognitive communication difficulties but then the people for whom English isn't their first language

All Yes yeah

Sarah The people that you would naturally adapt your your communication style above and beyond speaking to them you know and that was definitely more challenging with people and we have many clients for whom English isn't their first language and then they acquire a brain injury on top of that so they might have aphasia or word finding difficulties and I think we're naturally good at filling those gaps and you know we think about we would see... and here's the the difference with Covid you find yourself going much closer to the person, you reading their lips they're reading yours you're saying you know bear with me and I'll figure excuse me I'll figure out what you're saying to me and then we find ourselves we have to keep the two meters distance and you're wearing a mask and you can't do that and definitely has an impact definitely has an impact

Fiona and following on from that then the interpretation like there are two clients in particular that I can think of from here in the corridor one I encountered last week and I was helping (name) with an IT issue so this woman had come in because she had my IT issue and her she's very flat like she's really really really flat and I suppose you know pre Covid it was just so important to see her face and for her to see yours so that she can pick up on kind of the social cues but we were down in the large room here and you know I was up the top of the room and she had a mask on and I had a mask on and there just wasn't as much interaction because as much as I was struggling I knew that she was really she she did not know what was appropriate

Sarah Yeah

Fiona She had none of the cues that she had been working off of and and the same with with then another lady who like she's doing really well and everything but those cues the small little things that she picks up from from peoples face they're no longer there

Sarah Yeah the social cognition difficulties you're absolutely right many of our clients particularly those with frontal lobe injuries would have social cognition difficulties and that's definitely exacerbated when you're not getting the feedback from other people's faces yeah absolutely and it's just more impersonal it's it it it formalises something in a way you know many of our clients will talk about (service name) being their safe space and which is ironic because that's what we're talking about now but the importance of tea of having tea with their peers with us during a break

Fiona Yeah

Sarah you know tea is very important for a... socially... for a lot of the groups they'd say you know that bonding that 20-minute break in between maybe a 2-hour group where they meet up and they have the chat and you often you find clients that would bring baking or they just you know stop and get biscuits on the way and that's important for them to bring to the group and none of that happens online

Fiona Yeah

Sarah Yeah and even the formalisation of the tea you know, I have to make your tea you can't just you know that that idea of the safe space where the clients would just wander into the kitchen between groups you'd have it set up and they'd have their biscuits and their cups and they chat away while they're making it and I'd make you a cup and all the that kind of informal interactions really important and and because of Covid that's missing now

Researcher Yeah

Sinead If that's the basis of anything, the trust and their shared relationship and you've got dropped connections online and

Sarah Yeah

Sinead and as much as yours trying to stay grounded in the moment and pick up you know there is a certain amount where again like that where you're kind of nearly under threat trying to maintain you know the relationship

All Yeah

Sinead Or reception or whatever whether that be online or actually I was just thinking as well on a one-to-one basis (researcher) in terms of that the physical rapport like when you're being split by Perspex screens and all the clinical signs are in the room of of fear basically between masks

Sarah Yeah

Sinead Sanitizers, you know so it was very delicate is the way I would have put it in terms of just your own learning or what to put out of sight even for for my needs during that time you know so that your focus was on the the session and not on COVID-19

Sarah and so many of them are at risk, so many of them have so multitude of underlying health conditions so they would be a very high risk anyway so that definitely adds an extra layer of where everybody is concerned about their concerns you're concerned and everyone is doing their best but you're right (Sinead*) it does add an element of caution and fear to to a situation yeah

Researcher Yes it's hard because I didn't realise how much the clients and how much I relied even on how animated people are

Sarah Oh yeah

Researcher Or you know yeah reading how how their form is or you know the minute that they come through the double door is kind of gauging their form you know how how's today going for them, aw you know they seem you know they seem good I got a big smile

Sarah yeah

Researcher You know it's it's amazing when that's when that's gone and then you you touched on it as well of like the rituals of just getting just getting tea just grabbing a coffee like you know and sharing that space together there's there's that divide now both physically and emotionally and you know that you think like I have to keep my space and it it creates that that that fear element for sure that you don't want to to pass on anything to them and you do the last thing you want to do is for them to get anything and they're looking at you the same way you know

Sinead and the first thing actually (researcher) in terms of sensory things when you come through the door of any of the entrances is the sanitizer you know and posters so even moving forward when we all learn from this you know how to incorporate...you know I don't know like a lovely moisturiser even just to soften the hands are you know because it was even like that the sensitivity of the skin for people so there was more than just keeping people just sanitized as well like

Sarah and the breathing difficulties you know yeah and many of our clients in wheelchairs who might just be you know because they're sitting down all of the time maybe it's harder for

them to to mobilise and to just go outside if they need it to take a break because they might be dependent on somebody else to to move them maybe and that's not always conducive either so you know being in a mask all day long if you're struggling with your breathing again we're talking about sensory overload it's very hard to concentrate on anything above your nose then isn't it

Researcher Yeah

Sarah Because you're hot and uncomfortable. I think it does as well on the other side show the importance of the service to people like they're willing to do all of that to come in

Researcher Yeah yeah that's what we found too with that and and the the peer group was lost you know we went from like having 16 clients in a room down to four spaced out toy know

Sarah Yeah

Researcher Don't go near each other you know

Sarah Yeah

Researcher and there was that loss

Sarah The craic

Researcher Yes exactly yeah the feeling of your coming in even though sometimes touched on that they they they enjoyed it better because they felt it was a more individual service that they they said it was daunting to come into a big room before I enjoyed it but I never felt comfortable enough to to kind of speak

Sarah Wow

Researcher Or to answer questions they always thought there's 15 more voices in the room you know where the four actually suited them but then you'd always hear we got very used to hearing which was sad it was where is

Sarah Yeah

Researcher So you know where is so and so where is (name), how is (name) getting on, you know where is (name)

All Yeah

Researcher You know so it just became part and parcel of of the conversation every day which they were obviously missing each other you know

Sarah and worried you know I think they're aware as well that that their peers are susceptible and at higher risk so that idea of you know as we know many of our clients live in nursing homes and come to (service name) during the day you know and then nursing homes are... were very prevalent the media for a long time there with Covid so naturally worried about how other people are doing as well you know

Sinead That's right actually (Sarah*) isn't like the the peer support group for (service name) split in half

Sarah Yes

Sinead Just in two groups (researcher) just through logistics online and and you're right actually so half will will not have seen the other half over a year now

Sarah Yes

Sinead They're comrades

Sarah and they would say that that they miss each other and even the last online group that we just finished there was a request that when things because they've never met each other then so you have the people who are used to being together and who are separated and then you have people who've developed relationships online but the one thing that they asked for was could they come in and have a cup of tea a cup of coffee together when face to face services resume could we organise that for them so that they can meet physically so it is so important I think there'll be elements of new services that we take with us going forward that will definitely improve services for some people but I think anytime you have a blanket imposition of well this is how we have to work now for a while

Researcher Yeah

Sarah That's going to limit with... no matter how hard we try a certain cohort of people

Sinead Yeah I suppose the plus side of Covid online I'm just thinking of when we were rolling out some of the the modules for the (online system) for clients and and some of the previous clients who were still in service but have been through most of their rehab so they they wouldn't be engaged as much with the services now and how much they took from being able to access those modules online so yeah you're right there (Sarah) in terms of pause for thought going hang on a second...are we missing or we can we learn from this can we actually provide services beyond you know the the rehab the person has received so I found that hopeful in terms of I haven't realised (researcher) how much somebody would take from it, even though they would have received the the rehab services that we could provide at the time

Sarah Yeah

Sinead I guess it's kind of opened it up in terms of flexibility and for people to still maintain contact really you know

Researcher Yeah

Sarah and you know a two-hour group maybe not taking four hours if you're coming from (location) for instance which some of our clients would would take a whole day for them they maybe can't drive so they have to ask somebody for a lift and overtime that becomes more difficult and people feel like they're imposing on people they save their lifts for acute hospital appointments

Fiona yeah

Sarah and excuse me and so for some of the clients they would definitely have a preference for working remotely so there is a good mix there and hopefully we'll have that mix that we'll be able to meet as best we can individual needs but be more cognisant of it

Researcher 100% I think when I was interviewing the the clients that were so good to participate they were saying that, one lady I thought she put it so well she was saying if you've ever watched home of the year she was equating it to her red spot and she was saying that we were just talking about what kind of environment she likes to to that there is really soothing for her and she was saying I had my my red spot for all the world my favorite spot in the world and she was describing it and I I thought of her later when I thought maybe you know maybe not all of the time but some of the time she could access services from that red spot

Sarah yeah

Researcher You know, and would that would that be helpful for her you know that she's in that she could you know she's in an environment that she's very comfortable with is is soothing for her needs and still can access those services or like you say chopping down a four-hour day to a 2-hour day but quality

Sarah Absolutely

Researcher over you know two hours

Sarah and you think we often ask claims to visualise a safe space you know we work with them on maybe a relaxation exercise for them to visualise a safe space and it's about thinking how can we actively provide that that soothing environment so that it's not imaginary

Researcher Yes exactly yeah they're in it.

Sarah Yeah

Researcher My final question is just about how your own experience have been working through Covid like we like talking about the peer group there I don't think I am even in my own peer group I don't think I realised how much we were informally debriefing at work you know somebody would come back into the office and we'd how was your day? you know straight away how was your day? and there was there was that lovely side of it where now we don't do that you know your your day is your day and you kind of you you log off and that's it you know. How have you found that if you don't mind me asking?

Sinead Hate it, I'll elaborate (laughing). I would have come from a place where I actually I enjoyed the benefits of it don't get me wrong and actually thank God for where we are with IT I have to say in terms of at least we have a Plan B here you know

All Yes

Sinead But I have to say for me for (service name) on a personal level I get my energy from people from my colleagues from my clients from the environment and so I find it quite draining and isolating and lonely without that. For clients my heart bleeds and you know let's not have the drama llama going on here but for sure in (service name) for me but what I'm learning as a (professional) that one to one rapport is so much more easily established in that one-to-one environment in a physical environment

Researcher Yeah

Sinead That shared trust, that shared safe space because really kind and online format be a safe space not for everyone or not for everyone every time you know and so don't get me wrong I really appreciate it and actually some of the clients will say they really enjoyed it a bit like what (Sarah*) said going yeah this could be either no service or a service that's really helped them so in that instance it it's it's great and it's wonderful and I have been able to establish relationships however my preferred format for sure is in a physical shared environment and for that reason if that makes sense so that's my elaboration of hate

Fiona So much yeah I feel that I feel the same and I guess from like my own personal you know like I have always enjoyed colleagues like I enjoy I enjoy the work but then I also enjoyed they're like you know in the kitchen and that kind of informal chattiness you know **Sarah** Yeah

Fiona I find it very like you know you're in an office and you're having your lunch in the office and you're you know it's 8 hours a day and it's quite in particular if the weather is bad you know it's it doesn't you don't you don't have the the same kind of (Sinead*) put it lovely you know that you get energy from people but then I also really miss the like for example the INAs are going ok they're going better than I ever expected online but I really I don't feel that the clients are getting that initial therapeutic contact that they used to get you know that kind of

initial Oh my God these people know what I'm talking about you know I don't feel they get that and then also I'm missing meeting the clients informally and just like kind of shooting the breeze and getting like this felt sense for it you know ok this this guy is doing well at the moment now he's he's in a good place but also being able to pick up when when they're not because sometimes just some the corridor and then you can go to the key worker and like very informally be like oh how's he getting on lately and it you know that is completely missing

Researcher Very much

Fiona and it's totally gone it's definitely definitely a loss so if we're feeling it I'm presuming that they're feeling it too you know

Sarah Yeah yeah and I think I think yeah I agree with everything that was said personally I really miss just having a cup of coffee

Fiona Yeah

Sarah Or having lunch with someone, it has formalised everything for you to talk to somebody about something now it's a teams meeting it's a formalised link in

Fiona Yeah

Sarah Can I talk to you and then do you have time at half 12 to go through this whereas before it'll be a quick knock on the door or pop in and have a chat and even that you know you see someone and the first thing you do is put on your mask they have to ask that question your yeah you know if you're in your office in your own and there's a barrier I think there's straight way

All yeah

Sarah So that's the personal side of it definitely. On a professional level it is working out better than I thought it would be this time last year, is it more exhausting? absolutely

Fiona Yeah

Sarah Absolutely you might see clients back-to-back face back-to-back face to face (laughing) that in person you might see them not any kind of Cirque de Soleil moves you know but you might see them you know have one after another but if you're in the same room as you said you get the energy from it and

Researcher Yeah

Sarah and you don't notice it as much but

Researcher Yeah

Sarah When it's back to back online appointments I definitely find it more draining cognitively and physically and the movement just really small movement getting up and down off your desk up down the corridor, as (Fiona*) said you meet one of the clients you're asking them how things are going or you have a chat with someone in the car park all of that is missing so I think it's definitely lead to a more a feeling of being separate

Fiona Yeah that's the word yeah

Sarah that yeah needs formalised structure to link in when it happens but it's not the same cohesiveness I think that that was there definitely definitely communicating is another job now

All Yeah

Sarah Where before it just kind of evolved just happened as you walked around the place

Fiona Yeah because when you think about it like you know I suppose maybe the way that myself and (Sarah) would have worked and presumably (Sinead) the same you know like I see (Sarah) coming in and we've a quick chat and I said oh by the way what do you think, and she gives me the answer now it's an email and

Sarah Yes

Fiona You know like it actually takes much longer

Sarah It does

Fiona You know just like if you add up all those little interactions

Sarah Yeah

Fiona She never would have needed to do for it because you just yeah you know it was just real

Sarah Yeah

Fiona Quick

Sinead and even being on this call I could hear (name of dog) barking for instance so then you're I'm always there's one ear out for what's happening in this environment (researcher) and that's the part I actually miss because when I'm at work my whole focus my undivided attention I don't need to listen out for the DPD dude knocking on the door bell or whatever is going to happen that part actually yeah for myself

Sarah and confidentiality is so crucial to (service name) and there is a given when the person is in the room with you obviously you go through limits and all of that, but you can see the space

Fiona Yeah

Sarah Many of our clients have memory difficulties

Fiona Yeah

Sarah So regularly regularly you're online and you're talking about something deeply personal, and you see that the clients make kind of like talking or making eye contact or somebody handing in a drink in the screen and you're like oh is there somebody else in the room

Researcher Yeah of course

Sarah Remember we have this and and where's that may not be so bad on a one to one, group safety is really important and so if you have a group of five people and they're all online and you know you've discussed confidentiality and then you see somebody muting themselves and talking then you know that there has been somebody in earshot maybe when somebody else has been speaking

All Yeah yeah

Sarah So even just that regular reiteration can I ask everybody to make sure that you're in a quiet confidential space where you can't be over heard

Fiona Yeah

Sarah For your confidentiality but also to protect the confidentiality of the other people in the group if somebody comes into the room can you just let us know you know so all of that

Sinead I would say too (Sarah*) the risk management piece I was always like we're always conscious of that in terms of you know people are coming to you in distress in (service name)

Sarah Yeah

Sinead That's so you're managing distress which you know that's our job

Sarah Yeah

Sinead and it's different when it's online

Sarah Yes

Sinead So it's you know you have to be very conscious of you you've one hour here online and the connection may drop and

Sarah Yes

Sinead and to be very conscious of how do we make sure this is a safe space once this person finishes so I found that start I suppose, it's not that you wouldn't you would always be cognisant of it in situ but it's easier to manage (researcher) but online it's it's a whole other level of risk management basically

Sarah and our clients with epilepsy so you know with the clients that I'm working one to one online with with epilepsy I would also have to make sure that there's somebody else in the house with them and that I have their number in front of me so that if the person has a seizure while they're online with me that I don't have to then look up (online system) to find out the wife or husbands number to ring them to say he's upstairs and he's had a seizure so they're all of those bits

Fiona and the other one as well actually following on from that and it was only this week, so we had an INA that is very obviously blatantly (details of case) and I guess from my time with (previous profession) we've a recording policy and we've all of this and I was so conscious because I I know that that is going to be a massive issue that particular case is going to come back to haunt us

Sarah Yeah

Fiona and even though like I can see that you're recording this and there is nothing stopping somebody having a phone to the side

Sarah Absolutely

Researcher Of course

Fiona Recording it you know so not only are you trying to manage

Sarah yeah

Fiona and watch you know but you've got this thing in your head that ok this could be recorded, and you know it's a really messy case

Sarah yeah

Fiona It's exhausting, really tiring a

Researcher and you have no control over that

Fiona No

Researcher You know it must be very draining to try and think of all of the things that you normally have to do in a session and the session itself but then all of these other logistical things that are are are playing in as well

Sarah and I think what happened is for many of our clients well not many but maybe 1/3 initially said they didn't want to go online maybe I'm just thinking of my own caseload and but overtime as lockdown last longer than we thought it would be then they in order to access the service when I would ring them up they they then opted to go online now it has gone better for them than they've anticipated but can add an extra layer of stress

Fiona Yeah

Sarah You know it's difficult for us to get all the systems up and running and then you're talking through somebody and as (Fiona*) said the Internet connection goes down and then their connection goes down and then you try another platform and then I've ended up seeing the person on the screen ringing them on the phone

Fiona Yeah

Sarah Putting the phone on speaker, I know even we were talking over each other today that's part of the course now because of the delay you can't read the social cognition pieces who's coming in next that natural transfer conversation all of that is definitely more and that's all extra work

Researcher yeah

Fiona and the whole piece around so you have so many clients and just like anybody else mainstream people with no impairments getting online and everything learning new tools we had to learn how to use (online system) you know

Sarah Yeah

Fiona All of that, perfectly normal the added layer with somebody with a brain injury is when it's not going smoothly they're thinking it's them

Sarah Yes

Fiona Like I don't know how many times with the lady you know I actually gave five hours trying to get her teams working right over a few days not in one go and eventually I remote accessed her desktop to see if I could get it going for her but the the worry that she was internalising this as something she was doing wrong, it wasn't, it was an IT issue but she must have said like 20 or 30 times you know this is me now I just can't get my head around it and you you see that before ever you see that with brain injury so now that's really like...

Sarah Reinforcing it for them

Fiona Reinforcing it you know

Sarah and you know I've had clients who have kind of confessed towards the you know that they can't see people in the group but that there were two anxious or for that very reason too stressed to say it

Fiona Yeah

Sarah So you'd say you know can everybody see and hear everybody else yeah we all set up and as (Fiona*) has been amazing and contacting people in advance and setting them up and yet feeling internalising that that this is something I'm embarrassed about because it's clearly something else I can't understand since my brain injury

Fiona Yeah

Sarah and I don't want to bring attention to that

Sinead Yeah that's a good point there actually (Sarah) the the camera and listen I've done it myself in some webinars and I have just turned off the camera going I'm not in the mood and

yet here we are asking people you know can you turn on your camera's or can you mute so sorry you're constantly managing what you can see and what you can hear (researcher) because sometimes it's the connection that lends itself to to you even to even though you know it would be more helpful for everyone to see each other there has been occasions in groups where you've had to go

Sarah Yeah

Sinead Turn off your camera turn off your mute unless you're speaking and that's not going to lend itself to the fluidity of the session at all ever

Sarah No

Sinead You know and it's what you have to do in order to be in order to have that group full stop

Sarah Yeah

Sinead So it is the cost benefit kind of weigh up for clients individually and as a service going you know we're doing the best we can and even actually the internet connection they have they've had to work on that during the whole Covid in the building

Sarah Yeah

Sinead So that has become paramount then you know in terms of connectivity then like an are they still resolving it or sure we're on hold now yeah

Sarah but before it it was like all your email might be down for a while are you might be able to access some something on the cloud or something and it might be mildly irritating, or you couldn't put up your stats or whatever but when your days caseload is dependent on it

Fiona Yeah

Sarah and everyone else is, at the same time

Fiona Yeah

Sarah When it goes down then then it really impacts people

Fiona It's completely, the level of oh I'm I'm not saying by the way that this is a really stressful job but the level of stress when you have a client awaiting you

Sarah Yes

Fiona Or a client on the call and IT is an issue is completely different it's a completely different type of stress to you know them coming in in the morning and the internet that's anger I just get annoyed at that whereas when you've got a poor... like the thought you know

Sarah It has a huge knock-on effect

Researcher it's no longer just affecting you

Sarah No, it affects your whole case so for the day yeah so if your first appointment is 20 minutes late then you can't penalize them by reducing their time because of that that means everyone then for the day you have to contact in advance and tell them I'm running half an hour later because the internet, I'm running 20 minutes late or whatever so there's a knock on effect then for the caseload for the rest of the day people have to be contacted and told so they're not waiting. I've been amazed at the client's flexibility to be fair the amount of times people have said to me ah yeah that's fine or just you know we go on the phone or like their adaptability and their flexibility because the one thing that we haven't said which is

important maybe is that many of the clients have said to us that in a way Covid has forced the world to work at their pace

All Yeah yeah

Sarah That it has slowed everything down so that people understand what it's like to be restricted in your movements but not because of everything is shut because your movement is literally sometimes restricted and that slower pace because of slower processing speed or that the world has slowed down to meet them and so some people have found it quite comforting and many of our clients have said well I think other people are just understanding what I've been living for the last X number of years

Sinead Yeah that's actually really apparent yeah

Researcher Yeah that's incredible yeah that's incredible to even think about you know that they've been living that you know

Sarah Yeah, everyone in the house is struggling with shops being closed or not being sees able to go here there or everywhere but I haven't been able to do that for years this is my life we hear that all of the time

Fiona Yeah

Sarah That I I adapted to this slow down X number of years ago

Researcher Yeah and their resilience to do that

Sarah Amazing, amazing

Researcher I can't thank you know for your feedback it's so invaluable to have this conversation and just to hear all of like I know that it's going to be hugely beneficial for the study and I'll present the the study when I have my my results and I'll feedback as well

Sarah Great

Researcher but thank you all so much

