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The hard learnt lessons – A personal reflection on O&M for adults with CVI (Editorial)

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Introduction

Cerebral visual impairment (CVI) is a term used to describe a wide range of visual difficulties due to damage or injury to the visual areas of the brain (Lueck & Dutton, 2015), and in recent times there has been an increased interest by Orientation and Mobility (O&M) practitioners around ensuring effective strategies and support for adults with these visual issues. This has provided me with an opportunity to reflect on my own personal and professional experiences in this area and the hard learnt lessons I have had over the years. The result of which has helped me to identify three key underlying principles that I believe are vital to effective O&M support for adults with CVI:

1. Developing an O&M CVI profile
2. Empowerment of the adults with CVI
3. The creation of a CVI toolbox

CVI is a term used to describe a wide range of visual difficulties due to damage or injury to the visual areas of the brain (Lueck & Dutton, 2015)My hope is that by sharing my unique perspectives as both an adult with CVI and an experienced O&M practitioner, I can help further the knowledge base in this area. However, in doing this, I feel it is also important to acknowledge that I am only one adult with CVI, and what I have found useful for me, may not be useful for other adults with CVI. As was recently highlighted by Lueck et al. (2023) one size does not fit all when it comes to supporting people with CVI. Each individual adult has a unique CVI profile and therefore, any implementation of O&M strategies must be based on their individual needs.

Prevalence of CVI in adults

While it has been well documented that CVI is the leading cause of visual impairment affecting children in the economically developed world, with a prevalence rate of approximately 3.4% (Sakki et al., 2018; Williams et al., 2021), there is limited data on the prevalence rate of CVI in adults. To help understand the potential numbers of adults with CVI, it is therefore, useful to be aware of the main causes of CVI in this population. On top of the children with CVI who grow up to be adults, other causes of acquired CVI in adulthood include (but are not limited to) degenerative brain disorders, traumatic brain injuries, strokes and inflammation of the brain due to infection or conditions such as multiple sclerosis (CVI Scotland, 2024a). In relation to strokes, it is estimated that there are 30 million new strokes each year worldwide, with at least 65% of these causing visual issues, including CVI, specifically visual perceptual abnormalities (Rowe

et al., 2022). Based on the numbers of adults with stroke alone, there is therefore, potentially a considerable number of adults worldwide who would benefit from O&M support for their newly acquired visual issues.

Visual perceptual abnormalities can make it difficult for the brain to make sense of visual information, which can lead to issues like difficulty with recognizing objects or people, understanding spatial relationships, visual attention issues and issues with processing moving and/or complex visual scenes (Chandna et al., 2021; Rowe et al., 2022). In terms of how these would manifest in an O&M context, affected adults may have difficulty with recognising people and places (including landmarks), struggle to judge speed of moving objects such as vehicles and to judge distance between objects, an inability (or reduced ability) to visualise routes, fluctuating ability to give visual attention to different areas of the visual field and difficulties with visually locating where sound is coming from.

Understanding the visual issues and O&M needs

While I acquired my CVI as a result of a brain haemorrhage at the age of 16, my experience is like that of an adult acquiring CVI. At 16, I was an independent traveller and had learnt all the skills I needed for this as a fully sighted child. While I was able to continue doing most of the activities I had done previously with very little adaptation, there were specific activities that I needed to learn new skills to be able to do safely and confidently. For instance, crossing a road. Unfortunately, however, at the time of the haemorrhage in 1996, the only CVI that had been diagnosed was a right hemianopia. So, when I received O&M support in the months following my time in hospital, it was centred around helping me to adapt to not seeing in my right visual field. While this did impact my mobility, the hemianopia was not the CVI that was causing the most difficulty for me when moving around different environments such as at school and in my community. My additional CVIs of simultanagnosia (the inability to see more than one or two things at a time), optic ataxia (issues with visually guided movement), hemi inattention (reduced visual attention in an area of the visual field) and difficulty processing visual and auditory information at the same time were actually more problematic from an O&M perspective. However, as these issues were not diagnosed for a further 17 years, my initial O&M support was not as effective as it could have been, because the strategies were focused solely on adaptations needed for the hemianopia. Unfortunately, many adult stroke survivors have a similar experience of this, with the support they receive not addressing their specific needs due to the symptoms they report not always pointing to their primary underlying visual problem (Rowe et al., 2022).

This highlights the importance of an accurate CVI profile as the first underlying principle of effective O&M support for adults with CVI. It is important to have a thorough understanding of the CVIs each person has and how they impact them in different environments. To help with this, a detailed CVI profile can be developed through a thorough review of medical and ophthalmic information, the completion of a CVI adult history taking inventory (for instance the Newcastle Adult CVI inventory), further assessment of functional vision and observations of the affected adult in both familiar and unfamiliar environments (McDowell, 2021). Taking the time to create this profile prior to developing the O&M programme could be the difference between effective and ineffectual support. To be able to do this, O&M practitioners, therefore, need to have a good understanding of the many different CVIs that can occur and how these can manifest in day-to-day activities.

Empowerment of the adult with CVI

Central to the CVI profile is empowerment of the affected adult through developing a collaborative partnership between them and the O&M provider, and then walking alongside them on their O&M journey. This is, in my opinion, the second underlying principle crucial to effective O&M

support. While I admit, at the age of 16, I was a reluctant receiver of O&M support, my main memory of the experience was of decisions being made for me, by others deciding what was best for me. Looking back at this experience, it felt more like a medical model approach, where an expert was imparting knowledge to me with limited opportunities for me to feedback and tailor the experience to best suit my needs. Unfortunately, this negative first experience with an O&M specialist had a lasting impact on me, similar to what parents have described in relation to their journey navigating disability services for their child. A negative first experience with a professional often meant that they are less likely to develop effective collaborative relationships with any future professional (Boshoff et al., 2018; McDowell, 2020). In contrast, when the person receiving the services is seen as being central to the process and involved in all decision making about the support, a more collaborative partnership is developed, resulting in a better outcome from the support (McDowell, 2020).

In an O&M service context, empowerment is meeting the person with CVI where they are at in their journey. Every affected adult is going to be in a completely different space or place depending on so many different factors (cause of the visual issues, overall health and wellbeing, age, living situation etc). For me, when I first received O&M support, I was grieving for my past life and desperate to try and find some sort of normality in my day. My brain haemorrhage and time in hospital had made me famous in the small rural town I grew up in and it felt like everyone was watching closely to see what I was going to do next. At a time where I was trying to hide in the shadows and not draw any more attention to myself, having an O&M practitioner parade me around the school grounds forcing me to use a mobility cane in front of all my peers was the last thing I wanted – and possibly needed.

Meeting me where I was at could have looked like the O&M practitioner introducing the concept of a mobility cane in a safe environment (such as my home) and letting me decide for myself if this was the right tool for me. If I had decided it was, my instruction could then have slowly expanded to using it in the school environment, starting by experimenting on the school grounds when no one else was there. This more gradual service provision, coupled with a clear explanation of why a mobility cane could be beneficial for me would have been a more empowering approach and would have allowed me to decide whether a mobility cane was the right option for me and if so, when and where were the best times for me to use it. Essentially, what I am advocating for here, is a more person-centred approach for developing and implementing an O&M programme for adults with CVI. This approach supports the perspective of Sauerburger (2002), who also advocates for a client centred approach in O&M for adults with vision impairment (not just those with CVI), which is centred on problem solving, allowing the client to make informed decisions on what approach would be best for them and working with them in collaborative relationship to help them achieve their goals.

Creating a CVI toolbox

The third and final underlying principle I see as being important for effective O&M support for adults with CVI is the concept of creating a CVI toolbox full of a range of strategies and tools that can be used at different times, depending on the situation and context. The concept of a CVI toolbox grew from my own personal experience of developing a rehabilitation programme for myself following the diagnosis of all my CVIs (in addition to the hemianopia) and my professional experience of implementing this approach for both children and adults with CVI. A fundamental concept of CVI that is important to understand, is that a person's vision can fluctuate, depending on both internal and external factors. Internal factors include fatigue, hunger, sickness and sensory overload. External factors relate to the environment and context and includes elements such as clutter, lighting levels and glare. This dynamic nature of CVI means that a strategy that worked in one context, may not work in another, or even in the same context on a

different day. It is, therefore, important for the affected adult to have a range of tools or strategies that they can pull out at any one time, depending on what they decide to be the most useful in that situation.

The role of the O&M practitioner is to help create this toolbox for each individual adult, by suggesting, trialling and exploring a range of different strategies in different contexts. For instance, when I am in a busy, cluttered environment, such as an airport or a shopping mall, I often use the wagon wheel visual search approach (CVI Scotland, 2024b), to allow me to build up an image of the visual scene. However, this approach is not helpful in a supermarket when trying to find a specific item on a shelf. Here, I need a more refined approach and have worked out that giving myself time and space to do this calmy and systematically is a more effective approach. Another consideration in relation to the CVI toolbox is the growing request by those with the lived experience (specifically young adults) for the opportunity to learn non-visual skills in relation to their CVI O&M needs (CVI Scotland, 2024c; McDowell, in press). While people with CVI often have useable vision (especially in an O&M context), the impact of constantly over functioning and working so hard to be able to engage with the world the same as a fully sighted person, often results in high levels of visual and overall fatigue and a significant reduction in visual abilities over the course of the day.

To help overcome this additional challenge caused by their CVI, many young adults who have CVI, have reported that they prefer to ‘switch off’ their vision and rely on their mobility cane or mobility dog when traveling independently in different environments. While some adults may find it difficult to learn how to use a mobility cane effectively, it is an option that can be explored as another tool to add to their toolbox. From my own experience, it took time to develop my CVI toolbox and I continue to add and remove tools as I experience different situations and learn more about CVI. Each new tool is carefully considered and trialled in a range of settings before I decide whether it is suitable to add to my toolbox. As an O&M practitioner, I have supported others to develop their own toolbox, essentially walking alongside them as they trial different approaches and supporting them on their journey.

Conclusion

As the numbers of adults with CVI needing O&M service provision and support continues to rise, the O&M profession as a whole will continue to evolve and further develop our collective knowledge base on how best to help this population. As we make this journey, I implore us all to keep one premise central to our practice – when it comes to CVI, there is no one size approach that fits all, there is no one gold standard O&M strategy that will work for everyone and we should not be forcing anyone into using an approach just because it worked for someone else with CVI. We can then apply the three principles of understanding the visual and O&M needs (by creating the CVI profile), empowerment through meeting them where they are at and walking alongside them on their journey to help them create their own personalised CVI toolbox.

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