The CVI Practice Framework: An Effective Approach to Supporting Children with Cerebral Visual Impairment (CVI)

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Abstract

Cerebral visual impairment (CVI) is the most common cause of visual impairment affecting children in the economically developed world, with the prediction that numbers will continue to rise with continued advancements in medical care for neonates. Despite this increase, many children are still being supported with approaches that have been developed for children with ocular visual impairments, as there are limited evidence-based approaches for supporting children with CVI. This thesis by publication therefore proposed a CVI practice framework to help meet the specific needs of children with CVI that can be used within an education or habilitation/rehabilitation context. The framework was based on the researcher's own experience of developing a successful rehabilitation programme to improve her visual and overall functioning following a late CVI diagnosis. From this programme, the researcher identified three main components that led to the improvements in her quality of life. These included the development of an individual CVI profile, an individualised programme, and empowerment through the attainment of knowledge. To ascertain whether a similar approach could be effective for children with CVI, the researcher conducted a number of different research projects to assess the effectiveness of each individual component and the overall framework. Results from the different research projects show that, firstly, the Austin Playing Card Assessment has the potential to be an effective tool to detect visual perceptual difficulties related to clutter and can be used as part of a wider assessment process to develop a child's CVI profile. Secondly, there are a number of generic strategies that can be implemented within a child's programme to support their visual, emotional and behavioural needs. Thirdly, information at the time of a child's diagnosis helps to empower parents and leads to them being more involved in the services their child receives. Finally, the CVI practice framework has the potential to be an effective approach for supporting children with CVI. Further research on the three components of the framework and the overall framework is needed to corroborate these findings.

Acknowledgments

Two roads diverged in a yellow wood,
And sorry I could not travel both
And be one traveller, long I stood
And looked down one as far as I could
To where it bent in the undergrowth;

Then took the other, as just as fair,
And having perhaps the better claim,
Because it was grassy and wanted wear;
Though as for that the passing there
Had worn them really about the same,

And both that morning equally lay
In leaves no step had trodden black.
Oh, I kept the first for another day!
Yet knowing how way leads on to way,
I doubted if I should ever come back.

I shall be telling this with a sigh
Somewhere ages and ages hence:
Two roads diverged in a wood, and I—
I took the one less travelled by,
And that has made all the difference.
Robert Frost

This is the story of a journey. A journey that started a long time ago and one that has taken me on many twists and turns. I will be forever grateful to my family and friends who have stood by my side and supported me in every possible way as I have made my way down this unexpected path.

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To Ross, you are my world. Thank you for giving me strength to continue my journey every day. To Angus and Hamish, my two wee men, this is for you. Although you may not always get to choose the path you take in life, remember that no matter what life throws at you, there is always a way forward.

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Chapter One – Introduction

Background information

Although blindness and low vision are relatively low incidence disabilities in children, being born with a vision impairment or acquiring one during childhood can have a significant negative impact on a child's development and overall quality of life (Chadha & Subramanian, 2011). To help reduce these negative impacts, early diagnosis, intervention and habilitation/rehabilitation for any visual difficulty is vital. However, in order to receive the necessary education and habilitation/rehabilitation services, children first need to be identified as having a vision impairment. This may depend on the nature of their visual difficulties and the definition of vision impairment used by medical practitioners in their home region. The International Classification of Diseases 11 (2018) classifies vision impairment into two groups, distance and near presenting vision impairment. A distance vision impairment ranges from mild low vision to blindness, and a near vision impairment is defined as visual acuity worse than N6 or M.08[1] with existing correction (World Health Organisation, 2019b). However, from an educational perspective, a more functional definition of vision impairment for children is required to ensure a focus on the use of vision in learning and in the performance of critical and

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[1] N6 or M.08 is a visual acuity figure which translates into 6/12 and indicates that what a person with normal vision can see at 12 metres, a person with low vision needs to be 6 metres to see clearly.

meaningful tasks (Dutton & Lueck, 2015; Sakki et al., 2018). Moreover, as the ability to see effectively is not solely reliant on just the eyes, a more accurate definition needs to encompass the entire system that supports and sustains the sense of vision (Dutton & Lueck, 2015). As such, a more useful definition of visual impairment in children is: "damage to the visual system that impedes the ability to learn or perform usual tasks of daily life, given a child's level of maturity and cultural environment" (Lueck, 2004, p. 3).

This more functional definition covers the wider panorama of modern childhood visual impairment, as the term visual system includes both the eyes and the brain, and damage can affect one or both of these areas (Dutton & Lueck, 2015). This definition also reflects the significant shift in the main cause of childhood vision impairment in the last 40 years. Historically, children were diagnosed with ocular visual impairments (OVIs). However, in recent times, ocular conditions are being detected early and treated effectively with positive results for the affected child (Fazzi et al., 2007). With improvements in eye related conditions, issues due to the brain component of the visual system have come more into focus. Although the term *cortical vision impairment* had been used as early as 1946 (Feigenbaum & Kornblueth, 1946), it was only in the 1980s and 90s that both *cortical* and *cerebral visual impairment* were more commonly used to describe deficits of vision in children not related to ocular pathologies (Ortibus et al., 2011b; Whiting et al., 1985). However, since then, there have been subtle differences in the terminology and definitions used to describe this disorder, which have impacted on the accurate diagnosis of this condition around the world and the support children receive (Boot et al., 2010; Hoyt & Fredrick, 1998). These differences in the definitions used to describe visual issues in children not associated with ocular pathologies has also caused ongoing debate amongst researchers, medical professionals and practitioners working in the field of supporting children with cerebral visual impairment (Martin et al., 2016). Again, this is to the detriment of children worldwide, as the failure to reach a consensus on what is meant by either cortical or cerebral visual impairment, has resulted in many children missing out on the support they need.

Initially, the term cortical visual impairment was more commonly used, especially in America and referred specifically to reduction in visual acuity associated with limited visual fields, which could not be explained by pathology in the eyes (Dutton & Lueck, 2015; Sakki et al., 2018). As such, cortical visual impairment was defined as ‘impaired vision that is due to bilateral dysfunction of the optic radiations or visual cortex’ (Roman-Lantzy & Lantzy, 2010, p. 69). However, alongside this definition there was some debate as to whether cortical visual impairment could coexist alongside ocular disorders. Although Roman-Lantzy and Lantzy (2010) outlined that cortical vision impairment can coexist with ocular and ocular motor disorders, many medical practitioners have been disinclined to confirm a diagnosis of cortical visual impairment if there are ocular issues present. This significantly impacts on the affected child, as services and support then focus solely on the ocular visual impairment and fails to address the needs of the cortical related issues, which could greatly impact the child’s visual and overall functioning.

Over time it became apparent that a broader definition of cortical visual impairment needed to be considered due to the growing awareness of the interconnectedness of the visual system throughout the cerebral cortex (Ely, 2016). This supported the view of Hyvärinen (2005), who described the term cortical vision impairment as being limiting, as it did not encompass the full extent of visual dysfunction caused by damage in areas other than the visual cortex. With the acknowledgment that perceptual visual impairments commonly accompanied impairments in basic visual functions in children with cerebral visual impairment, the term cerebral was argued to be more suited, as subcortical damage to the posterior visual pathways is a common and accepted cause of the condition (Jacobson & Dutton, 2000; Ortibus et al., 2009). Also, as outlined by Ely (2016), the term cerebral visual impairment is generally accepted to include cortical visual impairment in addition to brain-related dysfunction of the visual system beyond the occipital cortex.

In more recent times, there has been a growing awareness that visual perceptual difficulties could also exist in children with normal or near normal visual acuities due to dysfunction in the temporal, parietal and frontal lobes of the brain, and also, that these issues were just as debilitating as issues with the basic visual functions (Ely, 2016). However, research into this area of visual difficulties is very much in its infancy, despite the fact that these kinds of visual perceptual difficulties were recognised in the early 1900s (Bálint, 1909) and again in soldiers injured during World War One (Holmes, 1918a, 1918b). Alongside the increase in research focusing on the visual difficulties associated with cerebral visual impairment, there has also been calls for a consensus on the definition of this complex condition (Dutton & Bax, 2010; Ely, 2016; Frebel, 2006). In light of this, following a systematic review of the literature, Sakki et al. (2018) have proposed the following definition of childhood cerebral visual impairment:

> *Childhood cerebral visual impairment is a verifiable visual dysfunction which cannot be attributed to disorders of the anterior visual pathways of any potentially co-occurring ocular impairment. (p. 430)*

The researcher believes that this is a positive step for the field, as it will result in more children around the world being accurately identified as having visual difficulties associated with cerebral visual impairment, leading to more consistent diagnosis of this condition. Therefore, this definition will be used throughout the thesis. Also, the use of the acronym CVI will indicate cerebral visual impairment.

The rationale for this research

A sharp increase in the numbers of children being accurately diagnosed with CVI around the world creates a pressing issue for the field. Although it has long been recognised that CVI is the most common cause of visual impairment affecting children in the economically developed world (Kong et al., 2012; Philip & Dutton, 2014), there is currently only a few evidence-based interventions for supporting children with this condition (Sakki et al., 2018). For this reason, many children with CVI are being supported with strategies that have been developed for children with OVI. This is despite the growing awareness that many of these approaches are not effective in the case of CVI and in some instances, could actually be detrimental (Martin et al., 2016). For example, while a child with an OVI may require written material to be enlarged; a child with CVI may find reading enlarged text more challenging due to the complexity and overlap of their diverse visual needs. Therefore, in order to best support children with CVI, further research needs to be undertaken to develop best practice approaches for assessment and interventions to improve visual and overall functioning, and also, quality of life. However, to further advance the field, this research must be undertaken with the principal aim of improving the understanding of a child's visual needs and limitations and helping to establish appropriate management strategies in a timely manner for each individual child affected by CVI (Sakki et al., 2018).

Purpose of the study

Following the diagnosis of CVI seventeen years after acquiring the condition as a teenager, the researcher set out to improve her functioning and overall quality of life by developing a deep understanding of this complex condition and how it impacted her on a daily basis. Although this process took a number of years, throughout this journey it was clear that there were three important components that aided the researcher on this journey and helped her to achieve her ultimate aim of improving her visual and overall functioning. The first component was developing a CVI profile of the specific visual difficulties she experienced. As outlined by Dutton and Bauer (2019), CVI has many possible variables, giving every affected person their own unique pattern of visual experiences, limitations and resulting behaviours. In order to help a person with CVI, therefore, this unique CVI pattern must be identified and understood. For the researcher, this meant, firstly, understanding CVI in general and then identifying and understanding her own specific CVI issues.

Once the researcher's unique CVI pattern had been identified and her CVI profile developed, the specific strategies she would need to help alleviate some of the challenges she faced became clear. This led to the second component: the development of an individualised rehabilitation programme to help improve daily functioning. This individualised plan included a range of strategies that were either introduced to the researcher or that she developed herself and were trialled over a period of time. The third important component that helped the researcher to achieve her aim and improve her functioning, was being empowered along this journey through the attainment of CVI specific knowledge and consequential understanding of her own disability.

From this personal journey and from her professional experience as an education and rehabilitation specialist supporting children who are blind or low vision, including those with CVI, the researcher strongly believes that a similar approach could be used for the children she supported. As such, the purpose of this study was to establish whether the three main components that lead to the researcher successfully improving her overall quality of life could be developed as an education/rehabilitation practice framework for supporting children with CVI. For children, the three components are:

- Individual CVI profiles that include information on a child's visual, emotional and behavioural responses related to CVI.
- Individualised habilitation/rehabilitation plans that are based on the child's unique CVI profile.
- Empowerment of the child and their family through education about CVI, to enable them to take a central role in their habilitation/rehabilitation programmes.

Research aim

This thesis by publication aims to present an effective framework for supporting children with cerebral visual impairment that incorporates working with the family to develop individual CVI profiles and individualised programmes that addresses both the visual issues associated with CVI and the resulting impact on a child's emotional and behavioural responses.

Research questions

1. What profiling and intervention strategies to improve visual and overall functioning can be extrapolated from the researcher's own experience? (Chapters 3 and 4).
2. What role does the attainment of knowledge play in empowering a person with CVI? (Chapters 3 and 4).

3. What role does the Austin Playing Card Assessment play in identifying visual, emotional and behavioural responses associated with CVI? (Chapter 5).
4. What are effective strategies for alleviating the impact of the visual difficulties and the resulting emotional and behavioural responses that are associated with CVI? (Chapter 6).
5. What role does the attainment of knowledge in relation to CVI play in helping to empower parents to be more involved in the services their child receives? (Chapter 7).
6. What is an effective framework for supporting children with CVI? (Chapter 6).

Research framework

Up until now, research on CVI has been conducted by medical professionals, scientists, vision educators and therapists with an interest in this complex visual condition. Their main focus has been on better understanding CVI, establishing effective ways to assess and diagnose the visual difficulties associated with CVI, and developing best practice education and rehabilitation approaches for children and adults living with this condition. Therefore, the information that is currently in the international literature is based on knowledge developed by people with normal vision, examining people who may not actually be able to effectively articulate what the world looks like when a person has CVI. As such, CVI is being understood by those from the outside looking in, trying to understand the complexities of the visual system and what happens when it goes wrong. However, in order to gain an accurate understanding of what it is like to live with CVI on a daily basis and how best to help children with this condition, research also needs to focus on looking from the inside out, by listening to those that know first-hand what it is like to live with this condition. This view is supported by Siu (2019), who outlines that research activities that ultimately impact blind or visually impaired people must begin and end with individuals who are blind or visually impaired.

With this in mind, the overall research framework (shown in Table 1) was developed to allow for the personal experience of the researcher to be explored and considered in relation to the many different voices involved in understanding and supporting children with CVI. As such, the research framework had to allow for the researcher to listen to and speak to these different voices in order to develop a best practice approach that could be applied in different settings around the world for children with CVI. An overall epistemology of pragmatism was therefore chosen for the research, as it allowed for a bottom up approach to research that focused on solving a real problem. Pragmatism is described by Creswell and Plano Clark (2011) as orientating itself towards solving practical problems in the real world. This approach supported the researcher's perspective that knowledge is always based on experience, that one's perceptions of the world are influenced by our social experiences, and that each person's knowledge is unique, as it is created by his or her unique experiences (Kaushik & Walsh, 2019).

Table 1. Research framework

	Selected	**Rationale**
Epistemology	Pragmatism	Allowed for the focus to be on the problem to be researched and the consequences of the research. Bottom up approach. Started with the data and used this to build the theory.
Theoretical perspective	Dialectical pluralism	Allowed for the researcher to listen carefully and thoughtfully to multiple perspectives.
Methodology	Qualitatively driven mixed methods	Allowed the researcher to investigate multiple research problems and questions and produce multiple kinds of data, resulting in a fuller set of knowledge.
Methods	Screening questionnaire Experimental research Semi structured interviews Focus groups Observations Online questionnaire (open and closed questions)	The range of research methods used allowed the researcher to develop a deeper understanding of the impact of CVI from the many different perspectives.
Practice framework	A set of principles of approach to guide practitioners	An approach was developed that was not a recipe book, but an approach which is flexible enough to meet the unique needs of each individual child.

Pragmatism also allowed for the use of different methodological approaches throughout the thesis to ensure that individual voices were heard. As outlined by Kaushik and Walsh (2019), pragmatism is based on the proposition that research should use the philosophical and/or methodological approach that works best for the particular research problem that is being investigated. Pragmatism also aligned with the theoretical perspective of dialectical pluralism. Dialectical pluralism can be described as a process of carefully, systematically, and thoughtfully listening, understanding, appreciating, and learning from multiple disciplines, values, methodologies, standpoints and perspectives to try and come together in order to help all stakeholders (Johnson, 2017). In terms of the research being undertaken for this thesis, it was important that the overall theoretical perspective provided a voice for those with CVI and to ensure that their voices were being heard in relation to furthering the knowledge and understanding in this field (Rawls, 2001). As such, dialectical pluralism fits well as the preferred theoretical approach for this research, as it advocates for a holistic approach to research and therefore aligns well with the concept of researching into the area of disability by interacting with those whose lives are impacted by disability (Leavy et al., 2014).

Dialectical pluralism also recognises that there are potentially different perspectives in research and allows for learning to occur from different and even contradictory ideas (Leavy et al., 2014). In terms of this research, CVI is a very complex condition and there were a number of different perspectives that need to be considered, including the difference between various medical and rehabilitation practitioners' approaches to understanding and supporting CVI. This exploration was justified in terms of dialectical pluralism, as it is important that multiple perspectives are concurrently and equally valued throughout the research process (Johnson, 2016). This is supported by Greene (2007), who outlines that dialectical pluralism emphasises the importance of different people with different mental models contributing ideas to research. Using a dialectical pluralist approach, therefore, helped to produce collaborative knowledge that represents multiple perspectives in relation to CVI (Johnson, 2016).

Due to the range of research projects that were undertaken for this doctoral thesis by publication and to ensure the voices of those affected by CVI were heard, a qualitatively driven mixed methods approach was chosen as the preferred overall methodological framework (Onwuegbuzie & Johnson, 2006). This approach is described as the core of the research being undertaken using qualitatively driven epistemology and methodology, with the quantitative approach and method taking on a secondary role in the mixed methods design (Hesse-Biber et al., 2015). In order to foster a more accurate description of views held within the field, a qualitatively driven approach was chosen to ensure that the researcher was able to obtain a clear and genuine expression of beliefs and values that emerged through dialogue with the research participants (Howe, 2004). For many of the research projects however, it was also important to have the option of using quantitative data, as this helped to provide different types of information which broadened the qualitative findings and helped to gain insight into how the multiple layers of CVI impacts on a child's life (Hesse-Biber et al., 2015). A qualitatively driven mixed methods approach also fits well within a pragmatist and dialectical pluralist research framework, as mixed methods research requires that the researcher thoughtfully addresses competing values, methods, methodologies, ontologies, and epistemologies (Johnson, 2016). This is supported by Leavy et al. (2014), who outline that dialectic pluralism is helpful for interactive mixed methods research because it is not set in a single paradigm. The different methods used for the different research projects (as shown in Table 1) are further outlined in the thesis structure section of this chapter.

By following this research framework throughout the research process, the researcher was able to develop an overall practice framework for supporting children with CVI that could be used within an education and/or rehabilitation context. In the literature, a practice framework is defined as a conceptual map that brings together, in an accessible design, an agency or organisation's approach to practice for working with a group of people, i.e. children and families (Connolly, 2007). However, for the purpose of this thesis, the term 'practice framework' was used to describe a set of principles of practice, which are flexible enough and can be tailored to meet the needs of each individual child with CVI. The CVI practice framework, therefore, is an approach that can help guide education and rehabilitation practitioners when supporting a child with CVI.

Researcher reflexivity

An important element of the research undertaken in this thesis by publication, was how the researcher was situated within the research and how this influenced different aspects of the research process. As a person with CVI, the researcher was conscious of her preconceptions and assumptions in relation to the research and how these might affect her research decisions. The concept of the CVI practice framework was developed from the researcher's own experiences, with the researcher essentially drawing on her own insights to form the basis of a more generalised understanding and interpretation in relation to supporting children with the same condition (Finlay, 2002). However, in order to ensure that this examination of the researcher's own experience was useful in helping to provide more generalised insights, a process of researcher reflexivity was required. Reflexivity refers to the examination of one's own beliefs, judgments and practices during the research process and how these may have influenced the research (University of Warwick, 2017). Researcher reflexivity requires the researcher to draw attention to themselves as opposed to 'brushing their experience under the carpet' and pretending that they did not have an impact on the research (University of Warwick, 2017). By being upfront and clear about her own personal experiences and how these helped to develop the concept of the CVI practice framework, the researcher believes she has shown an acceptance that she is part of the research in every stage of the research process (Finlay, 2016).

However, the researcher also recognised that this high level of researcher reflexivity throughout the research process, in a sense, created a challenge in terms of the research being acknowledged and respected by the many different stakeholders involved in the field of supporting children with CVI. As outlined by Finlay (2016), reflexivity should not be seen as an opportunity to wallow in subjectivity nor as permission to engage in legitimate emoting. The researcher, therefore, needs to move beyond 'benign introspection' to more clearly show the links between knowledge claims, the personal experiences of both the researcher and the participants, and the social context (Finlay, 2002; Woolgar, 1989). In order to do this, and to limit any researcher bias, the researcher regularly engaged and consulted with the main stakeholders involved in supporting children with CVI. This included people with CVI, parents of children with CVI, education and therapy specialists, and medical practitioners involved in diagnosing CVI (ophthalmologists and neuropsychologists). All research decisions around design and process and all interpretations of research data were run past one or more of these stakeholders at every stage of the research process. As such, the researcher believes that she was able to use researcher reflexivity within this thesis by publication to ensure that her personal experience was used to help create a more balanced approach for supporting children with CVI.

Thesis structure

The thesis has eight chapters, six of which have been published or, at the time of thesis submission, are in the process of being published in line with a thesis by publication requirements (see Table 2). Although each chapter focuses on a different element relating to the overall topic, they are all linked together by the common aim of developing an effective practice framework for supporting children with CVI. The proposed framework has three main components: individual CVI profiles, supporting a child with CVI through individual programmes, and empowerment of the child with CVI and their family. Each chapter within the thesis relates to one or all of these components, drawing all the components together in order to outline the CVI practice framework in the concluding chapter[2].

Table 2. Outline of publication status for chapters/articles

Chapter/Article	Research question	Publishing status	Date of publication
1. Introduction	N/A	Not for publication	
2. Literature Review	N/A	In press for a special edition in the *International Journal of Inclusive Education*	April 2020
3. Personal Case Study	1, 2	Published in *Case Reports in Ophthalmological Medicine*	March 2019
4. Personal Perspective on CVI	1, 2	Published as a chapter in the *Routledge Handbook of Visual Impairment*	March 2019
5. The Austin Playing Card Assessment	3	Published in the *British Journal of Visual Impairment*	January 2020
6. Case Studies	4, 6	Under review with *Disability Studies Quarterly*	March 2020
7. Parent Survey	5	Published in *Disability and Society*	April 2020
8. Conclusion	N/A	Not for publication	

Chapter 1: Introduction

This chapter summarises the guiding research problem and the context of the problem. This leads onto the main research aim, six research questions and a description of the overall research philosophy and methodology. The chapter concludes with an outline of the thesis structure and summary of each chapter.

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[2] The order in which each research project was conducted in terms of the overall thesis has been outlined in a table in Appendix A.

Chapter 2: Literature Review

The literature review outlines the current international context for supporting children with CVI and highlights current initiatives and tensions in the field. The review also outlines the proposed practice framework with strong links to relevant literature to support the proposal.

Journal for publication. The literature review has been accepted for a special edition of the International Journal of Inclusive Education, which is a Q1 ranking journal with an impact factor of 1.053 (2018). This journal publishes multi-disciplinary research on topics related to inclusive education from around the world. The special edition will showcase contemporary ideas around equity, inclusion, inclusive practices, and strategies or policies. As such, it was deemed suitable for this literature review, which outlines a practice framework of inclusion for children with CVI.

Chapter 3: Personal Case Study

This chapter is a published paper that catalogues the personal CVI journey the researcher has been on in order to improve her visual and overall functioning following the diagnosis of this condition in 2013. The paper provides relevant information related to the CVI practice framework for supporting children with CVI proposed by the researcher.

Journal for publication. This article was published in Case Reports in Ophthalmological Medicine, which is an open access journal that publishes case reports and case series related to the anatomy, physiology and diseases of the eye. This was deemed suitable for this article, which was co-authored with a paediatric ophthalmologist and involved the description of specific medical procedures and definitions (around 10% of the article was written by the paediatric ophthalmologist as the second author). The case study format also allowed for a systematic description of the journey the researcher has been on, providing a good platform to share strategies that had been used to improve visual functioning that were to be trialled with children as part of the doctoral research.

Chapter 4: Personal Perspective on CVI

In this chapter, the researcher describes what it is like to live with CVI and how it impacts her on a daily basis. The chapter also uses the researcher's own personal experience to identify the three main components of the proposed CVI practice framework for supporting children with CVI.

Book for publication. The researcher was invited to write a chapter for the Routledge Handbook of Vision Impairment on her personal perspective of living with CVI.

Chapter 5: The Austin Playing Card Assessment

The first component of the proposed practice framework is individual CVI profiles in which each child's specific visual difficulties are identified and understood in terms of how they impact the child on a daily basis. The Austin Playing Card Assessment was developed as an assessment tool to detect visual perceptual difficulties, that could be used as part of a wider assessment process to develop this profile. This chapter, which is a published paper on research undertaken to assess the effectiveness of the Austin Playing Card Assessment, reports on the success of the pilot study and outlines the potential uses of the assessment tool. The methods used for this research included a screening questionnaire, experimental research, and observations.

Journal for publication. This article was published in the British Journal of Visual Impairment, which is a Q3 ranking journal with an H index of 17. The rationale for choosing this journal is that because of the specialised content of the article, it needed to be in a specific vision journal to ensure a relevant readership who were familiar with the complex nature of CVI. It also needed to be in a journal that had previously published material focused on cerebral visual impairment and the definition of this condition used within the article.

Chapter 6: Case Studies

The second component of the proposed framework is individualised programmes that support the visual, emotional and behavioural needs of children with CVI. This chapter reports on case study research that was undertaken to assess the effectiveness of different strategies implemented within the home, school and community environments of three children all with CVI and a range of cognitive abilities. Although this chapter focuses solely on the effectiveness of the strategies implemented, each case study also followed the overall practice framework developed within this doctoral research for supporting children with CVI. The methods used for this research included semi structured interviews, focus groups, and observations.

Journal for publication. This article was submitted to Disability Studies Quarterly (DSQ), which is a multidisciplinary journal concerned with the issues of people with disabilities. The rationale for choosing this journal was around its open access and its focus on disability and promoting the full and equal participation of persons with disabilities in society. This article is aimed at practitioners working in the field and provides practical strategies that could benefit children with CVI. As such, the article needs to be easily accessible by people working in the field of supporting children with CVI once published.

Chapter 7: Parent Survey

The third component of the proposed framework is empowering children with CVI and their families through the attainment of CVI knowledge. This article reports on the role information plays in empowering parents of children with CVI to be more involved with the services their children receive. The method used for this research comprised an online survey with both open and closed questions.

Journal for publication. This article has been published in Disability and Society following an extensive peer review process. Disability and Society is a Q2 ranking journal with an impact factor of 1.613 (2018). The rationale for choosing this journal was because of its focus on the importance of the voices of disabled people. This article argues the need to empower parents of children with CVI by providing better information on the condition when their child is first diagnosed.

Chapter 8: Conclusion

The concluding chapter addresses the six main research questions and provides a summary of the main findings from the different research projects undertaken, as well as the two personal reflection chapters. These summaries provide evidence in support of the overall thesis aim. The conclusion chapter also includes recommendations for the field that have come out of the research, limitations of the research and suggestions for further research.

Conclusion

The present study is significant in its approach and its contribution to the current body of knowledge. Using personal experience to guide the development of a framework for supporting children with CVI ensures that this complex condition is understood from lived experience. It also provides a unique perspective of what is needed to ensure that children with this condition have every opportunity to thrive. As such, the CVI practice framework developed throughout this thesis offers a way forward for professionals working in the field that has the potential to significantly change the lives of the many children with CVI and their families.

Chapter Two – Literature Review

Chapter introduction

This literature review relates to the overall research aim of developing an effective framework for supporting children with CVI. It also provides a foundation of literature for all the following articles, as well as the thesis overall. As such, the review firstly provides a background on visual impairment in children. The review then links to relevant literature to support the need for a framework for the growing number of children with CVI. Lastly, the review outlines the proposed CVI practice framework and the three main components of individual CVI profiles, individualised plans, and empowerment of the child and family. The literature review was submitted for consideration in a special edition of the International Journal of Inclusive Education, which is focused on showcasing contemporary ideas around equity, inclusion, inclusive practices, and strategies or policies. The special edition also provides an insight into cultural perspectives, and diversity of contexts.

McDowell, N. (in press). A review of the literature to inform the development of an effective framework for supporting children with cerebral visual impairment (CVI). ***International Journal of Inclusive Education*****.**

Abstract

Cerebral visual impairment (CVI) is now the most common cause of visual impairment affecting children in the developed world. Due to the increased survival rates of preterm infants and other early insult brain conditions, such as cerebral palsy, hydrocephalus and periventricular white matter injury, the numbers of children with CVI will also continue to rise. As such, focus needs to turn to developing effective approaches for supporting the growing number of children with this condition. Currently, many children with CVI are being supported using approaches and strategies that have been developed for children with ocular visual impairments (OVI). This is despite current evidence suggesting that many of these strategies may not be effective for children with CVI and in fact, in some situations, may actually be detrimental for them. This detailed review of relevant medical/scientific, educational and rehabilitation literature outlines a potential practical framework that could be implemented to help support each individual child with CVI. The proposed CVI practice framework has three main components, including: individual CVI profiles that details the child's visual, emotional and behavioural needs; individualised habilitation/rehabilitation programmes based on the child's individual CVI profile; and empowerment of the child with CVI and their family.

Keywords

Cerebral Visual Impairment, Practice Framework, Empowerment

Introduction

Although effective education and habilitation/rehabilitation practices for children who are blind or have low vision are well established internationally, the majority of these practices have been informed by research focused on those with ocular impairments (OVI) (Gorrie et al., 2019). However, given that cerebral visual impairment (CVI) has now overtaken ocular pathologies to become the most common form of visual impairment affecting children in the developed world (Fazzi et al., 2007; Macintyre-Beon et al., 2013), focus needs to expand to ensuring the diverse needs of children with CVI are being met. Although there is a current international research focus on understanding and supporting children with CVI more effectively, many children with CVI are still being supported with strategies that have been designed for individuals with OVI (Martin et al., 2016). This is despite current evidence that many of these approaches are not effective in the case of CVI and in some instances, could actually be detrimental (Martin et al., 2016). This highlights the pressing need in the field, for a practice framework focused on supporting the specific visual, emotional and behavioural needs of children with CVI and their families. This literature review therefore, begins by considering the complex nature of this condition in order to better understand the main requirements of such a framework. The review also explores the main components that would be necessary to make such a framework effective for all children with CVI[3].

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[3] This review has informed a larger research study that has focused on developing an effective framework for supporting children with CVI.

Background

It is well documented that visual impairment has a considerable impact on the lives of not only the affected individuals, but also on their families (Atowa et al., 2019; Kong et al., 2012; Ravenscroft et al., 2008). For children that are either born with a visual impairment or develop it shortly after birth, the impact can be even more significant. As early visual experiences help to build the infrastructure for later learning, the role visual function plays in the early years in terms of development is crucial (Fazzi et al., 2004; Ortibus et al., 2011b). When a child's early experiences are limited by reduced visual functioning, this can cause substantial constraints on later development in areas such as integration of input from other senses, motor competence, language and cognitive concepts (Sonksen & Dale, 2002). Long term, this can have a negative impact on a child's academic outcomes, future career choices, social interactions and development of a fulfilling social life (Atowa et al., 2019; Ravenscroft et al., 2008). To help reduce these negative impacts, early diagnosis, intervention and habilitation/rehabilitation for any visual difficulty is vital.

Childhood vision impairment

Although it is difficult to calculate the prevalence of childhood vision impairment and blindness worldwide, the World Health Organisation (WHO) estimates the rates of blindness to range from 1.2 per 1,000 children in low-income countries, through to 0.2 per 1,000 in high income regions (Keeffe, 2019). For the numbers of children with low vision, the WHO estimates the prevalence is three times the rate of blindness (Keeffe, 2019), although the incidence and cause of childhood vision impairment and blindness differ considerably between developed and developing countries. Overall there has been a significant shift in the main causes of these impairments in the last forty years.

Previously, the main cause of visual impairment for children was ocular pathologies, such as congenital cataracts and retinopathy of prematurity (Fazzi et al., 2007). In more recent times, these ocular conditions are detected early and treated effectively, due to improvements in postnatal healthcare, especially in developed countries (Gorrie et al., 2019). However, this improvement of postnatal healthcare has also seen the emergence of a significant visual condition known as cerebral visual impairment (CVI) (Chong & Dai, 2014). CVI is caused by damage to some parts of the visual brain (the totality of brain elements that serve or support vision), (Dutton, 2015b) and can be defined as 'a verifiable visual dysfunction which cannot be attributed to disorders of the anterior visual pathways or any potentially co-occurring ocular impairment' (Sakki et al., 2018). CVI can occur at any time from pre-birth through to adulthood, however, one of the main causes of CVI is prematurity (Jacobson et al., 2006). Other common causes include; lack of oxygen and low blood sugar at birth, closed head injury, damage to specific brain locations, epilepsy, metabolic disorders and infections of the central nervous system (Dutton, 2015c, 2015e; Macintyre-Beon et al., 2013; Soul & Matsuba, 2010). The resulting change in the panorama of childhood visual impairment has meant that CVI has become the most common cause of visual impairment affecting children in the developed world (Fazzi et al., 2007; Macintyre-Beon et al., 2013).

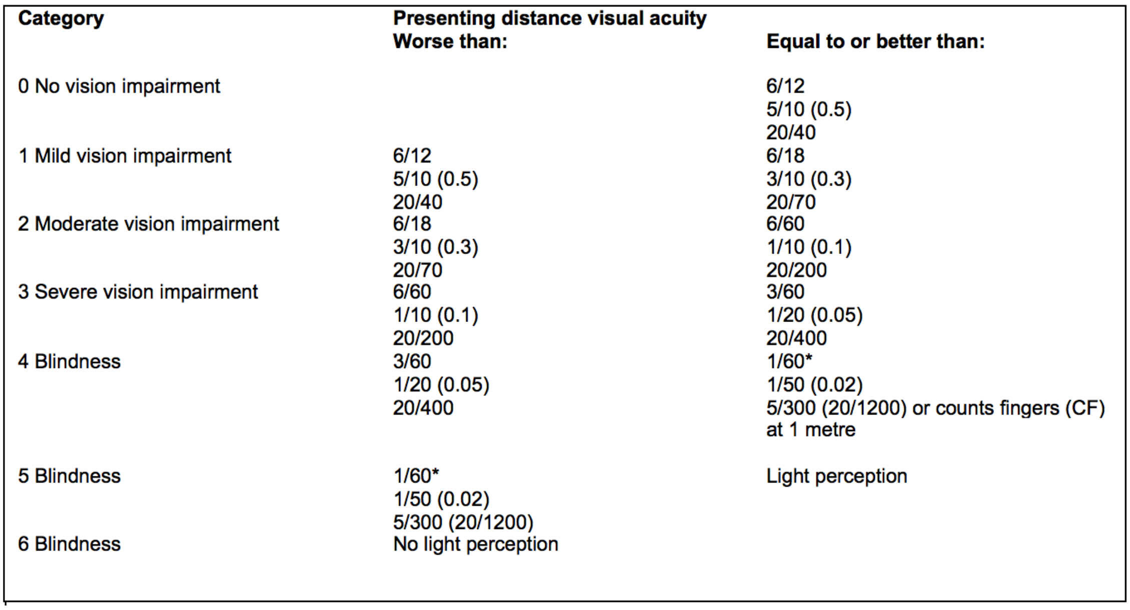
It is predicted that the incidence of CVI will continue to increase due to the advancement in medical care for many of the conditions that are associated with CVI (Good et al., 1994). Recent figures indicate that around 15 million babies annually are born premature worldwide, with children born extremely premature (between 26 and 32 weeks) having a high risk of experiencing neurological damage (Kooiker et al., 2019). Researchers estimate that as many as 86% of infants born before 32 weeks will be affected by cerebral visual dysfunctions (Jacobson et al., 2006). Given that there has been an increase in survival rates of infants born before 26 weeks in the last forty years, going from 25% to 73%, potentially there could continue to be a significant rise in the number of children presenting with CVI related visual difficulties (Ortibus et al., 2011b). The incidence of CVI in other early insult brain conditions, such as cerebral palsy, hydrocephalus and periventricular white matter injury (PVL) is approximately 33% to 58% (Andersson et al., 2006; Ego et al., 2015; Fazzi et al., 2007; Houliston et al., 1999; Stiers et al., 2002). Despite this awareness of the prevalence of CVI in certain conditions, it is currently very difficult to get exact figures for the numbers of children with CVI worldwide.

Prevalence of CVI

Although many countries are attempting to get a clearer picture of the incidence of this condition, many of these studies are limited by the criteria used to define CVI or the population on which the study was conducted (Chong & Dai, 2014; Kong et al., 2012). For instance, Chong and Dai (2014) state that CVI is responsible for approximately 30% of documented childhood visual impairment in New Zealand. However, they also quantify this by recognising that due to the strict acuity criteria used for diagnosing CVI in their study, the true prevalence of CVI in New Zealand may actually be much higher than suggested in their findings. The incidence of CVI in the United Kingdom has been reported to be much higher, partially due to less restrictive acuity criteria, with 48% of childhood visual impairment being caused by CVI in 2007 (Rahi, 2007). However, this number could have increased further, with recent figures of 57% of childhood visual impairment in Scotland being brain related (J. Ravenscroft, personal communication, August 13, 2019). The figure provided for the prevalence of CVI in the United States was much lower, at only 18%. However, this percentage was taken from a study that focused on schools for the blind and did not allow for the fact that many children with CVI do not attend these schools, especially those with CVI and multiple disabilities (Kong et al., 2012).

The figures on the prevalence of CVI stated above may also be inaccurate due to the current definitions of vision impairment and blindness. The latest International Classification of Disease (ICD-11), classifies mild vision impairment as having an acuity of between 6/12 and 6/18 and severe low vision being worse than 6/60 and equal to or better than 3/60 (as shown in Table 3) (World Health Organisation, 2019b). However, these definitions are potentially failing to recognise the full range of visual difficulties associated with CVI and forcing the diagnosis of vision impairment to be based on the singular criterion of visual acuity, which does not characterise the true overall functioning of the child (Martin et al., 2016). CVI can result in an extensive range of impairments, including: decreased visual acuity (ranging from no impairment to profound blindness), reduced contrast sensitivity, visual field deficits, eye movement disorders and difficulties in image processing or interpretation (visual perceptual difficulties) (Ortibus et al., 2011b; Williams et al., 2011). As such, CVI is a descriptor for a wide spectrum of visual disorders, with those severely affected appearing functionally blind with limited useable vision. Whereas, at the other end of the spectrum, individuals can have near-normal or normal visual acuity, but be greatly affected by higher functioning visual difficulties (often referred to as visual perceptual difficulties) (Fazzi et al., 2009). When children with visual perceptual difficulties are included in the prevalence statistics, the prevalence is significantly higher than previous studies have indicated. The most recent research from the UK looking at the prevalence of unrecognised CVI in children in mainstream schools, estimates the proportion to be as high as 3.8% of the population (Williams et al., 2019). Further analysis of the data from this study has also shown that 1 in 7 children identified as having an educational learning needs, has CVI. With figures out of New Zealand of 1 in 5 school-aged children needing extra support for their learning (Ministry of Education, 2019), and a likelihood of 1 in 7 of them having CVI (Williams et al., 2019), it is possible to surmise that the proportion of children with CVI in developed countries is significantly higher than that currently being recognised.

Table 3. ICD-11 Definitions of vision impairment and blindness (World Health Organisation, 2019b)



Category	**Presenting distance visual acuity** **Worse than:**	**Equal to or better than:**
0 No vision impairment		6/12 5/10 (0.5) 20/40
1 Mild vision impairment	6/12 5/10 (0.5) 20/40	6/18 3/10 (0.3) 20/70
2 Moderate vision impairment	6/18 3/10 (0.3) 20/70	6/60 1/10 (0.1) 20/200
3 Severe vision impairment	6/60 1/10 (0.1) 20/200	3/60 1/20 (0.05) 20/400
4 Blindness	3/60 1/20 (0.05) 20/400	1/60* 1/50 (0.02) 5/300 (20/1200) or counts fingers (CF) at 1 metre
5 Blindness	1/60* 1/50 (0.02) 5/300 (20/1200)	Light perception
6 Blindness	No light perception	

Visual difficulties associated with CVI

Historically, children with brain related visual difficulties have received a general diagnosis of CVI. However, as the term CVI is used to describe a myriad of different visual impairments, it is being recognised more and more that CVI should be referred to as an umbrella term (Goodale, 2013; Martin et al., 2016; Ortibus et al., 2011b). With over 40% of the brain being involved in processing and supporting vision, damage or injury to the brain can impair vision in a variety of ways (Lueck & Dutton, 2015). When identifying what specific visual difficulties a child has, it is important to understand the two main areas of visual functioning that need to be assessed; the basic visual functions and the higher, or perceptual visual functions. The basic visual functions include visual acuity, contrast sensitivity and oculomotor control. Difficulties in these areas could be either a result of changes in the anterior parts of the visual pathways, which often masks the brain damage-related vision impairment, or as a result of injury in some part of the primary visual cortex (Hyvärinen et al., 2012) or middle temporal lobes responsible for detecting and quantifying movement (Dutton, 2015c). Disorders of refraction and impaired focusing (accommodation), which affect the ability to see near information clearly, are also common in children with CVI and need to be diagnosed and managed appropriately (Philip & Dutton, 2014). This includes establishing whether the wearing of spectacles will aid their overall visual functioning (Hyvärinen, 2009).

The ability to see a wide area or field of vision is another basic visual function, which is often impaired in children with CVI. A visual field deficit occurs when there is damage to some parts of the pathway from the eyes to the occipital lobes at the back of the head, in what is known as the primary visual cortex (Dutton, 2015b). The area of visual field deficit experienced depends on the parts of the pathway that are damaged or dysfunctional. However, the most common form of visual field deficit for children with CVI, especially children who have been born prematurely, is a lower visual field deficit, which is commonly caused by periventricular white matter injury such as that due to periventricularleukomalacia (PVL) (Jacobson & Dutton, 2000; Jacobson et al., 2006), hydrocephalus or stroke (Dutton et al., 2004). Other forms of visual field deficit are shown in Figure 1. Issues with the basic visual functions are easily detected within a clinical setting and are, therefore, part of any routine ophthalmic assessment (van Genderen et al., 2012).

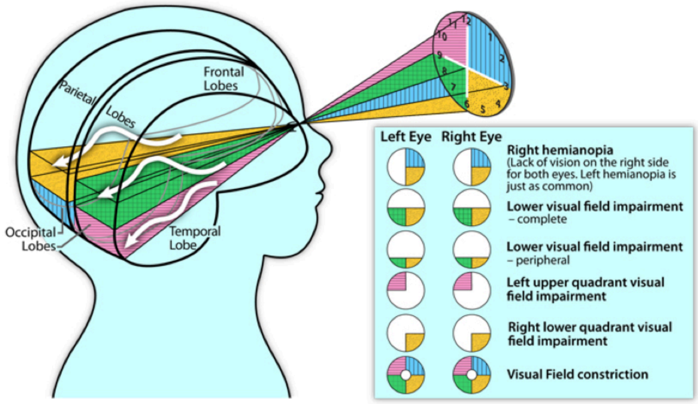


Figure 1. *Visual field deficits due to damage to the brain*
From Lueck and Dutton (2015). Vision and the Brain: Understanding cerebral visual impairment in children. Copyright: 2019 by Gordon Dutton[4]*.*

The second area of visual functioning associated with CVI comprises the higher visual processes associated with the visual pathways mediated by the dorsal and ventral streams of visual processing (shown in Figure 2). The dorsal stream runs from the occipital lobe to the posterior parietal cortex at the top of the cerebral hemispheres and is often referred to as the “vision for action” or the “where” pathway (Dutton, 2015b; Goodale & Milner, 2013). When there is bilateral injury to the posterior parietal lobes, it causes dorsal stream dysfunction. Common visual difficulties associated with this dysfunction include; simultanagnosia (an inability to see more than a few objects at a time), optic ataxia (impaired visual guidance of movement), and apraxia of gaze (the inability or difficulty with moving the eyes from one visual target to another) (Dutton, 2015e; Goodale, 2013; Pawletko et al., 2015). The ventral stream of visual processing, runs from the occipital lobe to the bottom and sides of the cerebral hemispheres in the inferior temporal region and is often referred to as “vision for perception” or the “what” pathway (Dutton, 2015b; Goodale & Milner, 2013). When there is a bilateral injury in this area, the associated

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visual issues include; an inability to recognise text, objects and familiar people, difficulty with negotiating complex environments and difficulty with recognising faces and reading facial expressions (Hyvärinen et al., 2012; Pawletko et al., 2015; Philip & Dutton, 2014). Currently, many of the visual difficulties associated with either a dorsal or ventral stream dysfunction are not routinely assessed in most paediatric eye clinics, resulting in many children going undiagnosed and experiencing many challenges in their daily activities (Williams et al., 2011).

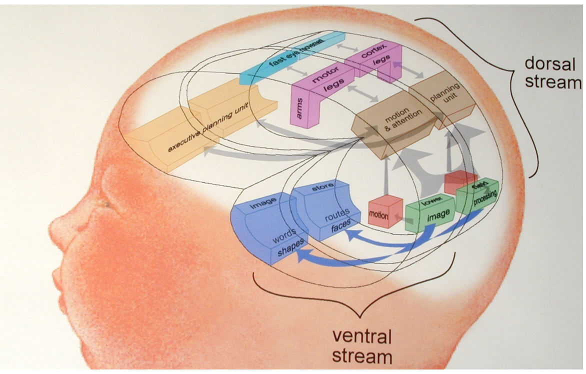

Figure 2. *Dorsal and ventral visual pathways*
From Lueck and Dutton (2015). Vision and the Brain: Understanding cerebral visual impairment in children. Copyright: 2019 by Gordon Dutton[5].

Impact of CVI

In general, the behavioural responses associated with the difficulties of the basic visual functions are often clearly visible and well understood in terms of habilitation/rehabilitation requirements. For instance; prescribing appropriate spectacles to cater for both refractive errors and lack of accommodation, providing good clear outlines and increasing font size on teaching material, establishing optimal luminance level and introducing magnification devices (Buultjens et al., 2010). For this reason, the

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impact of their visual difficulties can be greatly reduced, as long as a child has an effective support team around them. However, the visual difficulties associated with a dorsal or ventral stream dysfunction can be more problematic, especially when they have not been correctly diagnosed. The three main areas that a dorsal stream dysfunction impacts on are a child's ability to access information, their mobility and navigation in familiar and unfamiliar environments, and their social interactions (Hyvärinen et al., 2012). However, what makes a dorsal stream dysfunction more complicated, is that it affects unconscious visual functions, which means that the affected child and those around them, do not understand that the difficulties they are experiencing are actually related to their vision (Dutton, 2015b; Goodale & Milner, 2013). For this reason, a dorsal stream dysfunction and the visual difficulties associated with it, can lead to the adaptation of specific behaviours, including:

- Avoidance of crowded and cluttered environments, or the increase of negative behaviour when in these environments, such as tantrums and crying (Lam et al., 2010).
- Social withdrawals due to difficulties in finding their friends when they are in a group of people (Philip & Dutton, 2014).
- Avoidance of schoolwork as a result of issues with copying information from the board, difficulty processing the visual and auditory information that is occurring at the same time, impaired ability to find numbers on the printed page and problems locating items in their work station and within the wider classroom environment (Hyvärinen et al., 2012; Philip & Dutton, 2014).
- Reluctance to move around both familiar and unfamiliar environments due to past embarrassing experiences of walking into objects and people and appearing clumsy (Dutton et al., 2017; Hyvärinen et al., 2012; Lam et al., 2010).

- Unwillingness to participate in sporting activities due to issues with depth perception and eye-hand coordination (Hyvärinen et al., 2012).
- Memory difficulties, as visual information cannot be encoded in a robust and clear way (Fazzi et al., 2009).

The overall effect of living with these behaviours is that a child is often in a highly anxious state (Philip & Dutton, 2014).

Visual difficulties associated with a ventral stream dysfunction may also lead to the adaption of specific behaviours, including: avoidance of travelling independently in a familiar or unfamiliar environment due to the fear of getting lost, avoidance of social situations because of the inability to recognise people and follow facial expressions, and a reluctance to participate in specific classroom activities because of the inability to recognise objects (i.e. shapes) (Philip & Dutton, 2014). Added to this, there is often a frustration from parents and teachers due to the inconsistencies with the child's visual behaviour, which leads to incorrect assumptions that the child is not trying hard enough or associating labels to a child, such as 'noncompliant' or 'irritable' (Pawletko et al., 2015).

There are a number of known impacts of constantly dealing with a combination of issues relating to the basic visual functions and either a dorsal or ventral stream dysfunction, including avoidable mental health problems like anxiety, stress and low self-esteem (McDowell, 2019a; University of Bristol Research, 2019). It can also lead to the child being affected by visual fatigue, which results in children performing less well in vision related tasks in some situations, as compared with others. This disparity in relation to a child's overall visual functioning often leads to parents and teachers incorrectly concluding that the child is choosing not to perform in different situations, or that they are just being lazy (Erasmus, 2015). Added to this, often the behaviours of children with CVI are put down to other causes, or in some cases even diagnosed as other conditions, such as learning difficulties or psychological disorders (Dutton et al., 2017; Martin et al., 2016). When the cause of the behaviour is unknown and the child is incorrectly diagnosed with another condition, it can impact on their levels of academic attainment (Williams et al., 2011). Constant criticism from adults around them, can also lead to children with CVI starting to develop negative feelings of self-worth, which ultimately leads to low self-esteem.

Added to this, there are also a number of little-known emotional impacts of living with CVI that have recently been described by people with lived experience of this condition. These emotional impacts can have a considerable effect on an individual's overall mental wellbeing (McDowell, 2019a). An example of this is the description of a CVI meltdown. A CVI meltdown is defined as an incapacitating behavioural reaction to an overload of visual, auditory and other sensory information, which leaves the affected person completely unable to cope and is mentally incapacitated for a period of time (CVI Scotland, 2019b; McDowell, 2019a). As with other CVI related behaviours in a child that has not been correctly identified as having CVI, a CVI meltdown may be misinterpreted as a child misbehaving or simply having a tantrum. As such, any habilitation/ rehabilitation plan developed to support a child affected by CVI, will also need to include strategies specifically focused on supporting their mental and emotional wellbeing.

Identifying children with CVI

Given the continued rise in the prevalence of CVI, especially in developed countries, many are starting to recognise that this condition needs to be acknowledged as a pressing public health issue (Gorrie et al., 2019; Martin et al., 2016). As such, the focus needs to turn to how children with CVI related visual issues are being identified to ensure that the needs of all children with this condition are being met. Currently, in most countries around the world, CVI is seen as a medical problem requiring an official diagnosis by an ophthalmologist. However, as a number of recent studies have outlined, due to a common lack of awareness of the condition amongst healthcare providers and with few ophthalmologists being confident in the clinical markers of CVI, many children with CVI are not being identified (Gorrie et al., 2019; Maitreya et al., 2018; Martin et al., 2016). There is also a large number of children who are not even recognised as having visual difficulties, as they have normal or near normal visual acuities despite having visual perceptual difficulties (Fazzi et al., 2009). Since these children are not recognised as having a visual impairment and they do not have additional ocular pathologies they do not get referred to an ophthalmologist (Gorrie et al., 2019; van Genderen et al., 2012). The impact of not detecting visual perceptual difficulties in children can have a significant impact on their learning, development and independence (Martin et al., 2016). Children with these sorts of issues can develop certain behaviours to help cope with their visual difficulties that can be misinterpreted as developmental disorders such as: attention deficit hyperactive disorder (ADHD), autism spectrum disorder (ASD), dyslexia and dyspraxia (Pawletko et al., 2015), and auditory processing difficulties (Dutton, 2015c).

An alternative approach to identifying children with CVI through population screening of at risk children has, therefore, been suggested (Gorrie et al., 2019). Such an approach would greatly reduce the number of children who are currently being misdiagnosed with behavioural or developmental disorders, as well as the number of children who undergo costly expert testing, by ensuring that only the children that warrant clinical assessments are actually assessed. Two parent related screening questionnaires developed for this purpose; the CVI Questionnaire (Ortibus et al., 2011a) and the Five Questions (Dutton et al., 2010) have been shown to have good construct validity and, therefore, could potentially be used for screening purposes (Gorrie et al., 2019). Once the possibility of CVI has been established through the use of a screening approach, further assessment of the child's visual functioning would need to be carried out in order to understand the overall picture of the child's visual abilities.

However, given that injury can occur and affect any part of the overall visual system in any combination and degree, giving rise to a wide range of patterns of visual dysfunction, it needs to be recognised that CVI is heterogeneous in its expression (Hyvärinen, 2019; McKillop & Dutton, 2008). Additionally, as the way an individual sees the world is also shaped by their own individual experiences and preferences, no two people will ever experience CVI in the same way, even if they present with the same visual difficulties (Dutton & Bauer, 2019).

Main components of a CVI practice framework

This highlights the need for an individual CVI profile for each child, which outlines the specific nature of their individual visual issues. This is the first main component of a CVI practice framework.

1. Individual CVI profiles

As already outlined, historically, CVI has been investigated as a medical problem and although clinical investigation still has its place in detecting certain visual issues, such as reduced visual acuity, visual field deficits, or impaired contrast sensitivity and stereopsis (related to associated squint/strabismus); other issues are going undetected (Hyvärinen, 2009). However, in order to develop an overall picture of a child's visual functioning, all areas must be assessed, highlighting that different approaches for assessing a child's vision need to be used. In particular, a child's visual perceptual abilities, which can appear differently in the real world as compared with experimental tasks in clinical settings, need to be assessed within everyday situations (Hyvärinen et al., 2012; Williams et al., 2011). The need for this type of assessment requires a transdisciplinary assessment approach that is based on observations and testing by teachers, parents, caregivers and therapists, in addition to the clinical assessments by medical specialists (Hyvärinen, 2019).

Dutton et al. (2010) emphasise the important role parents can play in a transdisciplinary assessment approach in terms of profiling a child and have developed a structured history-taking inventory for parents. The aim of the inventory is to elicit vital information about a child's visual behaviours and their overall functioning in different environments based on parents' observations. The inventory runs through a number of specific areas related to visual dysfunctions and allows the interviewer to establish what areas are more problematic for a child and where the assessment of vision and functional vision needs to focus (Dutton, 2015a; McCulloch et al., 2007). An approach such as this, could be used as the first step in developing an effective CVI profile for each individual child. This view is also supported by Hyvärinen et al. (2012) who states that the perceptions of the parents and those teaching or caring for the child could be better utilised, as they observe these children completing day to day activities that cannot be observed in clinical situations.

Currently, teachers of students with visual impairments (QTVIs/TVIs) conduct functional vision assessments (FVA's), which focus on real-life evaluations of visual functions, with both eyes open, within the performance of activities, and often involves qualitative judgments of how vision is used and the limits it imposes on daily living (Kran & Mayer, 2015). Within these assessments, common areas of focus are: visual acuity, visual field, contrast sensitivity, colour vision, light sensitivity, what modifications or changes to the environment are needed and adaptations or tools needed to access information (Kran & Mayer, 2015). However, assessing visual perceptual difficulties in FVA's can be more challenging than for other aspects of vision, as there are a number of specific areas that need focusing on. These include: visual attention (the ability to highlight specific features or places within the visual field); visual search or apraxia of gaze (the ability to move the eyes within a scene to detect relevant targets); perceptual grouping or simultanagnostic visual dysfunction (the ability to combine components of a scene into a meaningful whole); unconscious use of visuospatial information to programme movements that interact with objects in 3-dimensional space; route finding and recognition of objects and people or optic ataxia (Goodale, 2013; Goodale & Milner, 2013; Williams et al., 2011). At present however, the recommendations for assessing these issues are complicated, time consuming and difficult for vision educators to implement unless they have a comprehensive understanding of how visual perceptual difficulties impact on a child's day to day functioning.

Indicators of visual perceptual difficulties. To support vision educators to conduct simple assessments to detect visual perceptual difficulties as part of their FVA's, it is, therefore, vital that more is understood about the manifestations of these difficulties. Research is beginning to explore this area, with work by Josef Zihl, outlined in Zihl and Dutton (2015), looking at the differences in how long it took children with and without a dorsal stream dysfunction (a combination of the visual perceptual difficulties of simultanagnostic visual dysfunction, optic ataxia and apraxia of gaze) to find a diamond in a diagram that was surrounded by an increasing number of dots. This research showed that children without visual perceptual difficulties, found the diamond at around the same time even when the number of dots increased. Whereas, the children with visual perceptual difficulties took longer as the dots increased.

What was also evident in this test, was that the children with visual perceptual difficulties used a more random search pattern to find the diamond than the children without difficulties. This often resulted in an increased number of darting eye movements compared with the children without difficulties and when the children with difficulties did find the diamond, it was possibly down to chance (Zihl & Dutton, 2015). This work is supported by recent research conducted by Bennett et al. (2018) who used a virtual reality (VR) toy box test to assess the visual search patterns and spatial processing strategies used by children with CVI. The test was based on the awareness that children with visual perceptual difficulties often have difficulty recognising familiar objects while viewing complex visual scenes and allowed for the tracking of eye and hand movements as the children completed the test (Bennett et al., 2018). Results from the toy box test showed that children with CVI had longer search patterns and reduced focus on the target compared to the control children, which was evident by an increased number of darting eye movements. However, a result that is more revealing for children with CVI, is that as the number of distractions (unique distractor toys, a colour/theme matched toy, background clutter), were increased within the VR toy box, their speed and quality of performance decreased rapidly (Bennett et al., 2018).

In regards to hand tracking, the VR toy box test showed that the children with CVI were slower at reaching and virtually touching the toy than the control children and their reaction times continued to decrease as the number of distractors increased (Bennett et al., 2018). Another common observation related to hand movement in people affected by a common visual difficulty; optic ataxia, or impaired visual guidance of movement, is the adaption of the hand position when reaching out to grasp an object (Goodale & Milner, 2013). Often, the finger and thumb are opened wider inflight than the object being grasped, indicating that the person is unable to accurately identify the size of the object and is overcompensating to ensure that they are able to grasp the object once it is reached (Goodale & Milner, 2013).

From the research outlined above, it can be ascertained that key indicators of visual perceptual difficulties include: darting eye movements, random search patterns, increased time to find objects as the complexity of the scene increases, and adaptive hand positions when reaching and grasping for objects (Bennett et al., 2018; Goodale & Milner, 2013; Zihl & Dutton, 2015). With these indicators in mind, it is now theoretically possible to develop a simple and effective assessment tool that could be used to help detect more of the growing number of children affected by CVI within functional vision assessments. This could also meet the need outlined by Bennett et al. (2018), to develop novel methods to better characterise visual perceptual deficits beyond what can be achieved within standard clinical testing. Once a thorough FVA and any other assessment of a child using their vision in everyday activities has been conducted, the information can be collated and analysed to determine the most appropriate education strategies that need to be implemented to ensure the child can access, understand and learn the relevant curricula material. As such, the overall picture of a child's visual difficulties and resulting needs, is not based on a clinical assessment only, but rather on their functional needs.

Understanding the whole child. Once a child's visual difficulties have been identified and understood, it is also important to recognise that the impact on the child will depend on the severity of the visual issues, the child's abilities, temperament, strengths and weaknesses and the extent to which their difficulties hinder him or her in their daily lives, and also, whether there are any additional disabilities (University of Bristol Research, 2019). In addition, a child's surroundings and family dynamics, and whether allowance is made for their impairment and/or strategies to help have been implemented, will also impact on a child's overall functioning and emotional well-being (University of Bristol Research, 2019). As such, a social-ecological framework needs to be considered when developing an individual profile for a child with CVI, as it will help to better understand the interaction of the many different areas relating to a child's life and develop an overall picture of the child within their own environment. One framework that has been suggested for this purpose, is the International Classification of Functioning, Disability and Health (ICF) (Hyvärinen et al., 2012; Ortibus et al., 2011b). This framework considers the interaction between a person's disability and their functioning of an activity and participation level, taking into account environmental factors, as well as internal factors relating specifically to the individual (as shown in Figure 3) (World Health Organisation, 2019b).

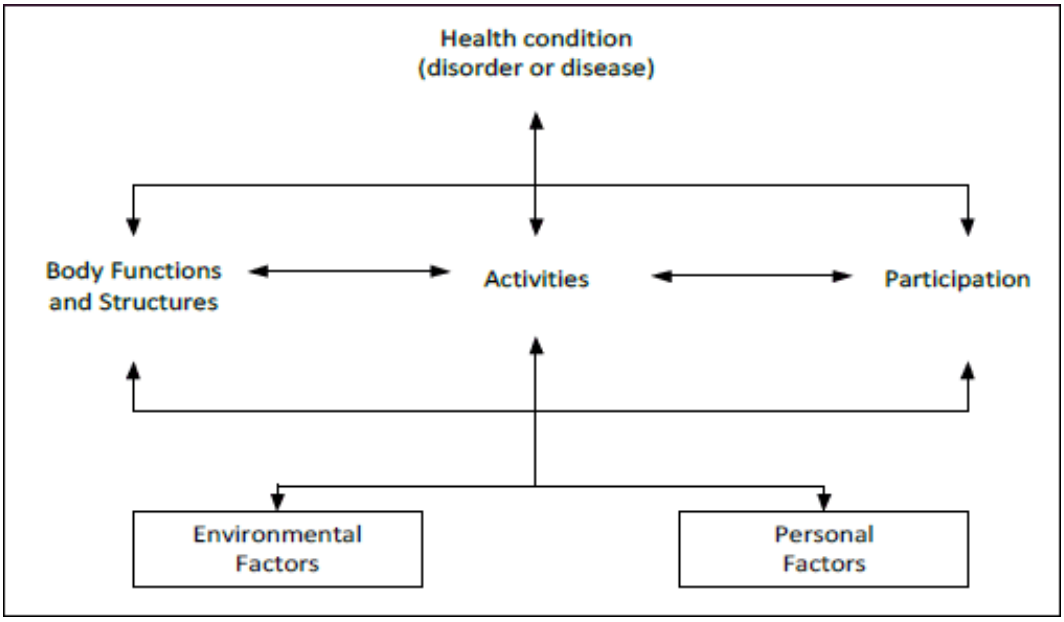


Figure 3. International classification of functioning, health and disability (World Health Organisation, 2019b)

By using a framework such as the ICF, it would also be possible to ascertain the behaviours that a child has developed as a result of their visual difficulties, and the impacts the combination of the visual difficulties and associated behaviours is having on their overall mental and emotional well-being. This is an important component of understanding and supporting a child with CVI, as it has been reported that children with these kinds of visual difficulties have an increased risk of additional mental health problems such as anxiety and depression and are less likely to have positive self-esteem (University of Bristol Research, 2019). Again, those closest to the child are in the best position to be able to provide relevant and useful information around a child's behaviours and emotional well-being. By following a similar format to that of the history-taking inventory (Dutton, 2015a), parents, teachers and other support people could be questioned about how they feel the child's visual difficulties impact on a child's behaviour and emotional well-being.

2. Supporting a child with CVI/individual programme

The second component of a CVI practice framework is the development of an individual programme based on the needs established from the individual CVI profile. This is an important element of the framework, as it ensures that the specific needs of the child can be met. As outlined by Dutton and Bauer (2019), the main aim for all children with CVI should be to give them full access to all information and skills they need to learn and to live in a visual world. However, as CVI has many possible variables, every affected child has their own unique pattern of visual experience, limitations and resulting behaviours, that needs a holistic approach to develop an effective habilitation/rehabilitation plan (Dutton & Bauer, 2019). As such, this plan will need to be based on areas related to the child's visual difficulties, address any adaptive behaviours that have developed, as well as introducing strategies to support their emotional well-being. Another important aspect of a habilitation/rehabilitation plan, is that any strategies suggested will need to be able to be implemented in all aspects of a child's life, as CVI can influence any aspect of daily living (Dutton & Bauer, 2019).

Developing effective strategies in relation to specific areas of difficulty may depend on the child's overall level of visual functioning, whether or not there are additional disabilities and their cognitive abilities. For this reason, Dutton and Lueck (2015) have identified that from a practical perspective in terms of working with children who have CVI, there are three main categories that children can be separated into. These include;

1. Children with profound visual impairment due to CVI, many of whom also have additional disabilities.
2. Children with CVI who have functionally useful vision and cognitive challenges.

3. Children with CVI who have functionally useful vision and who are able to work in or near the expected academic level for their age group.

In terms of specific strategies, these need to be based on what is known to be effective for children with CVI, as strategies based on the needs of typical children, or children with ocular visual impairments (OVI) may not be effective (Dutton & Bauer, 2019; Martin et al., 2016). For helping to alleviate the impact of the visual difficulties, strategies may include:

- De-cluttering the environments the child spends time in (i.e. their bedroom at home, other rooms in the house, their classroom) in order to decrease the amount of visual information they need to process at any one time (Little & Dutton, 2014; McDowell & Budd, 2018).
- Implementing ‘safe places’ at home and school, by creating a place which is clutter free that the child can go to for a break when they are feeling overwhelmed (CVI Scotland, 2019a; Little & Dutton, 2014).
- Using tents in a classroom environment to block out all visual information to allow the child to have use of their intact visual functions (Little & Dutton, 2014).
- Creating an area of blank wall space for the child to face into when they are required to do concentrated focused work at school (McDowell & Budd, 2018).

Although the overarching principles in relation to the visual difficulties will be the same for each category, the strategies used within a child’s individual habilitation/rehabilitation plan may have to be adapted slightly, depending on what category the child is in.

For any approaches to be effective, however, a child must also be encouraged to develop strategies to deal with the behavioural and emotional reactions they have as a result of dealing with CVI. As outlined by Goleman (1995), when an individual feels anxious or panicked, their sympathetic nervous system causes a fight or flight response in their primitive brain and when someone is experiencing the fight or flight sensation, their ability to think logically and coherently is diminished or absent. Relating this back to a child with CVI, if the environment or activity is overwhelming and making them feel highly stressed and anxious, they may not be in a position to implement any strategies that have been suggested. The constant drain of being on high alert and the resulting high levels of visual fatigue, may also cause an overall fatigue that again, makes it difficult to implement specific strategies. To help reduce this, the child also needs to be introduced to techniques that help calm them down and lessen fatigue levels.

One suggestion for this, is to introduce the child to regular mindfulness practices in a format that suits their abilities and functioning (i.e. through a child friendly mindfulness app or internet based mindfulness programme). Mindfulness has been shown to be effective in treating a variety of mental health conditions in adults and children, including anxiety and stress (Bailey et al., 2018; Bauer et al., 2019; Bohlmeijer et al., 2010; Chiesa & Serretti, 2009; Spijkerman et al., 2016). Although there is currently no literature around supporting children with CVI using such strategies, there is evidence of the effectiveness of these cognitive-based strategies in children with other developmental disorders, such as ASD and anxiety disorders (Conaughton et al., 2017; Perry-Parrish et al., 2016; Vigerland et al., 2016). Mindfulness interventions are also known to target regulation of emotions and coping processes associated with stress (Perry-Parrish & Sibinga, 2014), which suggests this could be an effective strategy for children with CVI, given that they are constantly under high levels of stress. A sample programme of mindfulness-based visualisation was recently trialled at the Royal Blind School in Edinburgh. Although not all the students involved in the programme had CVI, the students all had multiple disabilities, including visual impairments (Godek, 2015). After using the programme for three school terms, staff involved in the programme reported a reduction in students agitation and anxiety both at home and at school, especially when doing specific activities that used to cause high anxiety (Godek, 2015).

3. Empowerment of the child with CVI and their family

The third component of the proposed CVI practical framework encompasses an important element needed to ensure the success of any intervention recommended for a child with CVI; the empowerment of the child, their family, and their education and therapy teams. Empowerment can be described as a process of gaining personal power and control (Mulligan et al., 2012), with parental empowerment occurring as a result of parents utilizing knowledge, skills and resources to gain a sense of control and improve their families quality of life (Singh et al., 1995). Crucial to empowering those supporting a child with CVI, is the attainment of CVI specific knowledge in a language framework matched to their ability to understand and learn this new information. This is vital, because in order to best support a child with CVI, a well-informed, loving, positive and supported model of care needs to be implemented (Dutton & Bauer, 2019).

When the team supporting a child with CVI is well-informed and understands intuitively the impact of the child's visual difficulties; the strategies and support will become logical and intrinsic (Dutton & Bauer, 2019). This process is often helped when the parents are recognised and respected by medical and education practitioners as 'experts in their own right' (Avdi et al., 2000), as they are the ones closest to the child and have seem the impact of their visual difficulties on their functioning and emotional well-being in many different contexts. When parents are respected, they may feel more confident to actively participate in the services their child receives, be more aware of their choices in relation to their child, and be more involved in decision making (Shulman, 1992). The benefits of parents actively engaging in their child's habilitation/rehabilitation plan is significant, as they are able to serve multiple roles in supporting their child's quality of life, including being advocates, consumers, and implementers of strategies aimed at enhancing their children's well-being (Bode et al., 2016).

One simple way of ensuring parental empowerment, is through medical practitioners providing relevant information about the child's visual difficulties. This can occur when they are first identified and CVI is suspected, when a CVI diagnosis is confirmed, or as soon as possible following this; a process that is used for when diagnosing other conditions such as ASD (Mulligan et al., 2012). This should include information about CVI in general, information on the specific visual difficulties their child has, how these difficulties will impact upon them on a daily basis, and how to best circumvent limitations to access to knowledge, social interaction and mobility (Dutton & Bauer, 2019; Jackel et al., 2010). In terms of how this information is shared, Mulligan et al. (2012) highlight that information about a condition that a child has been suspected of having or has been diagnosed as having, should be provided verbally by the diagnosing professional, with follow up information being provided in the form of printed material. Given the age of technology and an abundance of information on many different platforms, websites and support organisations that are scientifically accurate, research and evidence based, and peer reviewed could also be utilised by parents. As outlined by Boshoff et al. (2018), an empowered parent, who has been provided with relevant information about their child's disability, may feel more in control and more confident in their ability to support their child. This feeling of empowerment can also have a positive impact on the parents' quality of life and, therefore, their child's quality of life (Dutton & Bauer, 2019).

Conclusion

This literature review has explored in detail the complex, yet common condition of CVI as it relates to children. This has included the causes and prevalence on CVI within the developed world, the visual difficulties associated with CVI and their impact on a child's visual and overall functioning, and also, the difficulty with identifying children with CVI. This detailed analysis of CVI has then allowed for the identification of three critical components that are necessary for a practice framework for supporting children with CVI to be effective. The three main components are:

- Individual CVI profiles that include information on a child's visual, emotional and behavioural responses related to CVI.
- Individualised habilitation/rehabilitation plans that are based on the child's unique CVI profile.
- Empowerment of the child and their family through education about CVI, to enable them to take a central role in their habilitation/rehabilitation plans.

When these three elements are executed efficiently and cohesively by everyone involved in supporting a child with CVI, the child's overall quality of life could be greatly improved. As such, these critical components are the foundations for a practice framework for supporting children with CVI.

Chapter conclusion

This literature review was related to the overall research aim of developing an effective framework for supporting children with CVI. It helped to lay the foundations of literature in relation to each article included in this thesis by publication. As such, the literature review provides an introduction in relation to the six research questions and a clear rationale for why this research needed to be conducted. In terms of the overall research framework for this thesis by publication, the literature was drawn from the many different fields involved in supporting children with CVI in line with the theoretical perspective of dialectical pluralism. The literature review was conducted using a systematic search of relevant databases, including Google Scholar, Discover, Eric and PubMed. Search terms included: cerebral visual impairment, childhood vision impairment, diagnosis, vision assessment and vision screening. Articles were excluded from the review if they did not use the same definition of CVI used throughout this research.

Chapter Three – Personal Case Study

Chapter introduction

Following the late diagnosis of CVI 17 years after acquiring it as a teenager, the researcher worked hard to develop a better understanding of the visual difficulties she experienced and the impact these had on her quality of life. She was supported in her endeavours by the ophthalmologist that had identified that she had CVI, Professor Gordon Dutton. Together they prepared a case study (with the researcher as lead author) documenting the personal rehabilitation programme the researcher developed for herself and the resulting improvements in her visual and overall functioning. This information relates to the overall research aim of developing an effective framework for children with CVI by highlighting the three main components that the researcher believed contributed to the success of her rehabilitation approach. The case study was submitted to *Case Reports in Ophthalmological Medicine* and accepted for publication following an extensive peer review process.

McDowell, N., & Dutton, G. N. (2019). Hemianopia and features of Balint Syndrome following occipital lobe hemorrhage: Identification and patient understanding have aided functional improvement years after onset. *Case Reports Ophthalmological Medicine, 2019*, 3864572. https://doi.org/10.1155/2019/3864572

Abstract

Introduction. Cerebral visual impairment (CVI) can present around birth or any time thereafter. Homonymous hemianopia is a common feature. The concept that functional improvement is unattainable augurs against active management. Dorsal stream dysfunction (or Bálint syndrome when severe) results from bilateral posterior parietal dysfunction but may go undetected, especially in children. *Case Presentation.* At 16 the patient suffered spontaneous left occipital lobe brain haemorrhage from a ruptured arteriovenous malformation. This was surgically excised. Short lived right upper limb intermittent jerking, with additional left sided weakness, ensued. Anomalous EEG recordings, with right-sided bias, arose from the posterior temporoparietal area. A right homonymous hemianopia was evident. During the ensuing 17 years she experienced multiple complex difficulties, until, at a lecture describing how to identify and support children with CVI, she realized she herself had many of the difficulties described. Visual assessment identified hemianopia and dorsal stream dysfunction. *Discussion.* Following identification, characterization, and explanation of the impact of her visual difficulties, she both gained greater awareness of her visual difficulties and their impact and developed a range of strategies leading to functional improvement of her visual field loss and amelioration of her dorsal stream dysfunction, with great improvement in quality of life.

Introduction

Cerebral visual impairment (CVI) can present around birth, often in relation to prematurity (Jacobson et al., 2006), hypoxic ischemic encephalopathy (Dutton & Bax, 2010), and neonatal hypoglycaemia (Macintyre-Beon et al., 2013), or it can be acquired at any time thereafter. Acquired causes include closed head injury, epilepsy, metabolic disorders, CNS infection (Dutton & Bax, 2010), and brain neoplasia (Grüsser & Landis, 1991). The most frequent manifestation of acquired CVI is homonymous hemianopia (Holmes, 1918a; Perez & Chokron, 2014; Zhang et al., 2006). However, this common impairment often goes uncharacterized and untreated, owing to the belief that functional recovery from visual field loss is unattainable (Perez & Chokron, 2014), despite recognition of the potential for persisting hemianopic blind-sight, comprising the facility to respond predictably to visual stimuli in the hemianopic visual field, but without visual consciousness (Chokron et al., 2008; Perez & Chokron, 2014; Weiskrantz et al., 1995).

The identification of blindsight may facilitate visual rehabilitation in patients with homonymous hemianopia (Ro & Rafal, 2006), founded on the hypothesis that residual nonconscious visual capacities can potentially be rendered conscious through training (Perez & Chokron, 2014). The requisite methodology has been shown to be beneficial in the case described by Arcaro et al. (2019) of a patient who lost vision due to bilateral occipital infarction. Two years after the injury, the patient developed the Riddoch phenomenon enabling her to walk around obstacles and to mirror other’s movements, despite reporting that she had no useful vision (Arcaro et al., 2019; Dutton, 2003). The patient was encouraged and empowered to develop strategies to use motion and self-motion to improve her visual abilities and her confidence to trust them. After an initial period of using these approaches to aid her vision, she became able to relinquish them as she learned to move freely through cluttered environments and achieve actions such as catching a moving ball (Arcaro et al., 2019).

Another well described CVI that results from cerebral injury in adults is Bálint syndrome (Bálint, 1909). This is caused by bilateral posterior parietal lobe dysfunction or injury

(Lehmann et al., 2011). It is characterized by three specific visual difficulties that impact on a person's visual access to the spatial characteristics of their surroundings. These comprise the following: simultanagnosia (an inability to see more than one or two objects at the same time; (described by Grüsser and Landis (1991) as a 'disturbance of grasping the whole'), optic ataxia (impaired visual guidance of movement) (Goodale, 2013), psychic paralysis, or apraxia of gaze (inability to volitionally direct visual gaze despite the requisite motor substrate) (Bálint, 1909; Philip et al., 2016). Bálint syndrome has been infrequently reported in children, but recent case studies have highlighted that children can be significantly impacted by this triad of visual spatial difficulties (Philip et al., 2016).

Bálint syndrome-like features can occur in patients who have experienced bilateral posterior parietal lobe injury, but who are not as severely affected as those with Bálint syndrome in its most severe form (Maia da Silva et al., 2017). This lesser, but yet still complex form of Bálint syndrome, is referred to as dorsal stream dysfunction and commonly occurs in children (Williams et al., 2011). The dorsal visual stream runs within the superior longitudinal fasciculus from the occipital lobe to the posterior parietal cortex and is often referred to as the "vision for action" or the "where" pathway (Goodale & Milner, 2013). Difficulties due to dorsal stream dysfunction include the following:

i. avoidance of crowded and cluttered environments or the increase of negative behaviours when in such places, such as tantrums and crying (Lam et al., 2010),
ii. social withdrawal due to difficulty finding friends in groups of people (Philip & Dutton, 2014),
iii. avoidance of schoolwork due to difficulty copying information, difficulty simultaneously processing incoming visual and auditory information, and impaired ability to find numbers on a printed page and problems locating items,

both on their work station and within the wider classroom environment (Hyvärinen et al., 2012; Philip & Dutton, 2014),

iv. reluctance to move around both familiar and unfamiliar environments due to past embarrassing experiences of walking into objects and people and appearing clumsy (Hyvärinen et al., 2012),

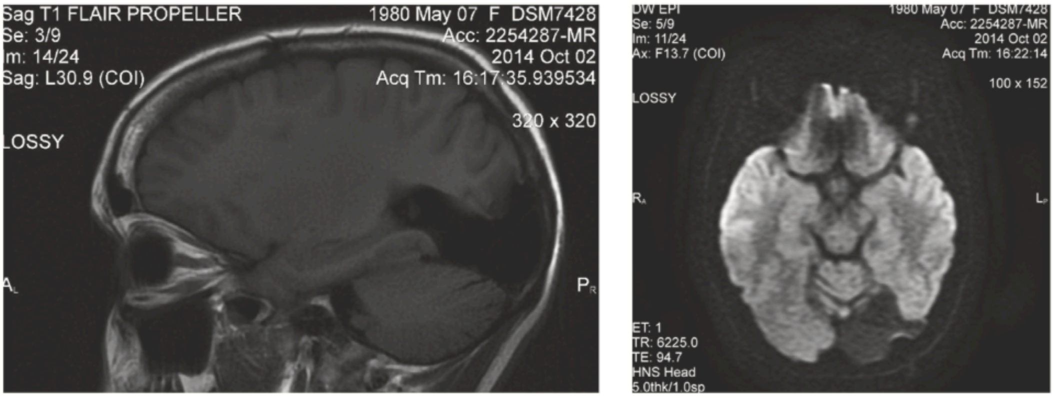
v. an unwillingness to participate in sporting activities due to issues with depth perception and eye-hand coordination (Hyvärinen et al., 2012),

vi. memory difficulties, as visual information cannot be encoded in a robust and clear way (Fazzi et al., 2009).

We report a patient with combined hemianopia and dorsal stream dysfunction, for whom the insights gained from identification and explanation have changed her life for the better.

Case presentation

A 16-year-old left handed girl suffered a spontaneous brain haemorrhage into her left occipital lobe. She lost consciousness and was resuscitated from respiratory arrest. Imaging showed left occipital and left frontoparietal subdural hematomata. Drug induced coma was implemented and maintained for eight days prior to left parietooccipital craniotomy and excision of the causative left occipital arteriovenous malformation (Figures 4(a) and 4(b)). At surgery small arterial feeders were evident 5cm from the midline. The hematoma cavity was evacuated. The arteriovenous malformation extended into the lateral horn of the left lateral ventricle and across the surface of the tentorium, draining into the transverse sinus. The medial aspect of the left occipital lobe was disconnected from the midline and the affected 4 x 4cm area was hinged up onto the draining vein. The vascular pedicles were coagulated and divided, and the vascular malformation was removed. Shortly following the surgery, the patient displayed intermittent jerking of the right upper limb, as well as marked weakness of the left side. EEG testing revealed irregular brain waves in the posterior temporal and parietal regions with a right-sided bias. Both the jerking and the weakness resolved over 4 days. A right-sided homonymous hemianopia became evident. On discharge, the patient and her parents were informed of a possibility of spontaneous recovery of the hemianopia, but this was deemed unlikely. Her neuropsychological tests showed focal visual dysfunction, suggestive of difficulties in visual search (Table 4), but their origin was not identified at the time. For the following 17 years, the patient experienced challenges with many aspects of her life, including her mobility, her ability to access learning material at school, her social interactions, specific daily living activities including finding items on a supermarket shelf or clothes in her wardrobe, and the control of emotion. In 2013, at a conference presentation on identifying and supporting children with CVI, the patient recognized the difficulties described as being identical to her own. The patient introduced herself to the presenter and explained this.



(a) Parasagittal view MRI image (b) Axial view MRI image

Figure 4. (a) Parasagittal and (b) axial T2 weighted MRI images of the patient's brain after removal of her left occipital arteriovenous malformation

Table 4. Neuropsychology tests as reported
(Dates of assessments: A. 30.9.96, B. 16.1.1998)

Intelligence Wechsler Adult Intelligence Scale – Revised (WAIS -R) (Pre-accident: High average range)	A. Not done	B. Superior range of functioning
Reading Wide Range Achievement – Third Ed (WRAT-3) and SCOLP spot the Word subtest	A. Low average (reading single words out loud)	B. Slight improvement into the average range (reading single words)
Confrontation naming Boston Naming Test	A. Low average range	B. Average range*
Speed of information processing SCOLP speed of compression subtest	A. 10th centile	B. Improvement into the average range*
Attentional and psychomotor skills WAIS-R Digit Symbol subtest and Trial Marking Test	A. Speed of visual motor responding and visual scanning low average	B. Slight improvement into the average range*
Verbal memory abilities California verbal learning test	A. Intact abilities in learning new verbal material preserved abilities in reading recently learned verbal material from long-term memory	B. 'No change' reported
Visuospatial skills and visual memory abilities Rey complex figure test	A. "Misplacement of detail"	B. "Copied the design in piecemeal fashion as she was unable to see the entire figure at a glance"
Executive and problem-solving abilities Trail making test	A. Slow speed of information processing	B. Now has no problems alternating her attention between number and letter concepts under time pressure
Cognitive flexibility and problem-solving skills Wisconsin card sorting test (for conceptual flexibility, hypothesis formation, testing abilities, skills in using feedback to modify problem-solving)	A. Above average range	B. Above average range

* 'Inconsistent with WAIS-R test results'

The items underlined are indicative of persistent difficulties with visual information processing

Visual assessment confirmed persisting right hemi- anopia. No evidence of visual impairment in the sighted visual field (Cavezian et al., 2015) was elicited. A body turn to the right (without a head turn) slightly extended the field of vision to the right, suggestive of an additional element of right inattention. Nevertheless, repeated small discreet finger movements made by the examiner in multiple locations within the hemianopic field were correctly intuited on more than 70% of occasions, consistent with blindsight. Uncorrected visual acuities and stereopsis were in the normal range. Structured history taking for evidence of perceptual visual impairment (Dutton, 2015a) revealed great difficulty finding an item from within clutter or within a pattern and great difficulty copying, consistent with simultanagnostic vision. Standard eye movement examination was normal, with normal convergence, pursuits, and saccades to command (e.g., ‘look right’), but instruction to look at specific items nominated by the examiner resulted in anarchic visual search movements until the specified item was eventually found. This feature is consistent with apraxia of gaze, a phenomenon known to accompany simultanagnostic vision (Maia da Silva et al., 2017). When asked to look at a large group of people, the patient could only identify the presence of one person. Careful observation of eye movements during such search consistently showed them to be sparse and apparently random.

In an outdoor café she was asked to count the number of support poles for the sun-shading roof. She randomly found and identified 3 out of 11, with the same lack of visual search strategy.

The accuracy of the patient’s visual guidance of reach was evaluated. Careful observation of the in-flight gap between the fingers, and their orientation while reaching for discreet targets in the intact visual field showed consistent features of a gap much wider than necessary, with inaccuracy of orientation (Goodale & Milner, 2013). These features are consistent with a degree of accompanying optic ataxia.

The patient was given a detailed tutorial concerning the nature of her vision and strategies that she could employ to make best use of her vision.

Discussion

Receiving an in-depth explanation for the unexplained challenges that she had lived with for 17 years had an immediate impact on the patient's feelings of self-worth and overall well-being. Just the knowledge that she had been living with a significant visual impairment that had only recently been identified helped her to understand that it was this impairment that impacted on many aspects of her daily life, as opposed to her feeling 'useless' and unable to achieve simple activities, such as the grocery shopping for her family.

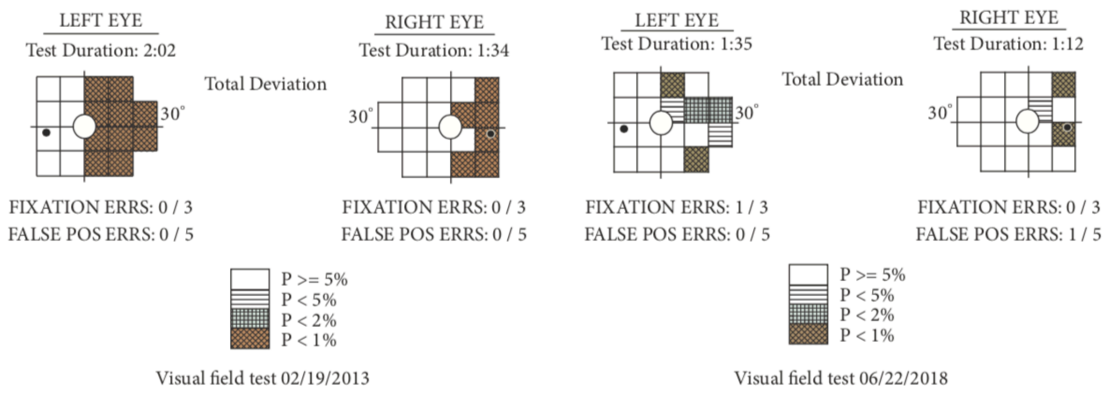
As each specific visual difficulty was assessed and thoroughly explained to her, she found herself able to connect her anomalies of visual function, to the specific challenges she experienced. For example, the reason she did not like spending time in crowded and cluttered environments (supermarkets and shopping malls) was not only due to her hemianopia, but also because of a combination of her simultanagnostic visual dysfunction and hemianopia together. Also, the reason she often got frightened by people suddenly 'looming' in front of her, when walking in a busy environment, was because of a combination of the hemianopia and her impaired visually guided movement making it difficult for her to judge how far away people actually were. But probably the most important concept that she learnt about her CVI was that she had the potential to improve her visual functioning through personal endeavour.

As with patient MC, described by Arcaro et al. (2019), the patient was surprised that she had been able to accurately respond to stimuli in her right visual field, even though she felt she could not 'see' any image. Although she had previously been aware that at times she was able to detect movement in her right visual field, the concept of blindsight had never been explained to her. Therefore, her new recognition that she had the potential to improve her awareness of movement within her right visual field, to begin to look and see, was empowering (Zihl & Werth, 1984). As with MC, the patient was encouraged to develop strategies to use motion and self-motion to improve her visual abilities and her confidence to trust them (Arcaro et al., 2019). Although at first she used the motion of head nodding to experiment with detecting visual stimuli on her right in her home environment, it was not a strategy she used when out and about. However, not long after receiving her CVI diagnosis following the conference presentation, she began to become more aware of movements in her right visual field. When this occurred, she made a conscious effort to try and interpret what she was seeing, instead of ignoring it, as she had in the past. She soon found that the more conscious awareness she gave to understanding what she was seeing, the more she became able to interpret her visual responses to the movements on her right. This is in line with studies focusing on increasing the detection and awareness of stimuli within the blind hemifield, which have shown that with repeated stimulation, the incidence of reported awareness also increases (Sahraie et al., 2013) and may well relate to the type of increased saccadic amplitudes resulting from more structured training in visual search, recently shown to be effective in extending the functional field of vision in children with hemianopia (Ivanov et al., 2018).

Each day she challenged herself to interpret movement she was detecting on her right side. Her approaches included attempting to detect any movement the driver on her right was making while she was sitting in the left hand passenger seat, looking straight ahead; walking on the left hand side of the path when out for her daily walks and trying to establish the exact moment, runners, other walkers, or cyclists passing her on her right hand side (while wearing headphones and listening to music so she could not hear them); and choosing a place to sit in her lounge that meant that the doorway was on her right and trying to detect any movement through the door while looking straight ahead at the television while ensuring she acknowledged and described everything she saw when detecting stimuli on her right side.

These approaches are in line with visual field training techniques described by Pollock et al. (2011) where patients are trained to detect stimuli that are repeatedly presented in their blind hemifield, to help increase their overall sensitivity to them by helping the brain to enhance visual awareness. Within the first year of implementing these strategies, the patient was beginning to be aware of more stimuli in her right visual field. After two years of her continuous visual self-training regime, she was surprising even herself on the occasions that she detected and correctly identified that the family (black) cat was on her right side or that someone was walking past her from behind. Her most exciting detection was when she looked up from reading her book to respond to an air hostess at the exact moment she appeared on her right side. With the continued self-training, over time she also began to detect more and more stimuli that were unrelated to her training regime, for instance, detecting changes in a familiar environment, such as furniture being moved.

During the six years following her diagnosis, visual field testing was performed by her optometrist using the Humphrey FDT Viewfinder (Figure 5). The first was undertaken in 2013 and showed little change from the plots of 1996 following her brain haemorrhage. Successive testing, however, revealed progressive improvement in the right visual field of both eyes. This remarkable functional improvement supports the hypothesis that it is potentially possible for neuroplastic brain change to occur through focusing on the belief and expectation that things can change, while striving to gain greater conscious visual awareness, perhaps through modulating processes in the brain that control and facilitate change (Merzenich, 2013).



Visual field test 02/19/2013

Visual field test 06/22/2018

Figure 5. Visual field tests[6]

As well as focusing on functionally improving her visual field, the patient also concentrated on improving her overall visual function. An important aspect of this was to firstly develop an in-depth understanding of her Bálint-like symptoms / dorsal stream difficulties of simultanagnostic visual dysfunction, optic ataxia, and apraxia of gaze and how they impacted on her in everyday life. This meant focusing on each specific issue separately, followed by the combined impact of living with a significant visual spatial impairment. Once the patient understood the nuances of her impaired unconscious visual functions, she was able to compare her current experiences of the visual world to how she had previously seen the world prior to her brain haemorrhage. With this unique insight, she was able to develop strategies to help improve her visual functioning in challenging activities and environments.

As a dorsal stream dysfunction largely affects nonconscious visual functions (Goodale & Milner, 2013), the patient used the analogous approach to the one she used for developing her Riddoch phenomenon and focused on becoming more conscious of what was

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[6] It comprises images of two visual field plots on a Humphrey FDT Viewfinder, demonstrating improvement in visual fields. The first image is from 02/19/13 and the second is from 06/22/18.

occurring when she was experiencing difficulties as a result of her simultanagnostic vision, optic ataxia, and apraxia of gaze. To strive to develop effective conscious viewing, she followed the concept outlined by Doidge (2015) of using conscious actions to overcome unconscious processes, which requires a focused meditative level of concentration. This process has been used successfully for a man suffering from Parkinsonian symptoms, also described by Doidge (2015) as using a form of conscious walking, whereby he trained himself to overcome many of his symptoms, by forcing himself to focus on the specific actions of walking and not letting his body adopt compensatory movements as a result of his Parkinson's disease.

At first, she adopted a different form of conscious viewing for each of her visual difficulties. For instance, for her simultanagnostic vision, she developed a strategy that she termed as 'wagon wheel visual fixation.' This strategy required the patient to consciously recognize when her gaze had wandered from what she was looking at in a crowded or complex environment, to enable her to build up the complete visual scene over time. For this strategy to be effective, she found the first step was to establish an anchor point (an obvious and appealing visual target in the middle of the chosen environment). She then trained herself to consciously recognize whenever her gaze had moved from this anchor point and work hard to force her gaze back to it. This process was repeated over and over again, applying a wagon wheel approach to consciously chosen eye movement, until the whole scene had been mapped out.

To aid her mobility in relation to her optic ataxia, especially in busy environments, she again adopted a process of conscious viewing and worked hard to focus her attention on processing and interpreting the visual information in her surroundings. For this, as she was moving, she focused her visual attention upon the space ahead of her that she would be moving in to. She then repeatedly glanced at the different elements in her travel pathway to make sure she had an enhanced opportunity to accurately map the environment around her. To ensure that this process was effective, she had to mentally block out all other sensory distractions, so that she could focus solely on processing the visual information.

Both of these techniques were difficult to implement and although she could immediately see the potential benefits of each strategy, they both had to be repeatedly practiced in the environments that required such strategies, before she was confident with her ability to implement them. However, while experimenting with these strategies, the patient also realized that she could only use them when she was feeling calm and relaxed. If anxious or stressed in any way, especially in a complex environment, she found them difficult to implement. Although she had developed a very good understanding of what types of environments were difficult for her (supermarkets, busy restaurants, shopping malls, and crowded parks), this knowledge alone was insufficient to help her cope in such locations. She then came to realize that along with her unconscious visual behaviours, she was also experiencing unconscious emotional reactions, including anxiety, panic, and high levels of stress as a result of the dorsal stream dysfunction (Freeman, 2010).

The difficulty in implementing strategies requiring forced conscious actions necessitating intense cognitive functioning is in line with the awareness that when a person's sympathetic nervous system causes a fight or flight response in their primitive brain, their ability to think logically and coherently is absent (Goleman, 1995). The patient, therefore, realized that to be able to implement the specific visual strategies she had developed, she needed to identify techniques to keep herself calm, to allow any chance of overcoming both her visual difficulties and her behaviours due to her emotional reactions. To help reduce her constant high levels of anxiety when in complex environments, the patient began daily mindfulness practice, which has been shown to be useful in preventing feelings of anxiety and stress by helping a person to concentrate on their breathing and to not focus on negative or disruptive thoughts or feelings (Williams & Penman, 2011). To aid in her practice, she used an online mindfulness based intervention program, as this has been proven to be effective in treating a variety of mental health conditions in adults, including anxiety and stress (Bailey et al., 2018; Bohlmeijer et al., 2010; Chiesa & Serretti, 2009; Spijkerman et al., 2016). Although there is currently no literature concerning the use of cognitive based therapies such as mindfulness to support children and adults with CVI, they have been shown to be effective in helping children with High Functioning Autism Spectrum Disorder (HFASD) and anxiety disorders (Perry-Parrish et al., 2016). The concept of focusing on her breathing also helped reinforce the strategy of focusing on an anchor point when implementing the wagon wheel visual fixation process. Over time, focusing on an anchor point became easier to achieve, which supports the concept that regular mindfulness practice changes the brain patterns that cause day to day anxiety and stress (Williams & Penman, 2011).

With regular practice of both the mindfulness exercises to reduce environment based anxiety and her specific visual strategies of wagon wheel visual fixation and conscious viewing, the patient started to notice that the uncomfortable compensatory behaviours she had developed on account of her visual difficulties started to diminish. For instance, she stopped withdrawing from social activities and interactions and instead started engaging in activities such as going out for dinner with friends once more. She also started feeling more confident in her mobility, even in crowded environments, and felt more comfortable travelling independently in these environments. She found it easier to control her emotions and greatly reduced the number of occasions where she experienced high levels of anxiety and stress around her visual difficulties. It also helped to improve her overall well-being and confidence and helped to render normal daily activities, such as taking her children to the playground less fatiguing and more enjoyable.

Most significantly, she also noticed that her visual functioning had greatly improved and that she was less handicapped by her simultanagnostic vision, optic ataxia, and apraxia of gaze. She could now cope in busy, crowded environments for longer periods of time. She did not feel as clumsy and was not frightened by people looming in front of her. She also found it easier to spot objects in the distance that were pointed out to her, and she felt confident in her ability to handle any situation and environment that she found herself in.

Conclusions

What this case highlights is that for patients who do not have other cognitive disorders (such as memory or frontal disorders), it is possible to overcome some of the most disabling effects of a homonymous hemianopia and dorsal stream dysfunction. This is despite the fact that both these conditions can greatly impact on the quality of life for those affected, both physically and mentally (Freeman, 2010; Pollock et al., 2011; Sahraie et al., 2013). However, for this to happen, the patient needs to firstly, whenever possible, fully understand the nature of their visual difficulties and how they impact on their day-to-day living. This requires timely and accurate diagnosis of not only the overarching condition of CVI, but also the specific visual difficulties of simultanagnostic vision, optic ataxia, and apraxia of gaze. In regard to their hemianopia, patients also need to be introduced to the concept of blindsight and the Riddoch phenomenon, so that if they do experience subconscious or conscious perception of movement in their blind visual fields, they are aware that this could aid their rehabilitation. Secondly, the patient also needs to be empowered through this understanding and the awareness that they have the ability to possibly functionally improve their impairments, through utilizing the resilience and plasticity of the brain to be able to reorganize itself after brain damage (Brodtmann et al., 2015; Pollock et al., 2011; Sahraie et al., 2013). This case study also gives weight to the hypothesis that along with passive bottom up processes that can influence the cortical reorganization, neuroplastic brain change can occur through simply the belief and expectation that things can change (Merzenich, 2013), if the patient has the desire to implement strategies to bring about such change.

Consent

The patient has read the manuscript and consents to its publication.

Conflicts of interest

The authors declare that they have no conflicts of interest.

Chapter conclusion

This chapter, which is a published paper in *Case Reports in Ophthalmological Medicine*, reports on the researcher's own experience of improving her visual and overall functioning after developing and implementing her own rehabilitation programme addressing her specific CVI needs. This information relates to the overall research aim of developing an effective framework for children with CVI by highlighting the three main components that the researcher believed contributed to the success of her rehabilitation approach. The paper also addresses the first two research questions: What profiling and intervention strategies to improve visual and overall functioning can be extrapolated from the researcher’s own experience? and What role does the attainment of knowledge play in empowering a person with CVI?

In order to answer these research questions within this paper, the researcher used researcher reflexivity to examine her own experiences in relation to learning she had CVI and using this information to improve her overall quality of life. From this process the researcher was able to extrapolate the main profiling and intervention strategies that were used to improve her visual and overall functioning. These included a history taking inventory and a thorough assessment of vision conducted by a medical practitioner with a deep understanding of CVI, an in-depth tutorial of the researcher’s specific visual issues, training her blindsight through visual field training techniques, implementing conscious viewing and wagon wheel visual fixation strategies, and regular mindfulness practice. The paper also showed the significant role the attainment of knowledge played in empowering the researcher in relation to her CVI.

This paper related to the overall research framework of pragmatism, as it highlighted the issue of CVI and used the researcher’s own unique experience to outline how this issue could be overcome. In this way, the researcher has helped to develop a theory or approach for supporting children with CVI based on data from her own experience. This paper is also in line with the overall theoretical perspective of dialectical pluralism, as it considers the perspectives of different stakeholders, including the medical, scientific and rehabilitation expertise in relation to supporting a person with CVI. In addition to listening to these different voices, it also speaks to them by being published in a medical journal and provides clear strategies that can be adopted within a rehabilitation programme.

Chapter Four – Personal Perspective on CVI

Chapter introduction

The researcher was invited to write a chapter in the *Routledge Handbook of Vision Impairment* on her personal perspective of living with CVI. The handbook examines current debates around visual impairment, as well as cross-examining traditionally held beliefs around blindness and low vision. CVI is one of the ten main themes covered in the handbook. Contributing to the handbook provided the researcher an opportunity to use a reflective process to explore her personal experiences in relation to the journey she has been on since being diagnosed with CVI in 2013. This information relates to the overall thesis aim, as the three main components of the CVI practice framework are discussed within the chapter and the role they played in contributing to the improvements to the researcher's visual and overall functioning.

McDowell, N. (2019). A personal perspective on CVI. In J. Ravenscroft (Ed.), *The Routledge handbook of visual impairment* (1st ed., pp. 70-78). Routledge.

Introduction

Imagine living in a world of visual uncertainty. A world that at times seems to shimmer and shake and there is nothing you can do to make the image you are seeing stay still. A world where you can suddenly be surrounded by unknown faces, even when you are in a room full of your family and friends. A world where personal possessions, such as clothing, books and jewellery can suddenly disappear into a black hole, seemingly never to be found again, no matter how hard you try to find them. A world that in the blink of an eye, can become so frightening and overwhelming you feel as if your life is in danger and the resulting panic you feel makes it hard for you to breathe. A world that at times makes you start to doubt your own sanity and ability to mix with your peers. Now imagine that this world of visual uncertainty is actually a common, yet often undiagnosed, invisible disability. A disability that is not only invisible to everyone around you, but also invisible to you. Now imagine living with this disability and in this world for years, without realising that your brain is actually not correctly interpreting the image your eyes are seeing. I don't have to imagine what this world would be like, I live with this uncertainty every day.

A CVI journey

I have a disability called cerebral visual impairment (CVI) and although it is now the most common cause of vision impairment affecting children (who grow up to be affected adults) in the developed world (Fazzi et al., 2007), it is a very poorly understood impairment, which is an issue I can relate to. I have lived with CVI for over 20 years now, as a result of a brain injury when I was a teenager. However, for 17 of those years, I was completely unaware I even had this condition! Although it seems hard to imagine now, for most of these years, I did not even realise that the many challenges I faced in everyday life, such as having difficulty mixing in a large group of people, struggling to get through a family meal without knocking over a glass and not being able to navigate my way around an unfamiliar environment, actually had anything to do with my vision at all.

As a result of my impairment not being identified, I adopted certain adaptive behaviours that were often misinterpreted as anti-social, controlling and being obsessed about routines and organisation. Thinking about it now, it is very easy to understand why these kinds of behaviours developed. The main CVI issues I am affected by, including simultanagnosia (an inability to see more than one object at a time), optic ataxia (difficulties with visually guided movement) and apraxia of gaze (difficulty with directing one's gaze to different visual objects) (Dutton, 2015d; Goodale, 2013; Pawletko et al., 2015), caused me to start to doubt my ability to participate in society. Over time, I simply lost all confidence in doing activities that most people take for granted and as an adult I struggled with tasks such as doing the weekly grocery shop for my family, getting money out of an unfamiliar cash machine or taking my children to the playground by myself.

I therefore see myself as fortunate to have finally received the correct diagnosis of CVI. This happened as a result of a chance meeting with an expert on the subject, at a conference for professionals working in the field of educating children with visual impairments. For someone who understands this condition, my visual behaviours were easy to recognise and attribute to CVI. For me, finally getting a reason for my difficulties, was life-changing, as it explained why I find the world so different to those around me. Getting the right diagnosis, therefore, helped me to understand myself again, which allowed me to start developing strategies to help alleviate the effects of my visual difficulties. This in turn, resulted in me slowly rebuilding my confidence in my ability to participate in society again. However, as I have learnt the hard way, simply getting a diagnosis of CVI does not make it obvious to the general public or even to the people close to you, including family and friends, what your specific needs are.

The reason for this is that I am an independent, professional adult and CVI is my only impairment, so I do not look any different to the next person. I can walk down the street and blend in with the crowd, as I do not use a mobility cane (out of pure stubbornness and possible denial of the potential benefits), or have a guide dog, which are often seen as the symbols of blindness and low vision. This means, that to the outside world, I look just the same as everyone else going about their daily business and therefore everyone just assumes that I do not require any assistance – which is exactly how I want it to be, most of the time.

Unfortunately, however, this also means that people do not see the intense emotional struggle that occurs every time I walk in a busy, crowded environment. People do not see the constant battle of trying to fight the vision issues, which cause strangers to loom unexpectedly at me from all angles, which at times can be very frightening. People do not see my confusion, knowing that often things are not where my eyes seem to tell me they are, and I know I will embarrass myself by either grasping at thin air or knocking things over. People do not see the constant game of roulette that I face, while trying not to barge into unsuspecting pedestrians because I have misjudged their movement and inaccurately mapped the environment around me. People do not understand the unconscious emotional reactions I have developed from past negative experiences that cause me to feel anxious without really understanding why. These emotions exacerbate the exhausting impact of being constantly on the alert, with my brain's primitive fight or flight response ready to trigger at any moment and cause me to completely panic. People do not see that at the same time as all of this, I am trying to achieve the almost impossible task of attempting to look normal and totally in control. If the people around me were aware that I was constantly battling this internal turmoil, they would realise that at times I am not actually a capable adult at all, and I would be exposed as a fraud; an exposure that I am constantly fighting against.

However, there is a problem with keeping this inner turmoil hidden. When my CVI causes me to do something that seems unacceptable to the general public, such as knocking over a small child, whose unpredictable movement is impossible for me to follow, or stepping out in front of a car or a bike on the road that I just did not see, I do not get the special considerations someone with a disability might receive. Instead, when these kinds of encounters have occurred, I have been yelled at and abused for being careless, self-absorbed and not watching where I am going. Most people can brush off an experience like this as simply a moment of inattention and an accident, but not me. I have experienced humiliating encounters such as this on so many occasions in the last 20 years that it has slowly eroded my confidence in being in society, and on many occasions has resulted in my doubting my ability to even leave the safety of my own home.

At other times, forcing myself to cope in challenging environments has led to a state of being in which I am so incapacitated by the overwhelming amount of sensory information swamping my already reduced cognitive processing abilities, that I am unable to function in any normal way. This state has been referred to as a “CVI meltdown” (CVI Scotland, 2019b). When I am subject to a CVI meltdown, I am functionally blind and cannot move independently, I also lose all of my cognitive abilities and cannot even string a sentence together or understand what people are saying to me. Being in this state is incredibly emotionally overwhelming and I often panic that I am not going to be able to save myself from the situation. A good example of experiencing a CVI meltdown in a public arena was the time I decided that I would try and walk up the main shopping area of Melbourne by myself, while visiting the city for a conference. After having spent three days in this unfamiliar environment, I was already physically and emotionally exhausted from the extra exertion it took just to map my new surroundings. Therefore, this seemingly simple feat of walking up town by myself may have already been outside my capabilities at the time and it was probably extremely foolish of me to even try. However, I was urged on by a strong sense of determination and just a small touch of stubbornness to carry on with this activity, which I had been planning for a couple of days. As the storm clouds of a CVI meltdown started to gather, I became increasingly more terrified that I would get lost and be unable to find my way back to anywhere that was remotely familiar. Although I am quite capable of looking after myself when in a cognitively conscious and functioning state, and know what to do if I feel that I need help, this all changes when I am completely overwhelmed by my visual disabilities. When experiencing a CVI meltdown, I am powerless and unable to implement any strategies that will help me to get through this. In most situations, I also do not really know what I perceive to be the terrifying monster I am facing and fighting to get away from. I cannot articulate the terror I am feeling in any way and I understand, that to anyone else, it just seems incomprehensible that I could be so frightened by the world around me. During my walk in Melbourne, the full impact of my CVI meltdown saw me cowering in a corner between a shopfront and a building column, trying desperately to find enough oxygen in the air to stop myself from passing out.

The very nature of my CVI means that I am constantly walking a tightrope between the able-bodied and disabled worlds. A tightrope that I often have no control over when I am going to fall. At times, however, the disparity of living between these two worlds – going from being totally independent and fully capable one moment, to being completely overwhelmed by my visual issues and requiring assistance the next – is soul destroying. Each morning I wake up wondering how much my visual impairment is going to impact on me over the course of the day. Depending on the environment I am in and my emotional state at any given time, I can move from being almost fully sighted and fully functional, to having low vision and needing some assistance to move around, to being functionally blind and struggling to make decisions for myself, all in a matter of minutes. I constantly have to weigh up the relative benefits of declaring my disability in different situations and trying to explain to the people around me how I am affected (which is no easy task, as CVI doesn't just have a simple explanation one can spout out to people and expect them to understand straight away), or keeping my situation to myself and maintaining the fierce independence my personality mostly demands of me.

But as I have learnt the hard way, desperately holding on to a level of independence out of pure stubbornness can actually do more harm than good, especially in this fast-paced, modern world we live in. Take, for example, a challenging situation I experienced when trying to fly domestically after a work trip away. As anyone who does this regularly can appreciate, the irritating announcement over the loud speaker that your flight has been cancelled and that you need to retrieve your luggage from the baggage-claim area and re-check in for alternative flights, is something we all dread. For most people, although frustrating, completing the required steps would be relatively straightforward. However, this may not be the case for someone who is in an unfamiliar airport and who went through the initial check-in with a colleague, so did not take any notice of where the desks were, but is now by themselves and most importantly, they have CVI. This is the situation I found myself in, and the debilitating effects of anxiety and panic kicked in before the announcement had even been completed. For me it was like the perfect storm. I was already tired from a mentally draining couple of days of intense new learning and now the thought of not getting home to my family that night was enough to send me into a downward spiral. I’m sure most people can understand the emotional upheaval of disrupted travel plans, but it’s the impact of these emotional behaviours on one’s already impaired visual functioning skills that is often the final nail in the coffin for someone with CVI. As I panicked, the world started to visually crumble around me. I was unable to read signs and I did not feel that I could move safely among the throngs of other travellers, as I couldn’t work out whether the tiles on the ground in front of me were flat or actually steps. I also had difficulty hearing any further announcements and instructions over the loud speaker, and I could not establish where I was and where I needed to go. All I wanted to do was slump to the floor and cry. Imagine that! A grown woman, professionally dressed and clutching a lap- top bag, collapsed on the floor sobbing! Although I had enough cognitive ability left to realise that this wasn’t going to help, I did not have enough functioning to do much else. So, I did something that I find extremely difficult – I asked for help. However, again, my hidden disability fooled the general public and the airport assistant simply started spouting off directions for where I needed to be. Another CVI-related issue is that I am unable to mentally picture or map a verbal image or directions, so after his first “turn left at” I was more lost than ever. This nightmare threatened to continue unabated, as I stumbled around the airport, fighting the tears from rolling down my cheeks. Luckily, I was saved from this nightmare, when I was rung by an assistant from the airline to inform me of the cancelled flight (something I obviously already knew). To this hero on the phone, I simply said that I was visually impaired, that I was lost in the airport and that I did not know where to get my bag from. She straight away detected the emotion and panic in my voice, and simply told me to stay where I was and that she would send someone to find me and help. My faith in humankind’s support of people with disabilities was completely reaffirmed that day, as a kind and compassionate airline assistant located me after I had given a couple of landmarks as to where I was, took care of getting my bag and checking me into an alternative flight home. She then personally guided me to the gate lounge where I could wait and recover in relative peace.

Having the flawed character trait (for someone in my situation) of always fighting to be independent, the thought of needing to be rescued was something that I thought I would struggle to deal with. However, this experience actually taught me an important life lesson. I have a disability that most of society is not even aware of, and consequently, does not really understand. It is therefore up to me to make my disability known and understood. Not only is it important for me to do so, it is also my responsibility as a disabled person, especially for everyone else that also lives with CVI. People in general are very willing to help those in need, which is some- thing we see on a daily basis all over the world. However, to do so, people need to be given the opportunity to understand what one is dealing with. No one can possibly help if they do not understand what the world is like for someone with CVI.

With this enlightened awareness, I have been able to develop simple strategies to help make these situations somewhat easier to cope with. For instance, while in crowded and cluttered environments, I make sure I give myself regular breaks away from the noise and visual clutter, to give my brain a chance to unwind and reset, before it has to wind up again and interpret the chaos around me. This is an extremely important strategy and has saved me in situations similar to the Melbourne shopping expedition, and stopped the CVI storm clouds from rolling in on a number of occasions. Implementing this approach can be as easy as finding a quiet spot where I am away from crowds. If I cannot find somewhere to remove myself to, I simply shut my eyes and use mindfulness breathing techniques to block out the other sensory information, such as noises and smells. I also better understand the limits of my capabilities and do not venture into environments that I know will be difficult for me, such as a hectic shopping mall on Christmas Eve. I now take more notice of my emotional state and fatigue levels, and make sensible decisions about whether I will be able to handle different situations and events, such as going out for dinner at a busy restaurant after a stressful day at work. I have also recognised the importance of having “safe places” (CVI Scotland, 2019a) that are clutter free, quiet and peaceful for me to be in. A safe place is somewhere that I can regularly retreat to when I am feeling overwhelmed by the events of everyday life, even when I am away on holiday. The most obvious safe place is my home environment, however, I have also learnt to turn hotel rooms and outdoor environments, such as the beach, into safe places as well. Probably the most important strategy I have implemented, and the one that was the hardest for me to develop, was being open and honest with the people around me, and explaining my visual needs to them. This has made it easier to ask for help when needed, as people then understand what I need and why.

However, this has only become possible because I have been granted the gift of awareness and an in-depth understanding of my disability. I now understand the basic science of how the brain processes vision and how the different visual issues associated with CVI impact visual processing. I have also explored this further and have a clear understanding of how this impacts me specifically. For instance, because of my simultanagnostic visual dysfunction, I am aware that I am never going to be able to locate someone in a crowd of people. When meeting people, I therefore, ask them to find me, and so I plant myself in a certain location until they have spotted me, instead of my trying to search for them. I know this will be a fruitless search that will result in my becoming highly anxious and stressed and dealing with even further reduced visual function. Another example, is around my mobility in a crowded moving environment. As a result of my difficulty with creating an effective 3D map of the environment around me, especially when there are lots of visual and auditory distractions, I know I am going to miss obstacles, possible hazards and sometimes even people. If possible, I therefore ask to be sight guided by family, friends and colleagues.

Having the awareness that my disability can impact upon me more on some days than others, due to both external and internal factors, is also very important. As I have already explained, external factors such as the nature of the environment I am in, the number of distractions around me, issues with glare and lighting and internal factors such as my emotional state and fatigue levels, are elements I have to take into consideration every time I prepare myself to leave the house. Unfortunately, disasters can happen when I do not consider these factors. Recently on a whim, I decided to venture out on what should have been a straight-forward trip to my local shops to purchase a birthday present for my niece. On this day, I was quite fatigued and stressed after a busy morning at work. It was also very windy and bright outside, and the glare was making it difficult to see clearly. Not long after leaving the office, I noticed someone had left a stack of papers on the roof of their car while unlocking their car door across the street to my left. In an instant, I became completely engrossed in watching this person desperately trying to catch each page as they all started to flutter away down the street. I continued walking while watching this comical scene on my left, quietly chuckling to myself at their misfortune, when suddenly out of nowhere something attacked me on my right. I was instantly knocked to the ground and my heart started to pound as I struggled to get to my feet ready to run away from this daring midday attacker. Imagine my horror, when instead of turning to face this unknown assailant, I was greeted with a peaceful, sturdy parking meter that had always been there. It hadn’t moved, it hadn’t sprung up out of nowhere, it had just been completely invisible to me on my right-hand side. The distraction of someone else's misfortune had inadvertently caused my own visual inattention to kick in and I had forgotten all my rules of safe travel. Some might say it was justice served for laughing at someone else's expense, but the impact of the sudden collision severely jolted my head, causing a painful headache that lasted a couple of days, cracked a back tooth, injured my knee and severely bruised my pride. A lesson learnt in the most brutal of ways.

This incident served to remind me that it is difficult for me to be spontaneous and attempt to do something without fully considering the different aspects of a specific situation first. On this day, I did not think about how I was feeling, or whether I had enough energy to be able to maintain full concentration and visual attention while navigating my way through the unseen hazards and people on the busy city streets. The distraction caused me to turn my focus from the footpath in front of me and the resulting lack of visual attention had a disastrous effect. Although this was one of my worst vision-related accidents, there have been many others like this, which have caused me to adopt certain behaviours in order to try and keep myself safe. Most of the time, I am now a very cautious person. I also feel like I have to be in control of what is happening around me and what activities my family and I are going to participate in so that I am able to prepare myself beforehand for every potential issue that may arise during the activity. I find it hard to enjoy activities that have been sprung upon me when I do not have any time to prepare myself, especially when they are in unfamiliar environments. I also need to know if there is going to be a safe place for me to escape to whenever I am away from home, which can make holidays difficult. Unfortunately, these behaviours make me look like a very controlling and demanding person. But as I have just highlighted, at times it is necessary to be like this, in order to function in a world where my visual issues make it hard to understand the scene in front of me.

In some situations, however, I have been able to make changes to the way I go about living my life, to ensure that I am able to alleviate some of the more disabling effects of my visual condition in certain situations. An example of this is when I am participating in the enjoy- able social activity of eating out at a café or restaurant. Before I understood my visual needs, I would blindly enter different eating establishments, sit somewhere at random and struggle to cope for a period of time, before I would inevitably have to leave, as a result of experiencing another CVI meltdown. This occurred because I never thought of trying to make the situation better for my specific needs. I never thought about what the actual venue would be like, whether it would be cluttered and crowded with lots of tables and chairs that would make it difficult to move through, whether the lighting would be bright enough for me to see easily or whether it might be so dim that I would struggle to even read the menu. I never used to think about where I sat at the table or what I was viewing in front of me from that position. The reason for this is that I never considered that these factors could actually impact on how well I was able to function in these environments or how long I was able to stay there (most of the time, it was only about an hour at the most). Having to leave early all the time, as a result of challenging visual environments making me feel physically ill and triggering a severe headache, is something that I find incredibly frustrating.

But once I did start taking my visual needs into consideration, I was able to engage in this kind of activity more easily and I found that I also enjoyed these social outings a lot more. If possible, I now preview different environments to make sure they are “CVI friendly”. In my hometown, I have a number of different locations that I like to go, as I know I will not be so affected by my visual difficulties in these spaces. So, whenever possible, I organise it so that these are the venues we go to for different events, such as birthday dinners and nights out with friends. Specific requirements of these venues are that they are well lit and that any hazards are easily identifiable. For instance, the edges of steps and any trip hazards are painted a contrasting colour so that they stand out and easily grab my visual attention. I also ensure that all signage is clear and easy for me to read, especially bathrooms, which reduces the risk of an embarrassing incident, such as walking into the men's toilet (it is surprising how many men's and women's toilet signs are incomprehensible when one is highly stressed and visually not functioning well). I also think carefully about where I am going to sit within the restaurant and try to be the first person to sit at the table so that I get the most optimal spot before others join me. It is important for me to be facing into as blank a scene as possible, as this will reduce the visual distraction and allow me to converse with others more easily. Now that family, friends and colleagues understand this need, they have no issue with letting me pick my seat first.

For me, another important aspect of suitable eating places is that they do not have loud music playing in the background and that the space does not create an echo. Other people with CVI have described the difficulty of being able to concentrate on visual information in front of them when there is competing auditory information and vice versa. I know that for me, I find it impossible to hear what someone is saying if there is competing noise and an overload of visual information. I generally have to choose between listening to what my friends are saying and shutting out all the visual imagery, or viewing the visual scene and switching off to what they are saying. Of course, this also means that sometimes I have to be a bit ruthless about who I am going to be sitting next to. If I do not make a wise decision about my dinner companion, I can spend the entire night completely disengaged from everyone else, because I am unable to block out the one loud person sitting next to me.

However, as we all know, it is not possible for one to always pick the particular destination of a social gathering or work-related function or pick who you are going to sit next to. For this reason, I often find myself having to deal with challenging situations in unfamiliar environments, most of which I am unable to preview prior to the event. From experience, I know that after only a short period of time, I will struggle to function both visually and cognitively in these environments and this has led to changes in my social interactions and the development of specific, sometimes even anti-social, behaviours. A good example of this is the creative strategies I have developed to avoid being greeted by an acquaintance or friend with a kiss on the cheek. One of my main CVI-related issues is that I have a right-sided hemianopia as well as right-sided hemi inattention, and I quite often forget that I even have a right side at all and walk around oblivious to anything happening to the right of me (one day I left the house only brushing the left side of my hair and I sometimes leave half the washing on the line!). This means that when someone is coming into kiss me on the cheek on my right side, I often do not even know they are there until I feel their warm breath and gentle touch of their lips on the side of my face. As one can imagine, I find this sudden invasion of my personal space very frightening and the physical reaction of jerking my head away in surprise and panic has resulted in many a comical accident, including kisses on the neck, head butts and even for one unsuspected greeter, a kiss on the lips. Not only do these incidents humiliate me (and often the person who was simply trying to greet me), they also cause me a great deal of anxiety leading up to different events, as I spend hours trying to establish how I can avoid the whole greeting experience. However, the tactics that I use, such as standing at the back of the group and not making eye contact with people, or not responding to their greeting advances, just make me look rude and unfriendly.

There are many other situations that cause others to view me in this light – as someone that is impolite, aloof and who does not actually enjoy spending time with others. Most of the time, I can understand why I may be viewed like this. I often do not respond to people waving at me or calling out to me from a distance, which people assume is because I do not want to talk to them. When in fact, it's because I haven't even seen or heard them. I sometimes struggle to make eye contact with people while talking to them, because of any visual distractions in the environment behind them, which my gaze gets constantly drawn to. So I avoid large group discussions to reduce the chances of coming across as bad mannered and inattentive. I often pull out of social activities at the last minute, because on the day I have realised that I am actually just too exhausted to attend, which means people have stopped asking me to join them at different events. I am always the first person to leave any large social gathering to ensure that I avoid the stress and embarrassment of suffering another CVI meltdown in public, which again makes me look anti-social. The knowledge that I am autobiographically portraying this social outcast persona, is something that upsets me greatly, because this is not who I really am. I would love to be the last person to leave a party for once. I would love to feel comfortable and confident mixing and mingling in different social settings, and to initiate the kissing on the cheek of an old friend I have not seen in a while. And I would love to be known as a social, easy going and relaxed person.

I used to think this was the price that I had to pay for being able to continue walking the tightrope between the able-bodied and disabled worlds. But as I continue down this journey to CVI enlightenment, I am beginning to see the world a little bit differently. I have, therefore, realised that this might not be the best way forward. After only recently being empowered through the correct diagnosis for my difficulties, for the first time in over 20 years, I have now started to embrace the uniqueness of my life with CVI. For a long time, my impairments have been a big part of who I am and have, at times, restricted me from participating in different activities. However, I now know that these impairments do not define me. I am a person first and foremost and it just so happens that I have a "different normal" brain, which has created a very complex visual world for me. When I am open and honest about what it is like to live in this world, people are quick to accept the way I behave and the actions I take – no matter how strange it might seem!

When I sit back and think about this, I have also come to realise that it is important for me, as the disabled person, to have more faith in the way that society perceives me and my abilities. This is a message that I would like others affected by CVI to embrace. Fortunately, as a professional working in the field of education and rehabilitation of children who are blind or who have low vision, I am in the position to be able to pass on this positive belief in humankind to the children I work with, their families and support teams. I have finally learnt that when armed with an effective CVI toolbox full of diverse strategies and approaches for dealing with different challenging situations, and combining it with the knowledge that if I explain what support I need from the people around me, I do not have to continue through life worrying about which side of the tightrope I am going to fall on any given day. In fact, I do not have to worry about walking the tightrope at all. I can continue on, not living in two worlds, just living in one. A world that accepts me for who I am. And hopefully, by sharing this insight, children with CVI will grow up never experiencing what it is like to live life walking on a tightrope.

Conclusion

But I need help to make this happen. Society as a whole needs to understand what the world is like for those of us living with CVI and learn to interpret our behaviours and emotional responses. Especially when it relates to children. Teachers need to understand that the tantrums, aggression, crying and refusal to participate in different activities, might not actually be the child being defiant, not being interested in learning or not being able to participate in a formal educational setting. The child may simply be terrified by the frightening visual scene he or she cannot understand and is constantly on high alert, waiting for the CVI meltdown clouds to roll in once again, but is unable to articulate to anyone what they are experiencing. The adults around these children also need to realise that there is a reason for the child's controlling and demanding behaviour and it's not simply a way of getting more attention. Family and friends need to understand that the anti-social behaviours that both children and adults display, is not by choice. These behaviours are a necessity to be able to continue functioning in what can be a very confusing and exhausting world at times. People also need to realise, that often, we need help to feel safe in different environments, even when they are familiar to us. We need people to understand that clutter and crowds seem like terrifying monsters and make us feel that our lives are constantly being threatened. We also need to know that our emotional reactions in different situations will not be misinterpreted or trivialised. But most importantly, all of us with CVI, including both children and adults, need to know that it is acceptable for us to use whatever behaviours, strategies or methods we need to get through each day – even when they do not make sense to anyone else. With global acceptance of this, over time, we will learn to trust the world around us and be at peace with who we are.

Chapter conclusion

This chapter is a published chapter in the *Routledge Handbook of Vision Impairment* and outlines the researcher's personal perspectives of living with CVI. The chapter relates to the overall aim of developing an effective framework for supporting children with CVI by specifically addressing the first two research questions: What profiling and intervention strategies to improve visual and overall functioning can be extrapolated from the researcher's own experience? and What role does the attainment of knowledge play in empowering a person with CVI? The researcher was able to answer these questions by using a process of researcher reflexivity to explore her own experiences of improving her visual and overall quality of life after receiving the diagnosis 17 years after acquiring the condition as a teenager. As with Chapter 3, the intervention strategies extrapolated from the researcher's own experience were outlined in this chapter. These included visual field training, implementing conscious viewing and wagon wheel visual fixation, regular mindfulness practice, quiet spaces, and implementing calm breaks in challenging environments.

In terms of the overall research framework, this chapter is in line with the theoretical perspective of dialectical pluralism as the *Routledge Handbook of Vision Impairment* is a cross-disciplinary text that provides a bridge between medical practice and social and cultural research. It, therefore, includes, the perspectives of the different stakeholders involved in supporting people who are blind or who have low vision. As a person with a visual impairment, the researcher's own voice is recognised as an important stakeholder within the field and provides a unique contribution to the international literature.

Chapter Five – The Austin Playing Card Assessment

Chapter introduction

The Austin Playing Card Assessment is an assessment tool the researcher developed while working as an education specialist supporting children who are blind or who have low vision. While completing a simple maths activity of matching playing cards with a young boy who had cerebral palsy and CVI, she realised the difficulties he was having with completing the activity related to his visual difficulties associated with CVI and not his maths ability. From this, the idea of using an activity of matching playing cards to identify and characterise the degree of visual perceptual difficulties related to clutter was developed. The researcher then designed and tested a protocol for using the assessment, which became known as the Austin Playing Card Assessment. This article reports on the pilot study that was conducted to test the effectiveness of the Austin Playing Card Assessment to detect visual perceptual difficulties related to clutter.

This article relates to the overall thesis aim of developing an effective framework for supporting children with CVI; more specifically, the first component of the CVI practice framework of developing individual CVI profiles. The Austin Playing Card Assessment can be used in conjunction with other functional vision assessments, as part of a wider process to develop a child's individual CVI profile.

McDowell, N. (2020). A pilot study of the Austin Playing Card Assessment: A tool to detect and find the degree of visual perceptual difficulties related to clutter. ***British Journal of Visual Impairment.*** **https://doi.org/10.1177/0264619619896008**

Abstract

The Austin Playing Card Assessment was developed to help identify visual perceptual difficulties related to clutter and to determine the nature of each child's difficulties. The aim of this pilot study was to find out whether a task of progressively increasing difficulty, for pairing playing cards, is effective in identifying these kinds of visual difficulties. Parents of 11 research and 11 control subjects completed an inventory to ascertain whether their child's visual behaviours were suggestive of visual perceptual difficulties. All participants completed the Austin Playing Card Assessment in two separate locations, with an ABA experimental design. The time taken to complete each level of the test was recorded. Structured observations were made of the participants' visual behaviours when completing the assessment. Inventory scores from the research subjects indicated a higher likelihood of visual perceptual difficulties, whereas the control subjects' scores did not. Research subjects were also slower at completing the Austin Playing Card Assessment. Independent T-tests comparing the time taken across all levels of difficulty ranged between $p = .011$ to $p < .001$. Cohen's d calculations demonstrated a large effect size. Overall, research subjects demonstrated more indicators of visual perceptual difficulties. The Austin Playing Card Assessment has the potential to be effective for detecting and identifying visual perceptual difficulties in children. Information gathered through the assessment process could also be used to inform intervention. As this was a pilot study, further research is needed to support these findings.

Keywords

Assessment tool, cerebral visual impairment, clutter, visual perceptual difficulties

Background

In the last 30 years, there has been a change in the causes of childhood visual disability. Previously, the main cause was ocular pathology, such as congenital cataracts and retinopathy of prematurity (Fazzi et al., 2007). Now these ocular conditions are detected earlier and treated more effectively, but improvements in postnatal healthcare have led to an increased incidence of cerebral visual impairment (CVI) (Chong & Dai, 2014). CVI is caused by damage to parts of the visual brain (Lueck & Dutton, 2015) and can result in a range of impairments, including decreased visual acuity (ranging from mild to moderate impairment to blindness), reduced contrast sensitivity, visual field deficits, eye movement disorders, and difficulties in image processing or interpretation (visual perceptual difficulties) (Ortibus et al., 2011b; Williams et al., 2011). While some visual impairment can be detected in a clinical setting, others may not be (van Genderen et al., 2012). Williams et al. (2011) highlight that visual perceptual difficulties are not sought in most paediatric eye clinics, with the diagnosis of visual impairment being based on a singular criterion such as visual acuity. However, this criterion fails to characterise the overall functioning and potential of a child with visual perceptual difficulties, meaning that children with these impairments often remain undiagnosed (Chong & Dai, 2014; Martin et al., 2016).

One approach to identify visual perceptual problems in children is the validated structured history-taking inventory (Dutton, 2015a; Dutton et al., 2010; Houliston et al., 1999; Macintyre-Beon et al., 2012; Ortibus et al., 2011a) which is an effective tool to use as part of targeted screening for these types of visual issues. The 52-question inventory (Houliston et al., 1999) seeks to elicit vital information about the child's visual behaviour and functioning in different environments based on parental observations. However, further functional assessment of visual perceptual difficulties is also needed to understand the true nature of a child's difficulties and to ensure that support can be matched to specific identified areas (Dutton, 2015a). Concrete examples of a child displaying visual perceptual difficulties while completing a functional task may also help parents and practitioners better understand how these difficulties look in everyday activities. This further assessment needs to focus on the following areas: impairment of visual attention (the ability to mentally highlight specific features or places within the visual field); deficient visual search caused by inability to move the eyes to new targets or apraxia of gaze; disordered perceptual grouping or simultanagnostic visual dysfunction (the ability to combine components of a scene into a meaningful whole); dysfunction of the use of visuospatial information to programme movements that interact with objects in three-dimensional space, leading to inaccurate visual guidance of movement or optic ataxia; and impaired route finding and recognition of objects and people or visual agnosia (Goodale, 2013; Goodale & Milner, 2013; Williams et al., 2011). Unfortunately however, assessment of visual perceptual difficulties is not straightforward because children's visual perceptual abilities can appear differently in the real world when compared with experimental tasks (Williams et al., 2011).

Therefore, to establish effective methods for assessing these kinds of visual difficulties, more needs to be understood about their manifestations and the kinds of environments that exacerbate them. Recent research by Josef Zihl (outlined in a study by Zihl and Dutton (2015)), Bennett et al. (2018), and Goodale and Milner (2013) has identified key features of visual perceptual difficulties, including random search patterns using darting eye movements (quick, repetitive shifts of gaze to different locations in the visual field), increased search times (especially as the complexity increases), decrease in performance when the number of objects and distractions increase, and slower and more inaccurate reaching and grasping of objects. Research by Little and Dutton (2014) and McDowell and Budd (2018) has also shown that cluttered and noisy environments where there is an overload of visual and auditory information, as well as constant movement of others can negatively impact on visual and overall functioning of children with more severe CVI. These findings suggest that to detect visual perceptual difficulties in less-affected children who have near normal or normal visual acuities, assessments conducted in both quiet and cluttered environments (such as a child's classroom) to compare the child's performances, could help identify potential visual issues.

To identify and support the growing number of children with visual perceptual difficulties, low cost, simple, effective, and practical methods for detecting and categorising these issues warrant development. Such methods need to detect whether or not the child demonstrates a number of indicators of visual perceptual difficulties, including darting eye movements, slower processing of the visual scene with increasing complexity (Bennett et al., 2018; Zihl & Dutton, 2015), difficulties with visually guided movement (optic ataxia) (Bennett et al., 2018; Goodale & Milner, 2013), and whether the child is easily distracted by visual and auditory clutter and movement of others (Little & Dutton, 2014; McDowell & Budd, 2018). They also need to be applied in real-world situations, as opposed to clinical settings, to develop an accurate picture of the child's visual abilities. The benefits of designing an easily conducted, accessible assessment that can be used to confirm the information gathered through the history taking inventory, is that the results and information obtained can be immediately employed both intuitively and logically to support the child. This pilot study reports the first phase of development of such a tool and examines its potential as an assessment method for detecting and characterising visual perceptual difficulties related to clutter. It also considers how the information gathered in the assessment process can be used to inform practice and develop intervention strategies for those affected by visual perceptual difficulties.

Methods

A mixed-method research study was used to support the testing of an assessment tool to detect visual perceptual difficulties that the researcher had developed in response to working with a young child with cerebral palsy and multiple visual perceptual difficulties[7]. However, in New Zealand, as with many other countries around the world, children with visual perceptual difficulties are not often being diagnosed with CVI, especially if they have normal or near normal visual acuities (Chong & Dai, 2014; Fazzi et al., 2009; Gorrie et al., 2019; Martin et al., 2016). Therefore, to obtain participants for this research, children with developmental disorders were also considered, as many of these conditions have been shown to also have visual perceptual difficulties that overlap with CVI. For example:

- Autism spectrum disorder (ASD) has been shown to have facial processing and discrimination difficulties, abnormalities of visual acuity, contrast sensitivity, colour discrimination, visual form processing, orientation attention, and disorders of oculomotor control (Behrmann et al., 2006; Dakin & Frith, 2005; Milne et al., 2009; Pawletko et al., 2015; Simmons et al., 2009).

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[7] The child's name was Austin and the idea for the assessment developed after completing a maths activity involving matching playing cards. Austin had difficulty completing the acitivity and the researcher observed many of his visual perceptual difficulties during the activity. Austin's parents have given permission for the assessment to be named after him.

- Attention-deficit hyperactive disorder (ADHD)/attention-deficit disorder (ADD), where children can be seen to be inattentive, which can include difficulties with visual attention (Pawletko et al., 2015).
- Dyslexia, which is described as difficulties with visually processing words and difficulties with reading (Pawletko et al., 2015; Stein, 2018).
- Developmental coordination disorder (DCD)/dyspraxia which can cause visuospatial difficulties (Chokron & Dutton, 2016).
- Auditory processing difficulties which can cause difficulties with processing auditory and visual information at the same time (Dutton, 2015c).

Parents were invited to nominate their child for the research if they were concerned about their visual abilities, and they had been diagnosed with one or more of these conditions. Children could also be referred if they had difficulty in certain subject areas, such as mathematics and reading, as these subjects have been shown to be more problematic for children with visual perceptual difficulties (Reijneveld et al., 2006; Williams et al., 2011). Advertisements for the research were placed in four local schools' newsletters and on relevant Facebook parent support groups. Children between 6 and 11 years were sought to ensure that relevant issues had been identified and that they were old enough to be able to match playing cards. The research was approved by a University Human Ethics Committee.

Fifteen children were nominated for the research by their parents, with 11 children meeting the inclusion criteria. This was based on positive responses to three or more of five screening questions (Appendix B (12)), which have been assessed as suitable screening questions for identifying children who warrant more detailed evaluation (A. Chandna, personal communication, April 15, 2018) taken from the (Dutton et al., 2010) validated history-taking inventory. Once participants had been identified, the researcher visited each child in their home and with their parents, completed the full history-taking inventory to ascertain the pattern and degree of their visual difficulties.

Next, the assessment procedure under investigation, the Austin Playing Card Assessment, was conducted at each child's school on three separate occasions, in two different environments. The testing process followed an ABA format, which involved the assessment being conducted three times in two different environments to measure the participants' behaviours repeatedly within two different settings (Ary et al., 2014). The A1 assessment was conducted in a quiet, uncluttered environment away from the child's classroom. Assessment B was conducted within the child's classroom environment, while other students were following their usual routine. Finally, assessment A2 was conducted in the same room as the first assessment (A1). This design allowed for the evaluation of the impact of ambient clutter, noise, movement, and other distractions, upon visual functioning skills, as well as providing repetition of the assessment to seek pattern or consistency in the child's behaviour over time (Ary et al., 2014).

The control group of 11 age- and gender-matched children, who responded negatively to the five screening questions (indicating that they had not been observed to have visual perceptual issues) also completed the history-taking inventory, as well as the three separate tests of the Austin Assessment using the same ABA design.

Participants

Within the research group, seven participants had a range of diagnoses, including ASD, ADHD/ADD, dyspraxia, and auditory processing disorder. Two participants were under investigation for either ADHD or ASD. Two participants had not been diagnosed with any condition but were having difficulties at school with certain subject areas, including mathematics and reading. The final two participants both had medical backgrounds known to be associated with CVI, namely a hypoxic event at birth, and a brain tumour with hydrocephalus (Macintyre-Beon et al., 2013; Soul & Matsuba, 2010). All children were in mainstream classrooms, with only two requiring individual teacher aide support[8] (as shown in Table 5). All children had normal or near normal visual acuity apart from the participant who had experienced a brain tumour at age 2. For this participant, recent ophthalmological reports had differing visual acuities noted, ranging from 6/12 to 6/24 and no documented eye condition to explain this. Before starting the assessment, the researcher checked that this participant was able to see the images on the playing cards and there were no difficulties.

The 11 children in the control group did not have any such diagnoses and had no relevant issues at school.

Table 5. Research group participants

Participant	Gender	Age	Diagnosis	Individual teacher aide support in class
1	Female	9	Difficulties with reading	No
2	Male	6	Being assessed for ASD or ADHD	No
3	Female	9	Dyspraxia	No
4	Male	8	ADD	No
5	Male	8	ASD	No
6	Male	6	Being assessed for ASD or ADHD	No
7	Male	7	Dyslexia, Auditory processing, ADHD	Yes
8	Female	6	Difficulties with reading and maths	No
9	Female	10	Hypoxic event at birth	Yes
10	Female	11	Brain tumour, hydrocephalus age 2	No
11	Male	9	Auditory processing disorder	No

ASD: autism spectrum disorder; ADHD: attention-deficit hyperactivity disorder; attention-deficit disorder

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[8] Indicating higher learning needs.

Procedure

The Austin Playing Card Assessment process involved laying out pairs of playing cards in rows and columns on the table in front of each child while their eyes were closed. To ensure random placement, the cards were shuffled in advance. Once the cards had been placed, the children were asked to open their eyes, find and pick up the pairs, and pass them to the researcher. To ensure initial success and to maintain motivation, they were scaffolded into the assessment by progressively increasing the number of cards laid out in front of them. The first level commenced with four cards including one pair. This was increased by two cards for each level, until the fifth and final level of 12 cards contained five pairs. The cards used were standard playing cards with large numbers, letters, and shapes. Each level included at least one picture card pair to increase visual complexity and a nonmatching pair. Among the cards for levels 4 and 5, were 6s and 9s to see if the similarities between the numbers would cause recognition difficulties for any of the children (as shown in Table 6).

All assessments were video recorded for detailed further analysis and to time the process of finding the pairs at each level. Video analysis by the researcher, entailed qualitative observation methodology to seek behaviours indicative of specific issues related to vision and attention (Kran & Mayer, 2015). Following the video analysis and the creation of research and control participant observation tables of visual difficulties (as shown in Table 9), the masked videos were assessed by another vision education specialist to determine interrater reliability (IRR). Prior to analysing the videos, the second assessor completed a tutorial outlining how to analyse the videos and what specific indicators to focus on. Following the two analyses, the observation tables were compared and an IRR calculation was conducted for nominal data using Cohen (1960) kappa.

Data analysis

Each aspect of the research process (the history-taking inventory, the time taken to find the pairs, visual difficulties observed, and difference between assessment environments) was analysed separately to determine the value and importance of each aspect in detecting and determining the degree of visual perceptual difficulties related to clutter.

Table 6. Austin playing card assessment process

Assessment levels	Instructions for level
Prior to starting assessment and in between each level of the assessment	Participants were asked to sit at a table opposite the researcher. In the quiet assessment, participants were faced into an area of wall with very little clutter, for the assessment into the classroom, they were faced into the classroom. Participants were asked to close their eyes as the cards were laid out in rows and columns on the table in front of them When the cards were laid out, the participants were asked to open their eyes, find the pairs and pass them to the researcher
Level one (one pair)	4 cards, 1 pair Cards included: 2 black kings, black jack, black 8
Level two (two pairs)	6 cards, 2 pairs Cards included: 2 red eights, red 6, black 10, red queen, black queen
Level three (three pairs)	8 cards, 3 pairs Cards included: black jack, red jack, red 4, red. 3, black 3, red 2, black 10, red 10
Level four (four pairs)	10 cards, 4 pairs Cards included: 2 black sixes, black 7, red jack, red 7, 2 red kings, 2 black 2s, red 9
Level five (five pairs)	12 cards, 5 pairs Cards included: red 6, red 9, black 9, black 8, red 5, black 5, red 7, black 7, red queen, black queen, 2 black 4s

In addition: Participants were given the opportunity to check again if they mismatched a pair by being asked “are you sure they match?”, but were never told they were wrong. Participants were not told they were being timed. Participants were allowed to move the cards around anyway they wanted before picking up the pairs and passing them to the researcher.

Each child’s history-taking inventory was colour-coded into the seven specific visual areas covered: visual fields, perception of movement, search, guidance of movement, attention, crowded scenes, recognition and navigation (Macintyre-Beon et al., 2012). The responses were scored on a 1 to 5 scale, to match the 5-point Likert-type scale used in the inventory (1 = Never and 5 = Always) (Macintyre-Beon et al., 2012). Overall scores for the whole inventory and scores for each section were collated.

The length of time it took each child to find all of the pairs at each of the five levels was recorded, so that comparisons could be made across the three assessments and between the research and control groups. Independent t-tests were carried out on each level in all three assessments, to compare the means of the research and control groups and to establish if the differences were statistically significant. Cohen's d was also carried out on the t-tests to establish the effect size for each level.

The average times taken by participants of both groups to find one pair when there were four cards and then 12, were calculated by averaging each child's B (conducted in the classroom) and A2 (the second assessment conducted in the quiet room) assessments. The first level of the A1 assessment (4 cards – 1 pair) was excluded, as the times were considerably slower for both the research and control children due to the learning curve. By the second level of the A1 assessment (6 cards – 2 pairs), all the children had understood the test. To calculate the average time to find one pair when there were 12 cards, the B (conducted in the classroom) and A2 (conducted in the quiet room) assessment were averaged and then the total was divided by the number of pairs (four).

An observation table was created based on qualitative judgements of vision and general functioning observed in the videos for both the research and control participants. The observations were divided into the four areas of the history-taking inventory eliciting visual perceptual difficulties comprising visual attention, ability to handle the complexities of a visual scene, visual guidance of movement, and behavioural difficulties associated with crowded environments. If a specific visual difficulty was observed in any of the three assessment videos for any child in both the research and control groups, these were highlighted. An IRR percentage was calculated using Cohen (1960) kappa calculation:

$$k = \frac{P(a) - P(e)}{1 - P(e)}$$

where P(a) denotes the observed percentage of agreement, and P(e) denotes the probability of expected agreement due to chance (Hallgren, 2012).

Two control group children were removed from all the analyses involving the time calculations, as well as from the inventory scores, as behavioural and compliance issues (unrelated to visual abilities) meant they took longer to complete the assessments.

Results

History-taking inventory

In the four sections of the inventory relevant to the Austin Playing Card Assessment, the research participants' scores were much higher than the control participants (as shown in Table 7). The higher scores indicated issues with attention, guidance of movement, crowded scenes, and visual search. On the rare instance where the control participants' parents answered with sometimes, often or always, their responses could be explained by other contextual examples, such as the child not concentrating when moving around the environment, the child rushing to do everything, or a child not paying attention to what they were doing. Overall, the control participants' scores were considerably lower than the research participants in all four areas and in the overall scoring of the inventory, again indicating a higher likelihood that the subjects in the research group had a number of visual perceptual difficulties.

Table 7. Scores on the relevant areas of the history taking inventory (Dutton, 2015a; Dutton et al., 2010)[9]

Participant	Visual Attention (out of 95)	Complexity of a scene (out of 45)	Optic Ataxia (out of 55)	Behaviour in crowded environments (out of 20)	Overall score (out of 270)
Research Participants					
1	60	28	34	17	177
2	51	33	37	19	171
3	54	40	35	16	170
4	68	30	37	19	170
5	47	34	32	17	176
6	54	39	27	20	162
7	69	38	35	20	199
8	47	29	29	16	151
9	62	40	40	20	197
10	77	45	48	16	236
11	55	41	27	15	176
Control Participants					
1	22	15	13	7	72
2	20	14	11	4	63
3	19	11	12	6	68
4	19	9	13	4	60
5	19	13	1	5	65
6	23	11	11	4	65
7	22	11	11	4	63
9	19	9	11	4	57
10	21	16	11	4	66

Scoring: 1 – Never, 2 – Rarely, 3 – Sometime, 4 – often, 5 – Always, 0 - NA

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[9] The 52 question inventory was developed to elicit vital information about a child's visual behaviour and functioning in different environments based on parental observations.

Time taken to find the pairs

For each of the five levels assessed (4 cards – 1 pair, 6 cards – 2 pairs, 8 cards – 3 pairs, 10 cards – 4 pairs, 12 cards – 5 pairs), the research participants were considerably slower at finding the pairs than the control participants (as shown in Figure 6). This finding was consistent across the three different assessments. The range for the control participants was also smaller than the research participants with fewer outliers.

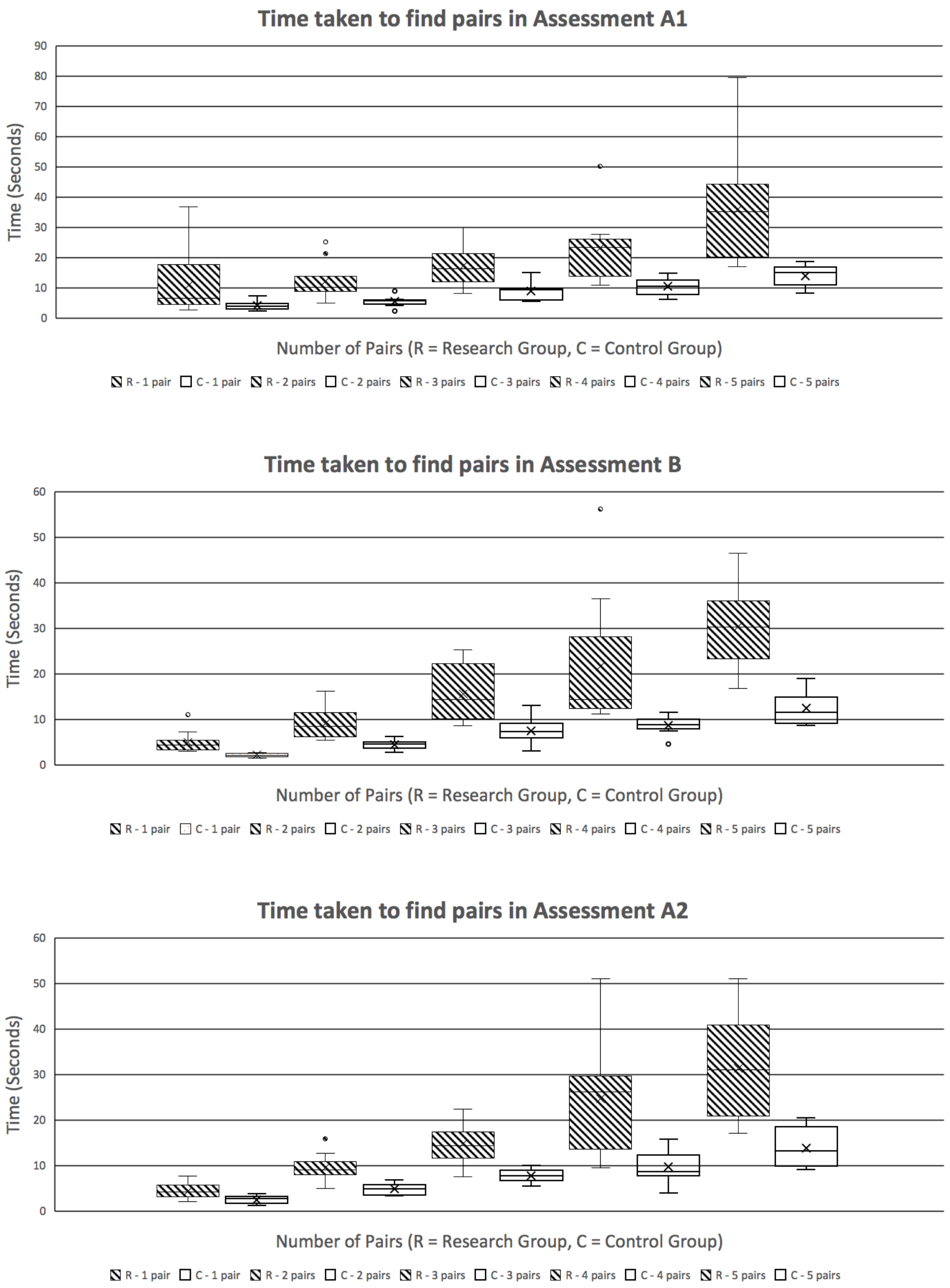
Apart from Assessment A1 (one pair), which was conducted in the quiet room, the results of the independent t-tests show that at each level, the findings were statistically significant, ranging between p = .011 to p < .001 (1.1% – less than 0.1% likelihood that the difference between the groups was due to chance; as shown in Table 8). The result for Assessment A1: one pair can be explained by the fact that children in both groups were often unsure what to do in the first level, so took longer to match the pair. Cohen's d calculations showed that each comparison between the research and the control participants (except Assessment A1: one pair), demonstrated a large effect size; as shown in Table 8).

Table 8. Results of t-tests

		Descriptives			Independent t-test			Effect size	
		n	Mean	SD	t	df	Sig.	Cohen's d	
Assessment A1: One pair	Research	11	10.925	10.188	2.211	10.521	.050	-	-
	Control	9	4.043	1.490					
Assessment A1: Two pair	Research	11	12.213	6.006	3.581	11.974	.004	1.540	Large
	Control	9	5.408	1.729					
Assessment A1: Three pair	Research	11	17.155	6.253	3.691	18	.002	1.715	Large
	Control	9	8.729	3.029					
Assessment A1: Four pair	Research	11	23.158	10.742	3.484	18	.003	1.640	Large
	Control	9	10.279	2.825					
Assessment A1: Five pair	Research	11	35.939	18.195	3.964	10.887	.002	1.697	Large
	Control	9	13.712	3.480					
Assessment B: One pair	Research	11	4.968	2.354	3.865	10.809	.003	1.664	Large
	Control	9	2.170	.430					
Assessment B: Two pair	Research	11	9.091	3.513	4.259	11.997	.001	1.832	Large
	Control	9	4.354	1.017					
Assessment B: Three pair	Research	11	15.621	6.082	3.977	14.634	.001	1.728	Large
	Control	9	7.436	2.803					
Assessment B: Four pair	Research	11	21.642	13.882	3.066	10.493	.011	1.310	Large
	Control	9	8.650	1.974					
Assessment B: Five pair	Research	11	30.495	9.519	5.865	13.076	.000	2.533	Large
	Control	9	12.348	3.467					
Assessment A2: One pair	Research	11	4.379	1.750	3.024	18	.007	1.409	Large
	Control	9	2.431	.871					
Assessment A2: Two pair	Research	11	9.436	2.959	4.438	18	.000	2.073	Large
	Control	9	4.751	1.209					
Assessment A2: Three pair	Research	11	14.748	4.218	5.161	12.616	.000	2.225	Large
	Control	9	7.752	1.408					
Assessment A2: Four pair	Research	11	24.706	11.770	4.030	12.167	.002	1.734	Large
	Control	9	9.627	3.556					
Assessment A2: Five pair	Research	11	31.366	11.013	4.509	18	.000	2.104	Large
	Control	9	13.724	4.349					

Independent t-test, comparing research group times to find pairs with the times for the control group.
SD: standard deviation.

The research participants took substantially longer to find each pair as the numbers of cards on the table increased (as shown in Figure 6), indicating that as the complexity of the scene in front of them increased, they found it progressively more difficult to match the pairs. The control participants' average time to find one pair did not increase to the same extent when comparing the differences between 4 cards and 12 cards on the table (as shown in Figure 7).



Note: A1 assessment was conducted in a quiet, uncluttered room away from the child’s classroom. B assessment was conducted in the child’s classroom during normal class time. A2 assessment was conducted in the same room as assessment A1.

Figure 6. Comparison between research group and control group to find the pairs in each assessment

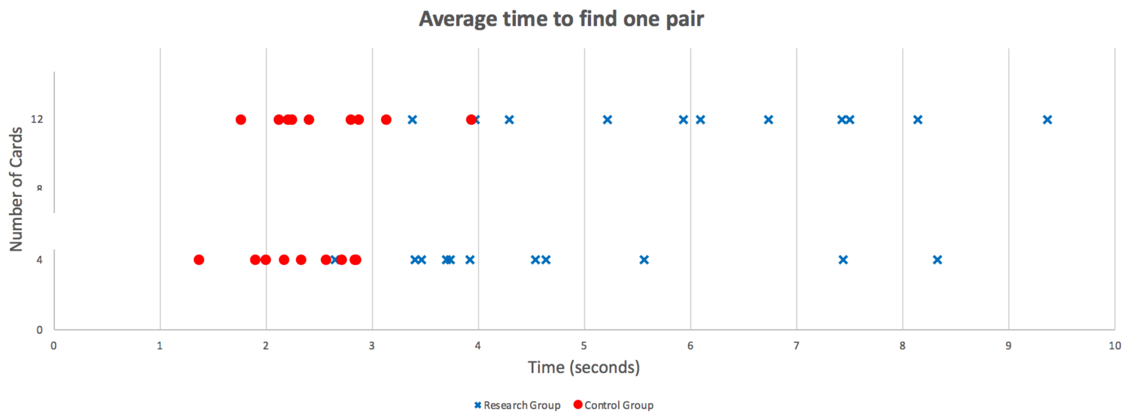


Figure 7. Average times taken to find a pair of cards

Visual difficulties observed

From the detailed video analysis of the children completing the assessments, a number of specific indicators suggestive of visual perceptual difficulties were observed. These indicators were categorised under the following four sections:

1. Visual attention: Mismatching pairs, inability to find all the pairs, difficulty matching picture cards, mixes 6s and 9s, showing signs of distraction, stares/fixes on cards without seeing them, head movement, adaptive eye movements, and darting eye movement.
2. The ability to handle the complexities of a visual scene: focus on one card/pair at a time, cannot match cards while talking.
3. Visual guidance of movement: accuracy of reach, adaptation of hand movement, hesitant when reaching, and knocks cards off the table/appears clumsy.
4. Behavioural difficulties associated with crowded environments: emotional responses, adaptive behaviours, signs of fatigue, and inability to sit still.

Although some of these indicators were also observed in the control group, each research participant had a greater number of indicators in each of the four sections, compared to the control participants who only had one or two (as shown in Table 9).

Table 9. Austin Playing Card Assessment observations, comparing results from research and control participants

Observations	Research participants											Total
	1	2	3	4	5	6	7	8	9	10	11	
Visual attention												
Mis-matching pairs	x	x			x	x					x	**5** (45.45%)
Inability to find all the pairs	x	x			x		x	x	x		x	**7** (63.63%)
Has difficulty matching picture cards		x	x		x							**3** (27.27%)
Mixed 6's and 9's		x				x	x	x			x	**5** (45.45%)
Showing signs of distraction	x	x	x	x	x	x	x	x	x	x		**10** (90.90%)
Stares/fixes on cards without seeing them	x		x	x	x	x	x	x	x	x	x	**10** (90.90%)
Head movement	x	x	x	x			x	x	x	x	x	**9** (81.81%)
Adaptive eye movements	x	x		x	x	x	x					**6** (54.54%)
Darting eye movement	x	x	x	x	x	x	x	x	x	x	x	**11** (100%)
Ability to handle the complexity of a visual scene												
Focus on one card/pair at a time	x	x	x	x	x	x	x	x	x	x	x	**11** (100%)
Cannot match cards while talking				x				x				**2** (19.18%)
Visual guidance of movement												
Accuracy of reach		x	x	x			x	x	x	x	x	**8** (72.72%)
Adaptation of hand movement	x	x	x	x	x	x	x	x	x	x	x	**11** (100%)
Hesitant when reaching		x	x	x	x		x			x	x	**7** (63.63%)
Knocks cards off the table/appears clumsy	x	x	x		x		x		x	x	x	**8** (72.72%)
Behavioural difficulties associated with crowded environments												
Emotional responses		x	x	x	x	x	x	x		x	x	**9** (81.81%)
Adaptive behaviours		x	x	x	x	x		x	x	x	x	**9** (81.81%)
Signs of fatigue		x	x	x	x	x	x	x	x			**8** (72.72%)
Inability to sit still	x		x									**2** (19.18%)

Observations	Control participants											Total
	1	2	3	4	5	6	7	8	9	10	11	
Visual attention												
Mis-matching pairs											x	**1** (9.09%)
Inability to find all the pairs												**0**
Has difficulty matching picture cards												**0**
Mixed 6's and 9's							x	x			x	**3** (27.27%)
Showing signs of distraction	x	x	x				x				x	**5** (45.45%)
Stares/fixes on cards without seeing them												**0**
Head movement								x				**1** (9.09%)
Adaptive eye movements	x											**1** (9.09%)
Darting eye movement								x				**1** (9.09%)
Ability to handle the complexity of a visual scene												
Focus on one card/pair at a time								x			x	**2** (18.18%)
Cannot match cards while talking												**0**
Visual guidance of movement												
Accuracy of reach					x		x			x		**3** (27.27%)
Adaptation of hand movement								x				**1** (9.09%)
Hesitant when reaching												**0**
Knocks cards off table/appears clumsy					x		x	x		x		**4** (36.36%)
Behavioural difficulties associated with crowded environments												
Emotional responses											x	**1** (9.09%)
Adaptive behaviours								x				**1** (9.09%)
Signs of fatigue	x			x				x				**3** (27.27%)
Inability to sit still							x	x			x	**3** (27.27%)

The IRR calculations using Cohen (1960) kappa, comparing the observations made by the researcher and the second observer were 0.88 for the control group observations, indicating almost perfect or perfect agreement (Landis & Koch, 1977). The kappa was 0.66 for the research group observations and 0.79 for the combined control and research observations, both indicating substantial agreement (Landis & Koch, 1977).

Difference between assessment environments

Although some participants in the research group were much slower at finding the pairs in the cluttered, busy classroom environment, overall the times taken by the research group were similar to those in the quiet environment. The control group also showed similar times to find the pairs between the three assessments. However, in the cluttered classroom, there was more evidence of issues associated with optic ataxia among the research group. As many as 9 of the 11 research subjects knocked cards off the table and were inaccurate with their reach and appeared more clumsy. This indicates that the majority of the participants in the research group found it more difficult to be accurate with their visually guided movement when the environment was more visually and auditorily cluttered. All but one of the participants in the research group also appeared to be more distracted and showed more signs of visual and general fatigue in the classroom environment. The control group did not demonstrate these features.

Discussion

The different aspects of the research process (history-taking inventory, time taken to find the pairs, visual difficulties observed, and difference between assessment environments), all played a significant role in helping to detect and determine the nature of the visual perceptual difficulties relating to clutter. By combining the information gathered through each aspect, a more thorough picture of each child's visual difficulties was developed. This information could then be used to determine the kinds of intervention and strategies that could be implemented to help the child, especially when in cluttered environments.

History-taking inventory

Using the structured history-taking inventory (Dutton & Bax, 2010; Macintyre-Beon et al., 2012; Ortibus et al., 2011a), it was possible to identify probable visual perceptual difficulties among the research participants. This is despite the lack of a formal diagnosis, highlighting the issue common in many countries, of difficulties identifying visual perceptual difficulties in paediatric eye clinics, or within the community (Chong & Dai, 2014; van Genderen et al., 2012; Williams et al., 2011). As seven of the participants in the research group had already been diagnosed or were under assessment for a possible diagnosis of a developmental disorder (including ASD, ADHD/ ADD, dyslexia, dyspraxia, and auditory processing disorder), it could be argued that their visual difficulties were related to these conditions and not CVI. However, no matter the cause of the visual perceptual difficulties, the issues still manifest in the same way, with the parents all reporting difficulties in the areas covered by the history-taking inventory. Moreover, as already discussed, many children with visual perceptual difficulties are not being correctly diagnosed due to a common lack of awareness of CVI among healthcare providers, especially when the child has normal or near normal visual acuity (Chong & Dai, 2014; Fazzi et al., 2009; Gorrie et al., 2019; Maitreya et al., 2018; Martin et al., 2016). Therefore, these seven children may well have had CVI, or a combination of CVI and a developmental disorder that caused their visual perceptual difficulties, especially when there is clear evidence that many developmental disorders have overlapping visual difficulties (Chokron & Dutton, 2016; Dutton, 2015c; Pawletko et al., 2015).

The use of the five screening questions (A. Chandna, personal communication, April 15, 2018) enabled rapid detection of suitable participants for the research and control groups and proved indicative of responses within the full history-taking inventory (Dutton & Bax, 2010). The higher scores in the four relevant sections of the inventory for the research group indicated that they were more likely to have these visual perceptual difficulties, and to a greater degree, than the control group and provided a specific focus area for the Austin Playing Card Assessment in terms of what visual difficulties may be observed. This accords with the view that the full inventory provides a platform from which to direct further assessment of visual functioning and is an effective tool that could be used for routine screening procedure for children at risk of visual perceptual difficulties (Dutton, 2015a; Ortibus et al., 2011a). For the participants in the research group, the visual issues detected using the Austin Playing Card Assessment and those identified in the inventories matched up. For example, Participant 10 scored 48 out of a possible 50 on the inventory questions focusing on optic ataxia and also demonstrated every indicator suggestive of difficulties with visually guided movement. Another example was Participant 7, who had a relatively high score on the inventory questions focusing on visual attention (69 out of 95). During the Austin Playing Card Assessment, this participant displayed 7 out of the 9 indicators suggestive of difficulties with visual attention.

Time taken to find the pairs

There were notable differences in the way the two groups approached the assessment leading to time differences in matching the pairs. First, the search technique used by the research group was very different from the control group. Upon opening their eyes, the control participants appeared to take in the whole visual scene in front of them and it was simply a matter of collecting the pairs. However, the research group searched for one pair at a time, initially focusing on one card and then seeking out its match. If this card did not have a match, they moved on to the next card. For many of the pairs, especially as the numbers of cards on the table increased, it seemed that they found the matching cards by luck. This accords with Josef Zihl's findings looking at differences in how long it took children with and without visual perceptual difficulties to find a diamond in a diagram surrounded by an increasing number of dots (Zihl & Dutton, 2015). Zihl found that the children with visual perceptual difficulties used a more random search pattern, and when they did find the diamonds, it appeared to be by luck (Zihl & Dutton, 2015).

This type of random searching for the matching cards also resulted in the research group displaying significant darting eye movements. Again, this is in line with the work of Zihl (Zihl & Dutton, 2015), who found that the children with known visual difficulties used an increased number of darting eye movements compared with the children with no difficulties. This finding supports the work of Bennett et al. (2018), who found in their virtual reality (VR) toy box test that the children with visual perceptual difficulties had longer search patterns and reduced focus on the target than the control children, which was evident by an increased number of darting eye movements.

Other issues accounting for the difference in time taken to find the pairs related to the children's abilities to accurately complete the assessment. Almost all the research group, but none of the control group, had difficulty with either matching the pairs correctly, mixing the 6s and 9s, having difficulty with finding the pairs for the picture cards and an inability to match all the pairs, especially as the numbers of cards on the table increased. This also accords with the work of Zihl and Dutton (2015) and Bennett et al. (2018), who show that children with visual perceptual difficulties find it more difficult to complete a vision dependent activity as the amount of visual information increases. With the Austin

Playing Card Assessment, this phenomenon was especially notable when there were 12 cards. Some subjects in the research group commented that there were a lot of cards on the table when they opened their eyes to start the task. For most of these children, this comment was repeated for all three of the assessments, even though they knew what to expect in their second and third assessments. No control subjects made such comments. One research participant, who had been able to find the pairs in the first four levels on the first assessment, was unable to find any pairs when there were 12 cards. He was surprised by this and commented 'there's no pairs, that's strange, there are no pairs there'. This finding supports the work of Bennett et al. (2018), who found that for the children with visual perceptual difficulties, as the number of distractions increased, their performance slowed down and became less accurate.

Another major impact on the time taken to find the pairs was the adoption of different adaptive behaviours which could be categorised into three main areas. These areas comprised the following:

1. Adaptive eye movements, where children were observed to either look at the cards, glance away, and then look back to find a pair, or move their face closer to the cards to see fewer at once, and some participants also stared at an area of blank wall in between levels, as a way of 'resting'.
2. Adaptive behaviours such as placing their hand or finger beside one card and then using the other hand to scan over the rest of the cards to find a pair, picking up one card and studying it for a period before searching for its match, and placing cards beside each other or lifting them both up to study them side by side before committing to a match.

3. Adaptive hand movements, where all participants in the research group changed their type of hand movement when reaching out and collecting the cards as the number of cards on the table increased. When there were only a few cards, they often used a refined fine motor action, of reaching out with one finger or using a pincer-type movement, but when reaching the final level with 12 cards, they resorted to a more gross motor movement using their whole hand to draw in the cards, or slap the palm of their hand onto the cards to gather them up.

The adaptive behaviours supports the work of Bennett et al. (2018) in their work with the VR toy box, where they described children with visual perceptual difficulties using their virtual hand as a reference as the trials became increasingly more difficult. The adaptation of hand movements also supports the work of Goodale and Milner (2013) who highlight that those with optic ataxia adapt their hand position when reaching out to grasp an object. More specifically, the in-flight thumb and finger position is wider than is necessary, indicating that the person is unable to accurately gauge the size of the object they are about to pick up and is overcompensating to ensure that they are able to grasp the object once it is reached (Goodale & Milner, 2013). This suggests that the research subjects completing the Austin Playing Card Assessment found it more difficult to accurately reach out and pick up the cards as the complexity of the scene increased and, therefore, developed a less refined movement to ensure success in reaching for each card.

Visual difficulties observed

The significant differences in the number of indicators on the observation tables of the research and control participants demonstrate how visual perceptual difficulties potentially affect a child's ability to complete a simple activity of matching playing cards. For all participants in the research group, there were three indicators: (1) darting eye movement, (2) focusing on one card/pair at a time, and (3) adaptive hand movements. These findings accord with previous work evaluating visual perceptual difficulties in children (Bennett et al., 2018; Goodale & Milner, 2013; Zihl & Dutton, 2015), suggesting that these are all effective indicators of visual perceptual difficulties.

The other indicators noted during the observations of the children completing the Austin Playing Card Assessment also provide valuable information in terms of understanding the different visual difficulties bought on by a visual clutter task. As each participant in the research group displayed a range of different indicators across the four sections, this information could be used to help understand the underlying behavioural issues associated with visual clutter and the interventions that might be needed for each individual child. So although the time taken and accuracy of completing the task is useful in detecting whether visual perceptual difficulties are present, the detailed analysis of how each child completed the activity can help to inform practical approaches for intervention and support.

Difference between assessment environments

Although the time taken to find all the pairs was not significantly different in the two different assessment environments, the cluttered classroom still impacted negatively for many in the research group. These children became more distracted, showed more signs of visual and general fatigue and showed less accurate visually guided movement in their classroom environments. This is in line with the work by McDowell and Budd (2018) and Little and Dutton (2014), who show that by reducing the amount of clutter surrounding a child with more severe CVI, their visual and overall functioning greatly improves. This highlights that the Austin Playing Card Assessment has the potential to detect a number of different visual perceptual difficulties, especially when the assessment is conducted in both quiet and cluttered environments and making appropriate comparisons.

Using the assessment process to inform intervention

The information gathered through the use of the history-taking inventory and by conducting the Austin Playing Card Assessment in two different environments has the potential to not only detect and understand the degree of visual perceptual difficulties related to clutter but to also help guide interventions. Each of the indicators that were observed while completing the task can be addressed by providing useful strategies to help overcome these difficulties or enhance the strategies adopted. Performance can then be compared preintervention and postintervention by reassessing using the Austin Playing Card Assessment and comparing the speed and accuracy outcomes. For many, being able to complete the assessment faster may also provide motivation for using different strategies that have been recommended.

Another aspect that is important to consider, is that, although slower, the participants in the research group were mostly successful in completing the assessment. A number of these children also implemented different strategies to aid them in completing the assessment (i.e., moving cards so that they were beside each other before committing to them being a pair). This suggests that these children should be encouraged to use different strategies that help overcome their visual difficulties, either that they have developed themselves or that have been introduced to them. However, further research on a larger population of children would need to be undertaken to confirm this finding.

Next stage of research for the Austin Playing Card Assessment

Although one of the potential benefits of the Austin Playing Card Assessment is its simplicity and ease of use, due to the nature of the research project, a number of elements were added that made conducting the assessment more complex. This was mainly due to the need to video record the assessments for further analysis. To overcome these challenges, the next phase of research on the Austin Playing Card Assessment will involve turning the assessment into an App. The first version of the App would facilitate measurement of the main elements that are potential indicators of visual perceptual difficulties. These elements include the time taken to match the pairs, eye movement tracking to detect darting eye movements and assess search techniques used, the accuracy of touching and moving the cards, and the ability to correctly match the pairs. Such measurements in an App will also help determine whether slower times to complete the assessment relate to visual perceptual difficulties or other unrelated behaviours, as was the case with two of the control group participants. This would ensure that even if a child took a long time to complete the assessment, the possibility of this being due to visual perceptual difficulties would only be elicited if darting eye movements and random search patterns are also present. Other features of the first version of the App will include questions about the environment the assessment is being completed in, including levels of visual clutter and noise levels. The cards on the screen will also be able to be moved around to enable strategies such as placing them side by side to compare them before deciding they are a pair. One card at a time will also be able to be enlarged to imitate bringing the card closer.

In future versions of the App, other behavioural indicators that were observed would also be integrated. For instance, confusion between 6s and 9s, difficulties identifying picture cards, level of distraction and head movement (noted by eyes off the screen), adaptations of hand movements, measurements of ambient noise, and more detailed assessment of search patterns. The long-term aim of the App is that all information that is needed to develop a clear picture of a child's visual perceptual difficulties can be obtained through the completion of the Austin Playing Card Assessment on a suitable device, such as an iPad.

Limitations

As a number of research subjects already had a formal diagnosis of a neurological condition (which could have also affected their ability to complete the assessment) it cannot be surmised that their performance on the Austin Playing Card Assessment was solely related to visual difficulties. However, as these conditions (ASD, ADHD/ADD, DCD/dyspraxia, and auditory processing disorder) are also known to have visual perceptual difficulties (Chokron & Dutton, 2016; Dutton, 2015c; Pawletko et al., 2015), this could be a potential explanation for their assessment performances and one that is worthy of further investigation.

Conclusion

Although this pilot study of an assessment tool to detect visual perceptual difficulties was conducted on a small number of children, the results indicate that the Austin Playing Card Assessment has the potential to be effective, and further research on the tool is warranted. As this is the first phase of development of this tool, the next phase of research will need to be conducted on a larger population to determine effectiveness and validity. Further research is also needed to refine the methodology and applicability of this novel low-cost easily administered investigation and whether the materials and methods used can also be employed to develop potential therapeutic approaches.

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Chapter conclusion

This chapter is a published paper in the *British Journal of Visual Impairment* and reports on research undertaken to test the effectiveness of the Austin Assessment to detect visual perceptual difficulties. The chapter relates to the overall thesis aim of developing an effective framework for supporting children with CVI by addressing the third research question: What role does the Austin Playing Card Assessment play in identifying visual, emotional and behavioural responses associated with CVI? From the pilot study, which included 11 research and 11 control participants, it was clear that the Austin Assessment could identify some of the visual, emotional and behavioural responses that are commonly associated with CVI. As such, the main finding from this research in relation to the research question, is that the Austin Assessment can play an important role in helping to develop a child's individual CVI profile. When used alongside a range of other assessments of vision, emotions and behaviours, the Austin Assessment can help build an overall profile of each child with CVI, which is the first component of the CVI practice framework.

In terms of the overall research framework, this research is in line with the epistemology of pragmatism, as it was orientated towards solving the practical problem of finding a novel way to detect visual perceptual difficulties in children (Creswell & Plano Clark, 2011). It also supported the theoretical perspective of dialectical pluralism by drawing on literature from different fields, including scientific, medical, education and rehabilitation, to support the development of the Austin Assessment. Within this research, a mixed methods approach was used, with both quantitative and qualitative methods being employed to help assess the effectiveness of the assessment tool. These included a screening tool, experimental research, and qualitative observations.

Chapter Six – Case Studies

Chapter introduction

Although the focus of this research was to assess the effectiveness of a range of strategies for supporting the visual, emotional and behavioural needs of children with CVI, the research also used the proposed CVI practice framework as part of the overall research process. The first component of the framework was to develop individual CVI profiles of each child in three in-depth case studies. For this, the researcher examined relevant medical information, including optometrist and ophthalmologist reports, paediatrician and other relevant reports. The parents of the three children (and their child where appropriate) were then asked to complete the history taking inventory (Dutton, 2015a; Dutton et al., 2010; Houliston et al., 1999) to ascertain the possibility of visual perceptual difficulties. Using the ICF framework (World Health Organisation, 2019b) as a guide, the researcher also gathered information on each child's visual, emotional and behavioural functioning at home, at school and in the community through interviews with the child's parents (and child where appropriate), their education and therapy teams. Finally, each child also underwent a CVI specific functional vision assessment, which was conducted by the researcher in their home and school environments. These individual CVI profiles were then used to help develop individual education/rehabilitation plans for each of the three children that were implemented within each child's home, school and community environments. Each individual plan included specific strategies to support the visual, emotional and behavioural needs of the child and were implemented by the child (where appropriate), their parents and education and therapy teams. Alongside the development of the CVI profiles and individual programmes, the researcher also spent time helping to educate everyone involved in the research, including the child (where appropriate), the child's parents, and education and therapy teams about CVI in general and the specific visual difficulties each child experienced.

This chapter relates to the overall thesis aim of developing an effective framework for supporting children with CVI by using the proposed CVI practice framework as part of the overall research process. It also relates to the second component of the CVI practice framework of individualised programmes to meet the visual, emotional and behavioural needs of children that have been identified in the individual CVI profiles. The strategies used within this research are a combination of approaches developed by the researcher for herself (outlined in Chapters 3 and 4), and approaches suggested in relevant literature.

McDowell, N. (under review, March 2020). Supporting the visual, emotional and behavioural needs of children with cerebral visual impairment (CVI). *Disability Studies Quarterly.*

Abstract

Purpose: Cerebral visual impairment (CVI) is now the most common cause of visual impairment affecting children in the economically developed world. As well as visual difficulties, CVI can also cause heightened emotional responses and challenging behaviours. Therefore, any habilitation/rehabilitation programme developed to support a child with CVI needs to focus on their visual, emotional and behavioural needs.

Methods: A case study design was developed to assess the effectiveness of strategies implemented to support the specific needs of three children each of whom had CVI and a range of cognitive abilities. Participants in the case studies included the children's families, and education and therapy providers. The strategies developed were tailored to each child's needs and were implemented in the children's homes, schools and community environments. The principal generic strategies trialled included: CVI education sessions, quiet spaces, calm breaks and mindfulness.

Results: Participants reported that the strategies significantly helped the children in relation to their visual needs and also, they greatly improved the children's emotional and behavioural responses and overall functioning.

Conclusion: The strategies trialled were fundamental, simple and easy to implement, suggesting that they could easily be introduced for children with CVI in a range of educational settings.

Keywords

Behavioural; CVI; Emotional; Strategies; Support; Visual

Introduction

Over the last 40 years there has been a significant shift in the main cause of visual impairment affecting children in the developed world. Previously, children predominantly experienced visual impairments due to ocular pathologies such as congenital cataracts and retinopathy of prematurity (Fazzi et al., 2007). In more recent times, due to improvements in postnatal healthcare, these ocular conditions are detected early and treated effectively (Gorrie et al., 2019). However, this improvement of postnatal healthcare has also seen the emergence of a significant visual condition known as cerebral visual impairment (CVI) (Chong & Dai, 2014). CVI is caused by damage to some parts of the visual brain (the totality of brain elements that serve or support vision) (Lueck & Dutton, 2015), and can be defined as 'a verifiable visual dysfunction which cannot be attributed to disorders of the anterior visual pathways or any potentially co-occurring ocular impairment' (Sakki et al., 2018). CVI can occur at any time from pre-birth through to adulthood, however, one of the main causes of CVI is prematurity (Jacobson et al., 2006). Other common causes include; lack of oxygen at birth, closed head injury, hydrocephalous, damage to specific brain locations and epilepsy (Soul & Matsuba, 2010).

As with other visual impairments, CVI can have a significant negative impact on a child's development and overall quality of life (Chadha & Subramanian, 2011). However, currently, many children with CVI are being supported with strategies that have been developed for children with ocular visual impairments (OVI). This is despite the growing awareness that many of these approaches are not effective in the case of CVI and in some instances, could actually be detrimental (Martin et al., 2016). Given that CVI is now the most common cause of visual impairment affecting children in the developed world (Philip & Dutton, 2014), it seems vital that strategies for supporting these children are developed. However, for these strategies to be effective, more needs to be understood in terms of how CVI affects the whole child.

The most significant impact CVI has on a child is in relation to their visual abilities. CVI can cause a range of visual issues, including: decreased visual acuity, reduced contrast sensitivity, visual field deficits, eye movement disorders and difficulties in image processing or interpretation (visual perceptual difficulties) (Ortibus et al., 2011b; Williams et al., 2011). As every child with CVI will have their own unique pattern of visual experience and limitations, thorough individual assessments of vision need to be conducted in order to understand the impact of their visual difficulties on their daily life (Dutton & Bauer, 2019). However, although the basic visual functions of visual acuity, contrast sensitivity, oculomotor control and visual fields can be easily tested within a clinical setting, the assessment of visual perceptual difficulties can be more challenging (van Genderen et al., 2012). This is due to the fact that a child's visual perceptual abilities can appear differently in the real world when compared with experimental tasks (Williams et al., 2011). This results in many children with CVI who experience visual perceptual difficulties being misunderstood in terms of how their visual abilities impact on them on a daily basis. This is especially the case in environments which children with CVI may find challenging, such as a cluttered classroom, due to the overload of competing sensory information making it difficult for their already impaired visual skills (McDowell & Budd, 2018).

When a child's visual perceptual difficulties are not well understood, strategies to help reduce the impact of these issues are not often explored or implemented, which can have a significant negative impact on the child's overall functioning. The world that is seen through the eyes of a child with visual perceptual difficulties can be confusing and uncertain and it has been described as an overwhelming kaleidoscope of visual imagery (McDowell, 2019b). This can lead to the child experiencing heightened emotional responses such as anxiety and panic, especially when in challenging environments (McDowell & Dutton, 2019). For children severely affected by visual perceptual difficulties, this regular spiral of uncertainty in their visual abilities causing high levels of anxiety can ultimately lead to a fight or flight response in their primitive brain, which as Goleman (1995) outlines, impacts on a person's ability to think logically and coherently and therefore, affects their cognitive functioning. At times, the fight or flight response can be so severe it extends to a freeze reaction, which essentially shuts a person down physically (Evans, 2019). A freeze response transforms a person into a profoundly low arousal state and leaves them looking blank and seeming to stare at nothing (Evans, 2019). These heightened emotional responses often lead to a disparity in not only the child's visual functioning, but also their overall functioning, which parents and teachers may incorrectly conclude is the child misbehaving in certain environments or being uninterested in learning (Dutton, 2015e; Erasmus, 2015).

As this response can occur whenever a child is feeling overwhelmed by the environment they are in, children with CVI often develop certain behaviours such as avoidance of crowded and cluttered environments, or the increase of negative behaviour when in these environments, such as tantrums and crying (Lam et al., 2010). They may also experience high levels of visual and overall fatigue which can affect their overall functioning (Erasmus, 2015). Some children can experience a 'CVI meltdown', which is defined as an incapacitating behavioural reaction to an overload of visual, auditory and other sensory information, which leaves the affected person completely unable to cope and is mentally incapacitated for a period of time (McDowell & Dutton, 2019). Often when these behaviours are not understood in the context of the visual difficulties experienced by the child, the child may get identified as having a developmental disorder such as: attention deficit hyperactive disorder (ADHD), autism spectrum disorder (ASD), dyslexia, dyspraxia (Pawletko et al., 2015), and auditory processing difficulties (Dutton, 2015c). If this occurs and the child is incorrectly diagnosed with another condition, it can impact on their levels of academic attainment, as the support they receive may not meet their visual needs (Williams et al., 2011). However, when these behaviours are understood in the context of the child's visual difficulties causing high levels of anxiety in certain situations and environments, it can be recognised that the behaviour is due in part, to their CVI and suitable strategies can be implemented.

Given that the impact of CVI extends beyond just the visual abilities of a child to also affect their emotions and behaviour, it therefore seems vital that any approach to supporting a child with CVI needs to focus on not just their visual needs, but also their emotional and behavioural needs as well. In relation to their visual needs, strategies to support the basic visual functions are well known and regularly implemented for children with CVI. These include the prescription of appropriate spectacles to cater for both refractive errors and lack of accommodation, providing good clear outlines and increasing font size on teaching material, establishing optimal luminance level and introducing magnification devices (Buultjens et al., 2010). However, strategies relating to visual perceptual difficulties are only just starting to be explored by those working in the field of supporting children with these kinds of visual difficulties. One such study by McDowell and Budd (2018) looked into the impact of cluttered classrooms on the learning and behaviour of children with CVI. They found that decluttering the classroom environment and creating areas for focused work with blank walls had a significant impact on their overall functioning.

In relation to a child's emotional needs, although there is currently no literature around supporting children with CVI using strategies such as mindfulness, there is evidence of the effectiveness of mindfulness in children with other developmental disorders, such as ASD and anxiety disorders (Conaughton et al., 2017; Vigerland et al., 2016). Mindfulness interventions are also known to target regulation of emotions and coping processes associated with stress (Perry-Parrish & Sibinga, 2014), which suggests this could be an effective strategy for children with CVI, given that they are constantly under high levels of stress. A sample programme of mindfulness-based visualisation was trialled at the Royal Blind School in Edinburgh, where children with CVI attend (Godek, 2015). After using the programme for three school terms, staff involved in the programme reported a reduction in students agitation and anxiety both at home and at school (Godek, 2015).

Given that much of the behaviour displayed by children with CVI is as a result of the constant strain on their visual skills causing visual fatigue (Erasmus, 2015), and also their high levels of anxiety, another simple solution would be ensuring that they have regular breaks in a calming environment. This strategy has been described by an adult with CVI as an effective way to recharge the batteries and reduce the feelings of anxiety that can occur when in a challenging environment (McDowell, 2019b). One of the benefits of this strategy is that regular calm breaks may help reduce levels of visual and overall fatigue, which in turn would allow the person with CVI to feel more confident in their ability to handle a challenging environment for longer periods of time (McDowell, 2019b).

When implemented together, strategies that focus on a child's CVI visual, emotional and behavioural needs have the potential to improve their overall functioning and quality of life. As such, this study reports on the effectiveness of individualised habilitation/

rehabilitation programmes that have been developed to support the diverse needs of children with CVI within their home, school and community environments.

Methods

A qualitative research design was developed to examine the effectiveness of the strategies implemented for children with CVI, as it allowed for the exploration of the personal views, meanings and lived experiences of the children with CVI, their parents and their education and support teams involved in the research. A qualitative approach also ensured that the strategies implemented to support the child's visual, emotional and behavioural responses relating to CVI were understood from the participants' frame of reference (Blaxter et al., 2010). For more in-depth exploration of the strategies implemented, a case study design was developed, as this ensured that the research provided richly descriptive interpretations of the complexity and context of the multiple individual cases involved in the research (Punch & Oancea, 2014). Ethical approval was obtained from Massey University and the Blind and Low Vision Network New Zealand (BLENNZ)[10] ethics committees.

Participants

As the research was focused on supporting children within an education framework, the three case studies were based on the three main categories outlined by Dutton and Lueck (2015) as being practical groupings of children with CVI from an educational perspective. The three categories are:

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[10] BLENNZ is the main provider of education support services for children who are blind or who have low vision in New Zealand.

1. Children with profound visual impairment due to CVI, many of whom also have additional disabilities.
2. Children with CVI who have functionally useful vision and cognitive challenges.
3. Children with CVI who have functionally useful vision and who are able to work in or near the expected academic level for their age group.

Each case study involved one child, their parents, their classroom teacher, and if receiving additional support, their education and therapy support providers (i.e. specialist teacher, teacher aide, Orientation and Mobility (O&M) specialist). Participant recruitment differed between the three categories. All names have been changed to protect the identity of the participants involved.

Case study one (category one): Mary is a 6 year old girl who has global developmental delay, hypotonia, epilepsy and CVI. Recruitment of Mary for the case study research followed a process approved by the BLENNZ ethics committee. This involved the identification of children in the researcher's home region who had complex needs, including CVI and were on the BLENNZ roll. Information about the research was then sent to the child's parents and they were invited to contact the researcher if they were interested in taking part in the research. Mary's mother contacted the researcher after receiving this information. Research participants involved in Mary's case study were Mary's parents, her classroom teacher, a teacher of students who are visually impaired (TVI), a specialist teacher for children with learning needs, an O&M Specialist and her teacher aide.

Case study two (category two): Beth is a 11 year old girl who experienced lack of oxygen at birth which resulted in mild cognitive challenges and auditory processing difficulties. Beth had been involved in previous research with the researcher, which had identified her as having significant visual perceptual difficulties commonly associated with CVI. The researcher therefore, invited Beth and her parents to also participate in the case study research. The research participants involved in Beth's case study were: Beth's parents, her classroom teacher, her teacher aide, the school Special Education Needs Co-ordinator (SENCo) and a specialist teacher for children with learning needs.

Case study three (category three): Olive is a 11 year old girl who was diagnosed with a brain tumour and hydrocephalus at age 2. Following the removal of the tumour Olive experienced numerous visual difficulties including reduced visual acuities and a lower visual field deficit, but she had not been diagnosed with CVI. Olive had also been involved with previous research with the researcher, which helped to identify significant visual perceptual difficulties. As such, Olive and her parents were invited to participate in the case study research. Olive does not require any additional support at school and works at an expected academic level for her age. The research participants involved in Olive's case study were: Olive, her parents and her classroom teacher.

Procedure

The first stage of the research involved the researcher developing an individual CVI profile of each child, which was based on their visual, emotional and behavioural needs. This included conducting comprehensive CVI specific functional vision assessments (FVAs) on the child, in both their home and school environments. A FVA focuses on real-life evaluations of visual functions, with both eyes open, within the performance of activities, and often involves qualitative judgments of how vision is used and the limits it imposes on daily living (Kran & Mayer, 2015). Areas assessed in the FVAs included: visual acuity, visual field, contrast sensitivity, colour vision, light sensitivity, establishing what modifications or changes to the environment were needed and what adaptations or tools were needed to access information (Kran & Mayer, 2015). The assessments also looked at visual difficulties that are associated with CVI, including: visual attention; visual search or apraxia of gaze; perceptual grouping or simultanagnostic visual dysfunction; unconscious use of visuospatial information to programme movements that interact with objects in 3-dimensional space; route finding and recognition of objects and people or optic ataxia (Goodale, 2013; Goodale & Milner, 2013; Williams et al., 2011). Assessment tools used within the FVAs included the structured history taking inventory that was developed by Dutton et al. (2010) to elicit vital information about a child's visual behaviour and their overall functioning in different environments based on parent's observations, the Austin Playing Card Assessment (McDowell, 2020), and other commonly used FVA tools, such as the LEA range of vision tests (Hyvärinen, n.d).

To complete the individual CVI profile, the International Classification of Functioning, Disability and Health (ICF) was used to guide the development of a semi-structured interview schedule to help develop an overall picture of the child within their own environment. The ICF considers the interaction between a person's disability and their functioning of an activity and participation level, taking into account environmental factors, as well as internal factors relating specifically to the individual (World Health Organisation, 2019b). Each research participant was interviewed separately, providing relevant information in relation to the child's visual, emotional and behavioural functioning at home, at school and in the community. This information was combined with the information gathered in the FVAs and used to develop a comprehensive, individual CVI profile for Mary, Beth and Olive. Using the individual CVI profiles, the researcher then developed individual education plans (IEPs) in consultation with the child (where appropriate) and their family, that included both specific and generic strategies to help support the child in relation to their visual, emotional and behavioural needs in their home, school and community environments.

Once the IEPs were developed, the first stage of implementation involved education sessions for all research participants (either separately or as a group). These sessions included the viewing of a recorded lecture provided by Professor Gordon Dutton on CVI at a parents information day (Visibility, 2017), information about the specifics of each child's visual difficulties and the introduction of the main strategies used to support the child's visual, emotional and behavioural needs. The implementation period then extended for three school terms. During this time, the researcher was available to visit research participants at home or at school upon request. Over the course of the implementation period this averaged out to about once a month, however, for the first month visits were once a week. Research participants were also encouraged to contact the researcher by text, phone or email at any stage if they had any questions pertaining to the research. During the implementation period, the researcher also spent time observing each child in different settings to assess the effectiveness of different strategies. Observations were mainly conducted at the child's home and school and consisted of the researcher observing specific activities from a distance with limited engagement with the child.

Each case study was concluded at the end of the third school term. The final stage of the research involved separate interviews for the parents (and Olive in case study three) and focus groups for the remaining research participants using the same semi-structured interview schedule.

Data analysis

Data gathered throughout the research period included interview and focus groups responses from all research participants (which were transcribed by the researcher), observation notes made by the researcher and the research participants and email/phone correspondence from research participants. Throughout the research, participants also had the option of making notes on a shared google document that could be viewed by all research participants, or in a notebook provided to them. All participants gave permission for information shared on the google document or in the notebooks to be used as research data. A six phase thematic analysis process was used on all research data, which allowed the researcher to become familiar with the data, develop initial codes, search for themes, review themes, define and name the themes and finally, report the findings (Braun & Clarke, 2006).

Results

Vision

For the majority of the participants, CVI was new to them and as such, they had no understanding of the visual difficulties associated with CVI. The exception to this was Mary's parents, as they had developed a basic understanding of CVI since receiving the diagnosis for Mary. Mary's TVI also had a good understanding of CVI as a professional working in the field.

Across all three case studies there were a number of common themes relating to the children's vision. Firstly, everyone reported that the children's vision was *"very confusing"*, with one participant commenting:

> *Mary's vision is interesting and diverse I would say is the easiest way of putting it. It's never the same every day, it's always different and that can be dependent on her tiredness levels her health and the situation or environment we are in.*

All three children were also described as being clumsy and were reported to trip over things a lot. From the FVAs it was clear that all three children had a lower visual field deficit and this was supported by comments from participants, such as *"that's the most notable thing for me, is that her head is down. Whenever she is doing anything her head is down"* and *"she is always looking at her feet"*. All three children were described as seeming to have better vision at home and to only trip up on things if they had been moved. This was in comparison to cluttered and noisy environments where their vision and functioning seemed to be much worse. This was summed up well by Beth's mum, who commented:

> *When she is out she is just a different child, she is a special needs child, the difference is huge.*

Finally, all three children were described to compensate well for the visual difficulties with examples of the children bringing things closer or moving closer to objects to see them better. Olive's mum also described Olive having to concentrate hard when she was in challenging environments and felt that this high level of concentration caused fatigue. Mary and Beth were also reported to experience high levels of visual and overall fatigue.

Strategies that were put into place to support the children's visual needs included:

i. education sessions for all participants about the specifics of each child's visual difficulties,

ii. the introduction of a quiet uncluttered space for focused work,
iii. the use of calm breaks.

The education sessions at the start of the implementation period made a significant difference for all the participants with comments including:

> *Yeah it was like everything just made sense. Having that knowledge, all of a sudden everything we were seeing without realising it suddenly made sense (Olive's parents).*

> *Now that I understand Olive's vision and what she needs, it is so much easier to help her (Olive's teacher).*

The introduction of the quiet space for focused work also made a considerable difference for all three children. For Olive, an area where she could face into blank walls was created in a quiet corner of her classroom and she used this space when completing tests and focused classroom work. Both Olive and her teacher reported that the standard of work produced when working in this space was much higher and that Olive's test scores had improved with using this strategy.

For Beth, a quiet office space was de-cluttered and she worked in this space for an hour each day with her teacher aide mainly completing maths and writing activities. After only a short period of time of working in this space, Beth's academic work was reported to improve dramatically, especially in maths. Observations were conducted comparing her functioning in both the classroom and quiet office with startling results. Firstly, Beth completed a basic facts maths test (where the children have to solve as many basic facts equations as they can in 10minutes) in the classroom and then in the quiet room. In the classroom, she solved 5 equations, compared with 22 in the quiet room. A similar comparison was done with a reading assessment, with Beth showing significantly better comprehension of the text in the quiet room compared to the classroom.

For Mary, two spaces were created for working with her. One with the TVI who pinned up black sheets over artwork on the walls in the quiet resource room where she worked with Mary, and the second in the special education needs unit where Mary spend periods of each day. In this space, a shower curtain was hung in one of the small work rooms and could be pulled to cover a wall of open resource shelving. When working with Mary in this space, the teaching team would face her into the shower curtain and reduce noise distractions by working with her one on one. Both spaces were reported to work extremely well, with Mary's TVI reporting a difference in her functioning when the clutter was covered with the black sheets:

> *When working with Mary today I couldn't find the pins to hang the sheets up, so had to leave the walls as they were. It took us 40 minutes to complete some basic maths activities that normally only take her 15 minutes and we had to have constant breaks.*

Following the implementation of these quiet spaces, both Mary and Beth's teaching team reported that they would only present new material to them in this space, as there was little point in the cluttered classroom, as they were not able to take it in.

The calm breaks were also important for each child but were developed according to each child's needs. For Olive, she was encouraged to acknowledge when she was feeling fatigued and to take small breaks away from busy environments. At home, this meant time reading in her bedroom or playing outside with her pet guinea pigs. At school, this meant a mindfulness break in the school library, her classroom library or her quiet corner.

For Beth, this meant allowing her to have quiet times by herself at interval and lunch times away from her peers and also the period of time in the quiet room each day. However, the most significant improvement in Beth's fatigue levels occurred when Beth's family was encouraged to reduce the amount of extra curricula activities Beth did. They introduced 'chill time' at home where Beth was allowed to quietly play in her room most days after school and for periods of time in the weekend. After only a couple of weeks of doing this, Beth taught herself how to do cartwheels from researching it on *YouTube* and practising in her backyard. This has been something she had been desperate to do for a number of years but had not been able to master. Beth's parents also reported a huge improvement in her functioning at home after introducing 'chill time', especially with activities such as independently getting her own lunch and getting ready for school. Beth's school team also reported that the reduction in extra curricula activities also improved her fatigue levels at school, commenting that she no longer struggled in the afternoons and seemed to have more energy throughout the day.

Calm breaks were also implemented for Mary throughout the school day with great success. Whenever needed, Mary was taken out of the classroom to a quiet space either in the resource room or unit, or outside in the playground for regular calm breaks. If this was not possible, she used headphones that were not plugged into anything and just sat quietly in the classroom. Once the headphones were introduced, Mary started requesting them for all her calm breaks, suggesting that they greatly reduced the sensory overload she was experiencing. Both Mary's teaching team and her parents noticed a big difference in Mary's functioning when the calm breaks were used regularly with Mary's mum reporting that she could tell straightaway whether or not she had had calm breaks that day by her level of fatigue when she got home. If she had had regular calm breaks, she had more energy at the end of the day, compared to when she hadn't had any breaks. Mary's teacher aide also reported Mary being able to achieve much more throughout the day when she had regular calm breaks.

Overall, the strategies implemented to support the children's visual needs appeared to have a significant impact on not only their visual functioning but also their overall functioning. However, another important outcome was that the strategies appeared to help empower the children in relation to their visual difficulties. This was especially the case for Olive who grew in confidence once she started to understand her vision more. This was highlighted when Olive was asked what the world looked like to her and she responded with: *"normal, but different to everyone else"*. For Beth and Mary this empowerment was highlighted in their ability to articulate their needs more clearly. Beth regularly reported that she found it so much easier to work in the quiet room and when completing the reading assessment in the classroom commented that it was too noisy and busy for her to concentrate, requesting to go to the quiet room to complete the assessment. Mary also started requesting calm breaks when she was starting to feel overwhelmed by pointing to her headphones or pulling her teacher aide to the quiet space.

Emotions

All three children were described as displaying heightened emotional responses, especially in the school and community environment. However, the manifestation of these emotions was different for each child. Olive described herself as anxious at times and admitted to having panic attacks in the classroom. When questioned what caused these panic attacks, she responded that it was when the routine changed and she didn't know what was happening. She also found moving around the school environment caused some anxiety, as often objects were moved and she didn't know where they were, for example the picnic tables. Olive's parents confirmed this by describing Olive as very sensitive, explaining that she was easily upset. They also reported that she was often anxious in crowded places and would panic in environments such as shopping malls.

Beth was also reported to get anxious and upset but would withdraw inwards when feeling overwhelmed. Her education team described this as Beth looking blank and starring into the distance, and not interacting with her peers or them. Beth's parents also reported that Beth always needed to know where people were, especially one of her brothers, who was her 'person' of choice at the time. Mary was described as mostly happy but would switch to being upset very quickly. This was highlighted by Mary's mum who commented: *"she definitely is either really happy or beside herself sad. She gets very sad pretty quick".* When Mary became emotionally distressed like this, everyone described her as being inconsolable.

To support the children's emotional needs, different mindfulness strategies were implemented for each child that suited their education setting and family's routine. For Olive, this was in the form of a web and app-based mindfulness programme called *Smiling Minds*, which she was encouraged to use once a day at home. Olive's teacher also used this programme in the classroom, including mindfulness sessions as part of the class's daily routine. At the end of the implementation period, Olive reported that she enjoyed the mindfulness sessions and had started to use the strategies learnt through the app, such as mindful breathing at other times when she was feeling overwhelmed. Olive's parents felt the mindfulness helped considerably, describing Olive as using "*mindfulness through the activity mindfulness"* (for example spending time with her guinea pigs). They also reported that she didn't seem to get as anxious anymore in challenging environments. Olive's teacher also reported that the daily mindfulness sessions helped reduce anxiety levels in the classroom, for not only Olive, but other children in her class as well.

Beth was introduced to mindfulness through a web-based programme for schools called '*Go Noodle'* and took to it straight away. To start with, Beth's team would offer her a mindfulness session regularly throughout the day, over time however, Beth started requesting mindfulness herself, particularly after a busy learning session in class and before they started a new learning block. At the end of the implementation period, Beth's teaching team reported that these mindfulness sessions had significantly helped Beth with her emotions and reported that she was withdrawing from her peers less and less. This had also helped improve her social interactions with her peers. Her teacher aide also remarked that it was great that Beth requested mindfulness herself, commenting:

> *She knows, I don't think she knows how they work but she knows that she feels good after she's done those, it is a fabulous strategy.*

Beth's parents also reported that Beth often asked to listen to quiet music as a way of having a mindful moment and this has become a great strategy to help keep her calm in busy environments. This suggests that Beth is developing the skills to be able to regulate her own emotions.

Mary's team also used quiet music and mindfulness clips from *YouTube* with Mary and her classmates in the unit after lunch every day. Mary's teacher aide also reported that Mary would request mindfulness at different times throughout the day by pulling a blanket onto the floor where they did the mindfulness sessions, or onto a couch for time out. Mary's teaching team all felt that these sessions had made a significant difference to Mary and helped to greatly reduce the episodes of distress.

Behaviour

All three children were described by the adults involved in the research as being great kids with generally no behaviour problems. However, when discussed in more detail, there were a number of common behaviour traits that they each displayed at different times. One particular behaviour that frustrated many participants, especially the teaching teams, was the children's inability to make eye contact with anyone that was talking to them. Beth in particular struggled with this and would often have her head down or her eyes covered when people were talking to her. All three children also thrived on routine and were really thrown when their routine was changed. The change in routine affected their behaviour differently, with Mary and Olive becoming upset, while Beth tended to start misbehaving. A good example of this was Beth's response to having people stay in her house and a complete change in their weekend routine; her mum reported:

> *Her behaviour over the weekend was so bad. She just withdraws and becomes this different person, it was so bad this weekend, incredibly bad.*

This also supported the view that for all three children, their home was their 'safe place' and they were all described as being much calmer in their home environment. However, if things were changed or moved in their home environment, both Beth and Olive were described as getting very angry and frustrated, while Mary would get upset and cry.

A number of common behaviours all three children had related to cluttered, busy environments, including avoiding crowds whenever possible. However, when crowds or challenging environments could not be avoided, they all had adopted strategies to make it easier for themselves. These included always needing a familiar person with them, with Beth's family reporting that Beth would yell out for a family member if she couldn't see someone near her, so they always tried to make sure someone was close to her. Olive's parents described Olive as not going anywhere without a family member or someone that understood her very well. Mary was also described as becoming clingy in unfamiliar places and would choose to stay in her wheelchair in busy places, as opposed to walking which she would do in environments she felt safe in.

Often being in challenging environments also lead to CVI meltdowns, which manifested in each child in different ways, however all resulted in the children being unable to continue functioning as normal for a period of time. For Olive, she would become increasingly more fatigued and seemed unable to take in any information both visually or auditorily. For Beth, although she didn't experience CVI meltdowns very often, when she did they were very severe and incapacitating. An example of this was observed by the researcher during a transition visit to a new school. In a very short period of time, Beth became so overwhelmed that she was unable to respond to anything anyone was saying to her and she was also unable to physically move herself away from the situation. In a sense she completely froze and shut down both mentally and physically. Mary's CVI meltdowns were more regular and were described as Mary becoming so emotionally distraught to the point that she was inconsolable.

Although no specific strategies were put into place around the behaviours, the introduction of the strategies for the children's visual and emotional needs helped support the children and consequently reduced the behaviours. In particular, understanding the children's specific visual issues and needs helped to understand the different behaviours the children had. This was summed up well by Beth's learning support teacher who commented:

> *I can see now why I was getting the bad behaviour from Beth in the Wednesday group, we needed to make sure she could access the activities visually. Little changes like that and seeing less of that sort of silly behaviours and I am sure that is about the changes I made.*

Having that understanding of the child's needs also helped significantly in the classroom, with the teachers letting the children use whatever strategies they needed to make life easier for themselves. A good example of this was in relation to Beth not making eye contact with the teacher and having her head on the floor when sitting on the mat. Her teacher now lets her do this, commenting:

> *Now that I understand why she does this, I let her do it and actually even with her head down she will often be listening and attending quite closely and even when things happen in class that are funny, she will get the joke and she will laugh along with everyone else, which sometimes surprises me because I think she is tuned out.*

The teaching teams also found the strategies practical and useful in helping to deal with the more challenging behaviours the children had. This was especially the case for Mary when she became emotionally distressed, which used to happen on a regular basis and the team had not been able to find a way to calm her down. They now used mindfulness and calm breaks regularly, reporting it made a significant difference with her teacher aide commenting:

> *Yep she used to be inconsolable but now we can calm her down, the mindfulness strategies and calm breaks are great.*

However, the most significant affect the implementation of the strategies had was in empowering the participants in relation to supporting the needs of the children in the case studies. The adults involved in the research all reported how important the education sessions were and how much difference it made for them to be able to understand the visual issues the children had. For Olive's parents who had experienced years of conflicting information and confusion from medical specialists, learning about and understanding CVI *"changed their lives"*. However most importantly, learning about CVI empowered Olive herself, which was made evident in her final words to the researcher: *"thank you for helping me to understand myself"*.

Discussion

The use of in-depth case studies to assess the effectiveness of a range of strategies to support the visual, emotional and behaviour needs of children with CVI has provided some valuable insights into the impact CVI has on not only the affected child, but also the people supporting the child. This is vital for the field, as although it has been shown that CVI is the most common cause of visual impairment affecting children in the developed world (Philip & Dutton, 2014), there is limited knowledge in terms of how best to support these children.

Vision

From the outset of the research, it was clear that the most pressing need for the research participants was education around CVI and the visual issues associated with this complex condition. This was even the case for Mary's team, who had already been informed that Mary had CVI, yet still did not understand what that actually meant and how it affected Mary on a daily basis. This highlighted the importance of conducting thorough CVI focused FVAs that allowed for the development of a detailed CVI profile of each child. This supports the view that thorough individual assessments of the child's vision need to be conducted in order to understand the child's unique pattern of visual experiences (Dutton & Bauer, 2019). This information was also important during the education sessions with the participants, as it allowed for detailed discussions about each child's specific visual issues.

The education sessions also ensured that the participants understood the reasons why the different strategies were being implemented and also, the effectiveness of the strategies, as everyone was on the same page in terms of how to best support the child. Once the participants understood each child's visual issues, the reliance on the researcher to support the implementation of the strategies also reduced. This supports the perspective that when the team supporting a child with CVI is well-informed and understands intuitively the impact of the child's visual difficulties; the strategies and support will become logical and intrinsic (Dutton & Bauer, 2019).

This was especially evident in relation to providing each child with a quiet, uncluttered space for focused work, as the participants could immediately see the impact clutter was having on the children's overall functioning. This is in line with the work of McDowell and Budd (2018), who found that quiet, uncluttered spaces improved the learning experiences and behaviour for children with CVI. Although the use of quiet spaces was implemented differently for each child in this research, the significant difference it had on each child's functioning suggests that this could be replicated in a range of different educational settings. For many schools, space is at a premium and it may not be possible to find a room that a child can be taken to as a quiet space. However, as shown in Olive's case study, simply having an uncluttered corner in the classroom can make a significant difference. Another positive outcome of providing an un-cluttered space for the children to work in, was how all three children intuitively understood how much it helped them, suggesting that children with CVI may be able to recognise their most optimal learning environment.

This was also the case with the introduction of the calm breaks. All three children instinctively knew when they required a calm break and once they understood that it was part of their daily routine, started requesting a calm break themselves whenever they felt it was needed. This supports the perspective that calm breaks can help a person with CVI to feel more confident in their ability to handle a challenging environment for longer periods of time (McDowell, 2019b). The impact the calm breaks had on the children's visual and overall fatigue was also promising. In all three case studies, the participants reported that the children functioned better and were able to achieve more when calm breaks were used throughout the day. This is another simple, yet important strategy that could easily be implemented for any child with CVI in any education setting.

Emotions

At first many of the participants did not relate the children's emotions to their visual difficulties. However, by the end of the research, they were able to see how different environments caused heightened emotional responses in the children, especially noisy and cluttered places. The use of mindfulness to help regulate the children's emotional responses worked well for all three children, supporting the work of Perry-Parrish and Sibinga (2014) and Vigerland et al. (2016) in that mindfulness can be an effective tool to help with anxiety and stress in children. However, more importantly, what this research has also shown is that the mindfulness approach used by a child with CVI can be based on their individual needs and circumstances. The three children in these case studies all used a different mindfulness platform, but all with equal success. Again, what was also promising was that all three children intuitively understood the benefits of doing regular mindfulness and started to request it at different times throughout the day whenever they felt they needed a mindful moment. This suggests that, although they may not have understood why, the children all recognised that the mindfulness helped reduce the feeling of anxiety and panic that they experienced in challenging environments.

This was backed by the adults in the research, who reported that they saw a reduction in the anxiety levels of all three children following the introduction of mindfulness into their daily routine. This supports the work of Conaughton et al. (2017) who found that mindfulness helped reduce anxiety in children with ASD. These findings suggest that mindfulness could be easily introduced into the daily routine for a child with CVI in a range of different education settings with the potential benefit of greatly reducing levels of anxiety and stress.

Behaviour

Although the three children in this research did not appear to have any significant behavioural issues, they all had a number of behaviours that had not been associated with their visual difficulties. For one child in the research in particular, her inability to make eye contact with people she was talking to, the constant need for routine and the disparity in her behaviour between known and unknown environments had resulted in discussions around the possibility of an ASD diagnosis in the past. This supports the perspective of Pawletko et al. (2015) who outline that when certain behaviours are not understood in relation to the visual difficulties that are causing them, children may get incorrectly labelled as having a developmental disorder such as ASD. However, once the visual difficulties were understood for the child in this research and also, the environments that exacerbated them, these behaviours were understood and were easily related to specific visual difficulties experienced.

This finding also highlighted that although no specific behaviour strategy was implemented within the case studies, the implementation of strategies to help support the children's visual and emotional needs ultimately also supported their behavioural needs. In particular, the better understanding of CVI through the education sessions made a significant difference for the adults supporting the children in this research, as they were more aware what was driving the different behaviours. In the final interviews with the parents of all three case studies, it came up time and again how they had changed their parenting approach around their child's behaviours because they completely understood what was causing the behaviours. This is in line with the view of Dutton and Bauer (2019), that in order to best support a child with CVI, a well-informed, loving, positive and supported model of care needs to be implemented.

Another important finding of this research in relation to the children's behaviours, was that the adults all reported a reduction in the challenging behaviours from all three children. This was partly to do with the behaviours that in the past had been incorrectly interpreted as the child misbehaving or being uninterested in learning, were now being recognised for what they actually were; the child experiencing a sensory overload, progressing towards a CVI meltdown or experiencing high levels of visual and overall fatigue. This supports the perspectives of Dutton (2015e) and Erasmus (2015) that an incorrect assumption can be made that children with CVI often misbehave, are uninterested in learning or are not able to learn. Alongside this, the introduction of the quiet spaces, calm breaks and mindfulness helped reduce these behaviours as the children were being provided with more optimal learning spaces, as well as opportunities to take breaks, recharge and reduce anxiety and fatigue levels. This supports the work of McDowell and Budd (2018) in using un-cluttered spaces to help enhance learning for children with CVI, and also McDowell (2019b) and McDowell and Dutton (2019) in that regular breaks away from challenging environments can help improve the ability to be in those sorts of environments for people with CVI.

Conclusion

Through the use of in-depth case studies, this research has highlighted that the impact of CVI on a child goes far beyond just the visual difficulties. Children with CVI commonly experience heightened emotional responses and challenging behaviours as a result of their visual difficulties, especially when their visual difficulties are unrecognised and unsupported. Therefore, any habilitation/rehabilitation programme developed to support a child with CVI needs to encompass the visual, emotional and behavioural needs for best possible outcomes. Moreover, as shown in this research, this can be easily achieved through the use of simple strategies that are easily implemented in a range of education settings and fundamental in terms of helping the whole child. Although they need to be tailored to meet each individual child’s needs, the use of CVI specific education sessions, quiet spaces for focused work, calm breaks and mindfulness could have a significant impact on the overall quality of life for a child with CVI.

Declaration of interest

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Framework discussion and conclusion

As described in the chapter introduction for this chapter, while conducting the research to assess the effectiveness of a range of strategies to support the visual, emotional and behavioural needs of children with CVI, the researcher also used the CVI practice framework as part of the overall research process. During the final interviews for each case study, the researcher also questioned the participants about the CVI practice framework to obtain their perspective on whether the framework had been useful in supporting the child. The parents of all three children reported that the implementation of the CVI practice framework helped them to feel more included in their child's education/rehabilitation plan and that they understood the plan better. The father of one child reported that they had previously felt disempowered (mainly by medical professionals), as their daughter's visual condition was never really explained to them. However, through the education sessions about CVI and their daughter's specific visual difficulties, they now felt they understood her much better and knew instinctively how to help her. This in turn, made it easier for them to advocate for her needs and support the strategies that were put into place to meet her needs.

For the education and therapy teams involved in the research, they felt the CVI practice framework was effective because it was evidence based and child centred. The process of developing the individual CVI profiles and then implementing strategies based on each child's individual needs was logical and allowed them to actually focus on the child's specific needs. They also felt that educating the team was important, as it helped ensure consistency. A number of participants reported that the connection between home and school was very strong because everyone had the same understanding of what the child's visual issues were and how to help them. This connection allowed them to walk alongside the child and their family on their CVI journey. Across all three case studies, the education and therapy teams also described feeling empowered and feeling confident in supporting the child. Overall, the participants reported that each aspect of the framework was important, and each component needed to be implemented together for the framework to be effective.

In conclusion, these findings suggest that the CVI practice framework, with the three main components of individual CVI profiles, individual education/rehabilitation plans, and empowerment of the child and their family, has the potential to improve the success of any education or habilitation/rehabilitation plan implemented to support the needs of children with CVI. However, in order for the framework to be effective, each component of the framework needs to be implemented in conjunction with each other. Further research on a larger population of children with CVI will need to be conducted to corroborate these findings.

Chapter conclusion

This chapter reported on the effectiveness of a range of different strategies implemented to support the visual, emotional and behavioural needs of children with CVI, as well as the effectiveness of the overall CVI practice framework. As such, the chapter related to the overall thesis aim of developing an effective framework for supporting children with CVI, and the fourth and sixth research questions: What are effective strategies for alleviating the impact of the visual difficulties and the resulting emotional and behavioural responses that are associated with CVI? and What is an effective framework for supporting children with CVI? From the research it was clear that there were a number of generic strategies, that when implemented within the child's home and school environment could help reduce the effect of the visual, emotional and behavioural responses associated with CVI. These included CVI education sessions, quiet spaces, calm breaks, and mindfulness. A summary of the findings from this research in relation to the research question: What is an effective framework for supporting children with CVI, can be found in the framework discussion and conclusion section of this chapter.

The chapter is also in line with the overall research framework by continuing to use pragmatism as the guiding epistemology. Each individual strategy implemented was intended to solve a specific problem, while at the same time help to determine whether using individualised programmes helped improve the functioning of children with CVI. In addition, in line with a pragmatist approach, the researcher used different qualitative research methods throughout the research process, including interviews, focus groups and observations, as these were deemed the most appropriate methods for this research. A theoretical perspective of dialectical pluralism also allowed for the inclusion of the different voices involved in the case studies, including the perspectives of the child and their family, the medical perspectives and the education and therapy perspectives. This paper has been submitted to *Disability Studies Quarterly* and is currently under review.

Chapter Seven – Parent Survey

Chapter introduction

The third component of the CVI practice framework is empowerment of the child with CVI and their family. As outlined in Chapters 3 and 4, the researcher believed that being empowered was an important component that led to the success of the rehabilitation programme she developed for herself. This empowerment came from being listened to and believed by the medical professional who diagnosed her with CVI, as well as the attainment of CVI specific knowledge. By developing a deep understanding of CVI and the specific visual difficulties she experienced, the researcher was able to understand intrinsically what was needed to help improve her visual and overall functioning. With this in mind, the researcher wanted to see if parents of children with CVI were similarly empowered through the attainment of knowledge and whether being empowered led to them being more involved with the services their child received. This article reports on the findings of an online survey for parents of children with CVI that looked to establish whether there was a link between relevant information of the child's condition at time of diagnosis and more involvement in the services their child receives.

This chapter relates to the overall thesis aim of developing an effective framework for supporting children with CVI; more specifically, the third component of the framework of empowering the child with CVI and their family.

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Abstract

For parents of children with cerebral visual impairment, the greatest need during the diagnostic period is to gain knowledge about their child's visual difficulties. Unfortunately, through lack of information, many parents are often left confused and unsure how to help their child. To better understand the impact this lack of information has in relation to empowering parents and helping them to confidently develop into parental advocates, parents of children with cerebral visual impairment were invited to participate in an online survey. Responses were received from nine different countries in North America, UK, Australasia and Europe. Information gathered included: parents' experiences during the diagnostic period, their attainment of knowledge as their child developed and their level of empowerment in relation to the services their child receives. Findings suggest that parents who did receive information at time of diagnosis have more positive relationships with professionals, feel more empowered and are more confident in being parental advocates.

Keywords

CVI, knowledge attainment, parental advocacy, empowerment

Points of interest

- Providing parents with information about cerebral visual impairment in a format that they are able to easily access at time of diagnosis helps parents to better understand the impact of this condition on their child's development.

- When parents are provided with information about cerebral visual impairment that is relevant to their child, it helps them to develop the confidence to effectively advocate for their child's needs by empowering them through knowledge and understanding.
- Providing parents with relevant information about their child's visual difficulties helps them to further develop their understanding of cerebral visual impairment and therefore, is seen as a tool for further learning.
- When parents are provided with clear information about cerebral visual impairment in relation to their child, it helps them to cultivate collaborative relationships with professionals supporting their child.

Introduction

Cerebral visual impairment (CVI) is a complex visual condition that in recent times has become the primary cause of congenital visual impairment affecting children in the economically developed world (Kong et al., 2012; Philip & Dutton, 2014). CVI is caused by damage to some parts of the visual brain (the totality of brain elements that serve or support vision) (Lueck & Dutton, 2015), and can be defined as a verifiable visual dysfunction which cannot be attributed to disorders of the anterior visual pathways or any potentially co-occurring ocular impairments (Sakki et al., 2018). Due to advancements in neonatal care in developed countries the prevalence of CVI is increasing, and will continue to rise (Chong & Dai, 2014) as a result of increased survival rates of preterm infants (Good et al., 2001) and those with other conditions caused by early brain insult, such as cerebral palsy, hydrocephalus and periventricular white matter injury (Andersson et al., 2006; Ego et al., 2015; Fazzi et al., 2009; Houliston et al., 1999). CVI can also be acquired at any age during childhood due to issues such as closed head injury, damage to specific brain locations, epilepsy, metabolic disorders and infections of the central nervous system (Soul & Matsuba, 2010).

As with other complex health conditions or disabilities, having a child diagnosed with CVI can be an extremely stressful and emotional time for parents (Rafferty & Sullivan, 2017). Recent research on raising a child with a disability indicates that, for some parents, the initial diagnosis can be an extremely distressing time, causing long lasting feelings of grief and trauma (Young et al., 2020). During this crucial diagnostic period, parents can be particularly affected by the uncertainty of not only the diagnosis, but also the strain associated with future caregiving (McGrath et al., 2007). First line health professionals therefore, have the potential to make this process less stressful, by taking parents' concerns, perspectives and observations seriously; recognising their emotional needs; and supporting them accordingly (Boshoff et al., 2018). Not only does this create a more positive experience for parents during the difficult diagnostic period, but it also has a lasting influence on future relationships with other service providers (Boshoff et al., 2018). This is vital, as the parent-professional relationship can often become problematic, especially if the parents do not feel listened to (Hodge & Runswick-Cole, 2008; Prezant & Marshak, 2006). Another important role for professionals during this crucial period, is helping parents to become confident advocates for their child. Parental advocacy can include behaviours such as making medical decisions, and seeking out a network of support that has the research, knowledge, and skills to improve their child's quality of life (Hinds et al., 2009). Many parents also describe the process of becoming an advocate for their child as a coping strategy, as it enables them to move forward by redirecting negative emotions into positive outcomes (Boshoff et al., 2016).

However, to ensure parents have the confidence to become effective advocates, parents need to be empowered. Empowerment can be described as a process of gaining personal power and control (Mulligan et al., 2012), with parental empowerment occurring as a result of parents utilizing knowledge, skills and resources to gain a sense of control and improve their families quality of life (Singh et al., 1995). Moreover, parental empowerment in the health care setting, may be marked by the attainment of knowledge and skills, active participation in the services their child receives, awareness of choices, and involvement in decision making (Shulman, 1992). The importance of the diagnostic period, therefore, becomes even more significant. Not only are professionals in the position to be able to foster and encourage a level of empowerment in parents, they can also help parents to become advocates for their child by providing them with knowledge about their child's condition, which parents can then build on to ensure that their child's learning is optimised. Unfortunately, however, many parents of children with disabilities are often left feeling disempowered by professionals, especially when they feel that their knowledge of their child is not valued (Hodge & Runswick-Cole, 2008).

For this reason, the greatest need for parents at the time of diagnosis, is to be provided with information about their child's health condition or disability (Rahi et al., 2004) in a language framework matched to their ability to understand and learn this new information. In terms of a CVI diagnosis, parents need information about not only CVI in general, but also about the specific visual difficulties their child has, how they impact them on a daily basis, and how to best circumvent limitations of access to knowledge, social interaction and mobility (Dutton & Bauer, 2019; Jackel et al., 2010). Unfortunately, however, anecdotal evidence from numerous parents, indicates that this is not always happening, with many parents being provided with very little information about CVI, or only general information not specifically relevant to their child at the time of diagnosis.

This is often due to a lack of understanding and awareness of CVI by medical providers (Gorrie et al., 2019; Jackel et al., 2010; Martin et al., 2016). Potentially, this lack of provision of relevant information at the time of diagnosis puts parents at a disadvantage, as they may not feel confident enough to be effective advocates for their developing child. As such, parents are at risk of being disempowered, at a time when being empowered is arguably essential. Unfortunately, this is an issue common to many parents of children being diagnosed with a disability, with a number of studies reporting that professionals often neglect to pass on vital information to parents during the important diagnostic period (Case, 2001; Hodge & Runswick-Cole, 2008; Prezant & Marshak, 2006).

How the information is provided to parents at the time of diagnosis is also important. Research conducted by Mulligan et al. (2012) into the diagnostic process for children with Autism Spectrum Disorder (ASD) has highlighted the need for information to be shared in a way that not only enhances parent empowerment, but also cultivates a collaborative relationship between the professional and the family. This research further supports the view that parents should be provided with the specifics of their child's condition and also the prognosis for the future (in the context of what is known) (Mulligan et al., 2012). In terms of how this information is shared, Mulligan et al. (2012) highlight that information about a diagnosis should be provided verbally by the diagnosing professional, with follow up information being provided in the form of printed material. The benefits of the printed material, is that it is something tangible that parents can take away and use as they start the process of obtaining more information about their child's condition.

With information and knowledge attainment being seen as vital elements of effective advocacy and parental empowerment, many parents are themselves turning to self-education in order to develop a better understanding of their child's condition (Boshoff et al., 2018). Fortunately, in this modern technological age, self-education has become more widely available and accessible, particularly with the use of platforms such as Facebook and other social media outlets, online parent support groups and relevant websites (Boshoff et al., 2018). All of these can offer a plethora of information about CVI and supporting children with CVI. For parents who are equipped with a basic understanding of CVI at the time of diagnosis, engagement in ongoing self-education is exponentially more beneficial than for those parents engaging in self-education but who are not equipped with a basic understanding of CVI at the time of diagnosis. This is because, as outlined by Sawyer (2006), new learning always takes place against the backdrop of existing knowledge. Knowledge begets knowledge in that equipping parents with a basic and accurate understanding of CVI at the time of diagnosis, supports their new learning. Parents are able to continue a process of developing useful and accurate knowledge and understanding in different contexts in order to help solve problems that may arise with their child (Bolstad et al., 2012). This is in contrast to parents who are not provided with any information about CVI and have to start their knowledge attainment journey without important foundational knowledge and understanding.

The significance of parental empowerment becomes even more apparent when considering the different responsibilities parents of children with disabilities have to take on. Right from the time of diagnosis, parents are thrust into a world of appointments and interactions with medical, education and habilitation/rehabilitation specialists. This can be overwhelming for many parents, with research suggesting that parents are likely to describe working with professionals as the most difficult aspect of parenting a disabled child (Hodge & Runswick-Cole, 2008). But as Rafferty and Sullivan (2017) highlight, empowerment gained through a clear understanding of their child's issues, allows parents to reassert control by being the primary coordinators of their child's care. This seems vital in supporting a child with CVI, because as stated by Dutton and Bauer (2019), children with CVI will learn best in the context of a well-informed, loving, positive and supportive model of care where parental involvement is central to all habilitation/rehabilitation services. An empowered parent may feel more in control and more confident in building a collaborative relationship with service providers, in which their advice about their child is heard and there is frequent, open and honest communication with the professional (Boshoff et al., 2018).

In contrast, a parent who is not empowered may feel and convey a sense of helplessness, hopelessness, and dependency (Zimmerman, 2000), which could have a negative impact in relation to the parenting and the services their child receives. For instance, a parent who is not empowered may develop negative attitudes towards service providers, underutilise the different services available, and may be hesitant to fully participate and engage with different service providers and organisations (Olin et al., 2010; Owens et al., 2002; Pescosolido et al., 2008). In the long run, these kinds of negative interactions and avoidance of different services, could have a negative impact not only on the child with CVI, but also their family. The end result could be that the child is not supported to develop to their full potential and that the demands of caregiving when the condition is not fully understood become too overwhelming for the family. To ensure this does not happen, professionals working in the field of diagnosing and supporting children with CVI, need to understand the role of the attainment of CVI specific knowledge during that crucial diagnostic period in relation to helping parents on the path to empowerment and cultivating effective parental advocates.

This research therefore, focuses on the influence the attainment of CVI specific knowledge at the time of diagnosis, has in empowering parents to build positive collaborative relationships with the professionals that support their child.

Research process

A mixed method, concurrent triangulation design was used in this research, which meant that both qualitative and quantitative data could be gathered simultaneously during one data collection phase (Creswell et al., 2003). This method also allowed for priority to be given to the qualitative data during the analysis phase, as it helped to develop a broader perspective of the parents experience in relation to knowledge attainment (Creswell et al., 2003). The analysis of the qualitative data followed a thematic process, which allowed the researcher to identify, analyse and report themes in the data relevant to the research questions (Braun & Clarke, 2006). Descriptive analysis was conducted on the quantitative data in order to describe the nature, incidence, and distribution in relation to specific questions within the survey (Ary et al., 2014). Both the qualitative and quantitative results were then integrated during the interpretation phase of the research (Creswell et al., 2003).

Procedure

The research was advertised via social media, CVI websites and through Blind and Low Vision support agencies around the world. Parents and caregivers of children with CVI of any age were invited to complete an online survey. Information about the research was provided on the first page of the survey and participants were asked not to provide any identifying information about themselves or their child; however an email address was included on the information page if parents wanted to contact the researcher to provide further information. Participants were also informed that they could withdraw from the survey at any point up until the final section, where clicking on the 'done' button would submit their response and they would be unable to edit them. Completion of the survey implied consent. The research was approved by a University Human Ethics Committee.

Participants

To ensure that there was an accurate representation of the number and percentages of people responding to each question, a data cleaning process was conducted that removed any survey responses that contained a lot of incomplete or missing data. As a result, seventy-six valid responses were obtained for the research. Participants were mainly from USA (49%), UK (30%), New Zealand (11%) with smaller numbers from six other countries (Australia, Canada, Croatia, Netherlands, Germany, Egypt).

Data gathering

The research was based on a multi sectioned, online survey for parents of children with CVI. The survey consisted of the following sections:

1. *Demographics*. Questions pertaining to the child's gender, age and country of origin. Also, at what age they acquired CVI and at what age were they diagnosed.
2. *Attainment of knowledge*. Questions pertaining to how parents obtained knowledge about CVI at the time of diagnosis. Also, how they have gained more knowledge as their child developed and how they use this knowledge.
3. *Parental involvement in the services their child receives*. Questions pertaining to parents' feelings of empowerment in relation to the professionals supporting their child.

Data analysis

Participants were divided into two groups based on their responses to the following questions:

> Q8. When your child was first diagnosed with CVI, did you receive any information about CVI in general?
>
> Q13. Did you feel that this information helped you to become an advocate for your child? Please explain your answer.

Hereafter, these groups will be referred to as the *informed* and the *not informed* (at time of diagnosis).

The rationale to divide the two groups into the informed and not informed was based on the literature outlining the often problematic parent-professional relationship (Hodge & Runswick-Cole, 2008), how important information is at the time of diagnosis in terms of empowering parents (Rafferty & Sullivan, 2017; Rahi et al., 2004), and the impact a negative experience during the diagnostic period can have on parents of children with disabilities (Boshoff et al., 2018).

Descriptive analysis was then carried out on the remainder of the questions pertaining to the information that was obtained at time of diagnosis. To support the quantitative analysis, thematic analysis was also conducted on the open-ended questions from this section. For this, a six phase thematic analysis process was used, which allowed the researcher to become familiar with the data, develop initial codes, search for themes, review themes, define and name the themes and finally, report the findings (Braun &

Clarke, 2006). Descriptive analysis to compare the two groups, was also conducted on relevant questions from the attainment of knowledge section.

Data from the third section of the survey (questions around the services their child receives), was analysed using SPSS software to obtain and compare frequencies of the two groups for specific questions. A non-parametric Mann-Whitney U test was also conducted on the questions that were answered using a Likert Scale.

Results

The ages that the participants' children developed CVI ranged from 0 to 10 years (average 3.5 months), and the ages that their children were diagnosed with CVI ranged from 0 to18 years (average 3.6 years).

Time of diagnosis

At the time of their child's diagnosis, 49 of the 76 (65.5%) respondents received information about CVI. On average this information was provided to parents through two sources, with 66.1% receiving the information through discussions with the professionals at time of diagnosis. Other sources included books, leaflets/pamphlets, links to local organisations, websites and parents' courses (as shown in Figure 8).

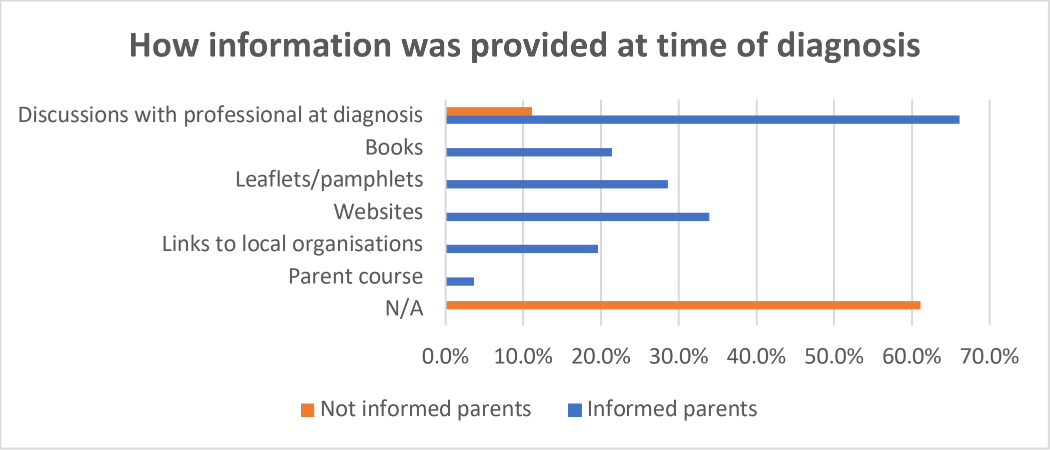

Figure 8. How information was provided at time of diagnosis

Of the 49 informed parents, 89.7% found the information relevant to their child, 85.7% were able to understand the information they received and 73.4% felt that the information helped them to become an advocate for their child. However, these responses were tempered somewhat by statements from parents such as: *"To be honest it wasn't much information beyond the fact that CVI is in the brain and manifests in various ways, however, it gave us a term to research".*

Of the 27 (35.5%) respondents who did not receive information at the time of the diagnosis, 7 (25.9%) felt that they were still able to be advocates for their child. This was qualified by stating that they had gone out and done their own research at time of diagnosis or in some cases, before an official diagnosis of CVI was given. These 7 respondents were categorised as part of the informed group, resulting in the final grouping of the respondents into 73.6% informed (n=56) and 26.3% not informed (n=20). Of the 26.3% not informed parents, 11.1% indicated that they did have discussions with the professionals around time of diagnosis, however, they all described not being able to understand the information that was provided to them.

The importance of becoming an advocate for their child and the role that knowledge played in this was described by many parents. Comments such as: *"Absolutely! It gave me a thirst to learn more",* highlighted how a positive experience of receiving useful information at the right time, propelled a parent into finding more information. This was compared with statements such as: "*I am and always will be his advocate but the information I received on CVI was not nearly enough, not very informative to help me in any way",* from parents whose experience was not as positive. Finally, a comment from a parent who did not receive any information at all: *"I don't know enough about CVI to be an advocate; I feel I'm letting my child down as no one else is advocating for her either",* highlighted the impact that not understanding their child's condition well enough had on them being able to ensure they were receiving the right support.

Developing an understanding of CVI as their child developed

There were a number of different avenues parents used to help them develop a better understanding of their child's visual world (as shown in Figure 9).

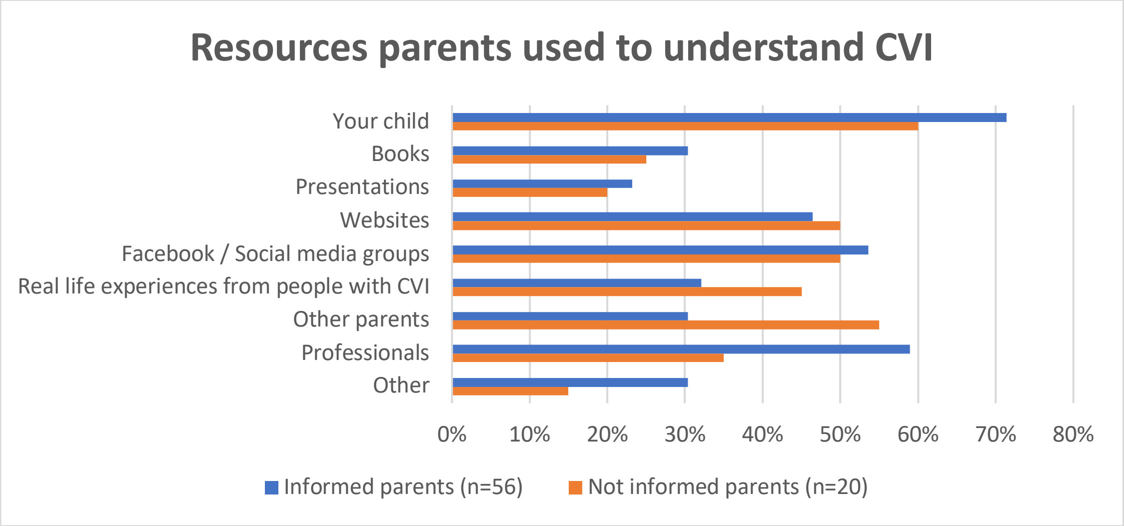

Figure 9. Resources parents used to understand CVI

When asked to describe how their understanding of their child's condition had developed over time, both the informed and not informed responded under four main themes: as my child developed, own research, professionals, and other parents. However, there was a different order of these themes in terms of importance and incidence between the groups. For both the informed and not informed groups, parents indicated that learning with their child as they developed was the most effective method of understanding their child's visual impairments. Second, both groups also outlined that conducting their own research helped them to develop a better understanding of their child's condition. For this, both groups used books, websites, social media and presentations. However, the groups then differed in their belief on the importance of the professional and other parents in helping them to understand their child. The informed parents preferred professionals as a source of information over other parents, whereas the not informed parents relied more on other parents over professionals to help them develop a better understanding of CVI.

Many parents also shared how critical the attainment of knowledge was in terms of helping their child. The following statements highlighted the level of determination and commitment parents had in terms of gaining the knowledge they needed: *"When you don't have the answers you seek them at all cost",* "*With knowledge comes power. The more information given to me provided me with the back up support for what I needed to request for my son"*. In contrast, statements such as *"Sadly, my daughter could have had a better start if I understood more"*, highlighted the emotional struggle parents experienced as a result of not having enough knowledge about CVI and their child's visual difficulties.

Parents were also asked to share how they had used the knowledge they had gained to help their children in their home, school and community environments. When asked to describe how they have used the information they gathered to help their child at home, three themes emerged from the informed parents responses. These were: implementing strategies, changing the layout of the house, and teaching my child. Respondents highlighted how significant CVI specific knowledge was in being able to help their child within the home environment, for example "*We find teachable moments all the time now that we understand CVI*" and *"our lives have improved immensely because we understand her better"*, highlighted how significant CVI specific knowledge was in being able to help their child within the home environment. In comparison, two themes emerged from the not informed group: implementing strategies and changing the layout of the house. Statements from this group focused on specific strategies that they had learnt, such as: using a blackout tent, de-cluttering, bright lights and bold coloured toys. However, these statements all used the terminology of implementing, as opposed to teaching.

When asked how they had used the information they gathered about CVI to help their child at school, both the informed and not informed parents responses related to collaborating with the professionals. However, the terminology used was quite different between the two groups. For example, the informed parents made statements such as *"advocate", "we helped train the teacher"* and *"we educated the preschool"*, whereas the not informed parents stated: *"we explained", "as much as they (the school) would accept it"* and *"trying to get people to understand"*. Many of the not informed parents also did not provide a response to this question, whereas the majority of the informed parents did.

In relation to how they used the information they have gathered about CVI to help their child in the community, two themes emerged from the not informed parents' responses: implementing strategies and avoidance of public places. The reasons for avoiding public places were explained with statements such as *"we are still working on public places. He shuts down in public places"*. In comparison, themes to emerge from the informed parents responses were understanding and educating, implementing strategies, mobility, and difficulties in the community. In relation to implementing strategies and mobility, the majority of the responses were very specific, with statements such as: *"we describe events, verbally warn when touching or moving", "we use visual aids such as the white cane when in the community"* and *"I use sighted guide techniques in busy places and let her run free and wild in the open places she loves"*. The responses for difficulties in the community were explained with statements such as: *"my daughter won't go out alone", "we are not really able to but we are working on it"*. Again, there were fewer responses from the not informed parents compared to their response rate for previous questions.

When asked if there was any vital information about how best to help their child that parents wished that had known at the start, both the informed and the not informed parents had strong views, with the majority of the responses falling into five main categories, with all of them being of equal importance. These included: earlier diagnosis, CVI training for the professionals, the potential to improve vision and how to help their child, reassurance that it was going to be ok, and relevant information in simple terms. The raw emotions in relation to the diagnostic experience were evident in the parents responses, with statements such as: *"The only information I really needed to hear was that it would be ok and that he could and would lead a productive and happy life"* and *"My heart goes out to families who don't know how to research like I do - and who have also fallen through the cracks in our system"*.

Parental involvement in the services their child receives

When asked whether they felt they had a clear understanding of the role of each of the professionals working with their child, responses from the informed parents (n=42) ranged from ‘sometimes’ (26%) to ‘always’ (52%). The most frequent response was ‘always’. Responses from the not informed parents (n=14) ranged from ‘never’ (7%) to ‘always’ (14%). The most frequent responses was ‘often’ (50%). The results of a Mann-Whitney U test showed that the informed parents (median = 5 [always]) were significantly more likely to feel that they understood the role of professionals, than not informed parents (median = 4 [often]), $U = 176.00$, $p = .018$, $r = -0.32$.

When asked whether they wanted to know more about the reasons why the professionals make the decisions they do, responses from the informed parents (n=45) ranged from ‘never’ (4%) to ‘always’ (38%). The most frequent response was ‘always’. Responses from the not informed parents (n=16) ranged from ‘rarely’ (6%) to ‘always’ (50%). The most frequent response was ‘always’.

In response to whether they felt they were able to ask for a more detailed explanation from the professionals working with their child, 68% of informed parents (32/47) responded with yes, while only 44% of the not informed parents (7/16) said yes.

When asked if they felt enough time was given to explaining the reasons behind the professional’s decision, responses from the informed parents (n=46) ranged from ‘never’ (2%) to ‘always’ (11%). The most frequent response was ‘often’ (48%). Responses from the not informed parents (n=15) ranged from ‘never’ (13%) to ‘always’ (27%). The most frequent response was ‘rarely’ and ‘always’.

When asked if they felt their role as parent was valued by the professionals working with their child, responses from the informed parents (n=39) ranged from ‘rarely’ (5%) to ‘always’ (39%). The most frequent response was ‘always’. The response from the not informed parents (n=15) ranged from ‘never’ (7%) to ‘always’ (33%). The most frequent response was ‘always’.

Discussion

By separating the survey responses into the two groups of parents that received information at the time of their child’s diagnosis and parents that did not, this research has provided an interesting insight into the role that receiving information at the time of diagnosis, has in relation to empowering parents. Although it is well documented that parents of children with complex health needs and disabilities such as CVI need to be given clear information about their child’s condition at the time of diagnosis (Boshoff et al., 2018; Jackel et al., 2010; Rahi et al., 2004), it was sobering to see that a third of parents in this research were still not being provided with any information at all. But even for the parents that did receive information, many reported not being able to understand the information that was provided to them, or that it was not relevant to their child. This suggests that there is still some work that needs to be done in the field of diagnosing CVI. This is in line with the view that there is still a lack of awareness and understanding of CVI by medical providers (Gorrie et al., 2019; Jackel et al., 2010; Martin et al., 2016) and highlights a need for further research and support around the diagnostic process. There were a number of main themes that emerged from this research, that if considered by the professionals working in the field, may help to enhance parent empowerment and cultivate collaborative relationships between the professionals and the family.

Providing information to parents in an accessible format

In terms of how parents received the information, a good proportion of the informed parents reported it was through discussions with the professionals at the time of diagnosis, with follow up information being provided in written form or suggestions to relevant websites and organisations. This supports the recommendations outlined by Mulligan et al. (2012) for children with ASD, of a best practice approach to providing relevant information to parents. However, even when provided with information, a number of parents reported that they did not understand the information they were provided with, or that it wasn't relevant to their child. This emphasises the need for information to be given to parents in a manner that is comprehensible to them and useful in helping them to better understand their child as they develop. But in order for professionals to understand the most accessible method of providing information to each individual parent, the parent-professional relationship needs to be fluid, with the professionals being open minded and prepared to listen to the parents perspectives in relation to their child's impairment (Hodge & Runswick-Cole, 2008). Moreover, professionals need to be guided by parents as 'experts' on their own child and respond with relevant information that is pertinent to each individual family's needs in the most accessible format (Hodge & Runswick-Cole, 2008).

The need for information to be provided in an accessible format, also suggests that some consistency is needed amongst the professionals that support children with CVI and their families to ensure that the information does not become confusing or overwhelming. This could be achieved by creating a 'family specific' guide, that all parents could be given during the diagnostic period, which covers the basics of CVI, how they can support their child and where to go for more information. A booklet such as this, could also be made country specific, to ensure that parents are provided with information that is relevant to where they live, such as local support networks. Further information on the specifics of their child's visual difficulties could then be provided to parents by professionals in the most appropriate format. This again supports the need for positive parent-professional relationships (Hodge & Runswick-Cole, 2008).

Information as a tool for advocacy

Another main theme of the research was around how crucial the diagnostic period is for parents and the role first-line health professionals have in helping parents to become advocates for their child. In this research, three quarters of the respondents reported that they felt confident in the role of parent advocate after either receiving relevant information at the time of diagnosis, or researching CVI themselves. This supports the view of Rahi et al. (2004) that the attainment of knowledge is one of the greatest needs of parents during the important diagnostic period, as it helps give them the confidence to develop into effective parental advocates. Sadly, in comparison, the feelings of inadequacy were apparent amongst the small group of not informed parents in this research, who felt that they were failing in being able to advocate for their child. This is similar to the sense of helplessness and hopelessness reported by Zimmerman (2000) in parents who have not been empowered by the professionals they engage with in relation to their child's condition.

For the parents in this research, the lack of information, or information that was not relevant to their child at time of diagnosis, not only impacted on their confidence in being an effective advocate for their child, it also influenced the process of how they then advanced their understanding of CVI as their child developed. Although both groups reported that their child was the best resource they had used in helping them to develop a better understanding of CVI, there were differences on how helpful other sources were.

The preference of the not informed parents for using other parents over professionals to help build on their knowledge of CVI, suggests that for these parents, their initial negative experience with the professional who diagnosed their child, may have had a lasting impact on the relationships they have with other professionals as their child developed. This supports the work of Boshoff et al. (2018), who outlined that a negative experience with a front-line health professional can have a lasting influence on how parents engage with other service providers in the future.

Information as a tool for further learning

Another advantage of receiving information at the time of diagnosis was also evident amongst the informed parents. A number of parents in this group reported that the information they received when their child was diagnosed provided a good starting point in terms of knowledge attainment, in which they could more easily seek and gain further knowledge in order to develop a better understanding of how to support their child. This is in line with the concept that it is easier to take on new learning when it is against a backdrop of sound existing knowledge (Sawyer, 2006). Another finding of this research in relation to knowledge attainment as their child developed, is the role of self-education. Both groups reported conducting their own research on CVI, turning to books, relevant websites and social media platforms in order to continue to develop their understanding. This is a similar finding to what has been reported on in more recent research, such as Boshoff et al. (2018), who also outlined that many parents of children with complex health conditions or disabilities are self-educating through platforms such as websites, Facebook and other social media outlets, and online parent support groups. However, this highlights another pressing need for the field in ensuring that the information provided on CVI websites and Facebook pages is scientifically accurate, research and evidence based, and peer reviewed to ensure parents are developing an accurate understanding of CVI.

Information as a tool for empowerment

The way parents used the information they were provided with or obtained through self-education to support their child in different environments was also slightly different between the two groups of parents reported in this research. The informed parents provided responses that suggested that they were coming from a place of feeling empowered, talking about how they were able to teach their child, how they provided education for people that engaged with their child and how they advocated for their child in the different contexts of home, school and community environments. From these descriptions, it appears that the informed parents in this research felt more in control and were more confident to take on the role of primary coordinator in relation to the services their child received. This is a similar finding to Rafferty and Sullivan (2017) who outlined that an empowered parent is able to reassert control by being the primary coordinators of their child's care. In comparison, only a small number of the not informed parents responded to these questions in this research, and when they did respond, they mainly described how they implemented strategies that they had either been shown by different service providers, or learnt from other parents. This lack of response to the questions, and when they did respond, the less forceful language used in these responses suggests that the not informed parents in this research felt less empowered, and in some cases, dependant on service providers to show them the strategies that would help their child. This is similar to the findings reported by Zimmerman (2000) and Olin et al. (2010), that a parent that has not been empowered may convey a sense of dependency and may underutilise the services available to them.

Information as a tool to help cultivate collaborative relationships with professionals

When it comes to the services that their child receives, the statistical significance of the difference between the informed parents and the not informed parents in this research in relation to having a clear understanding of the roles of each of the professionals working with their child is telling. For the informed parents, it appears that understanding the reasons why the professionals involved with their child make the decisions they do is an important aspect of being central to and in control of the services that their child receives, with almost three quarters indicating that the majority of the time they know what the professionals are doing. Moreover, not only did they feel well informed, there was no situations where they did not feel informed. This is in comparison with the not informed parents in this research, where almost a third of the parents reported that they were not clear on what the professionals were doing with their child. Although the reasons for this could be varied, it suggests that the not informed parents in this research felt unable to ask the professionals what their role is in relation to their child, or that they do not have enough understanding of CVI and how it affects their child specifically to be able to connect with what the professional does with their child. Both scenarios relate back to the failure to empower and support parents to become effective advocates during the diagnostic period by not providing them with relevant information about CVI.

The impact of not feeling like effective parental advocates also extended into whether the not informed parents in this research wanted to know more about the decisions made by the professionals in relation to their child. Almost three quarters indicated that they did want to know more, in comparison with only a half of the informed parents. What was also interesting in the responses to this question, was that almost a third of the informed parents indicated that they did not want to know more about the decisions the professionals made. However, when you consider this response in relation to the question asking parents if they understood the roles of the professionals, where the majority of the informed parents reported they did, it can be surmised that the informed parents did not want to know more, because they were already confident in their understanding of the role of the professionals.

The significance of the majority of the not informed parents wanting to know more about the role of the professionals can also be understood in terms of their responses to the question asking them if they felt able to ask the professionals for an explanation of their decisions they have made in relation to their child. While almost three quarters of the informed parents in this research reported that they were able to ask for a further explanation from the professionals, almost half of the not informed indicated that they were able to seek further information with some professionals, but not others. Although there will be many reasons why parents feel comfortable with certain professionals and not others, it also suggests that for these parents, not being empowered during the diagnostic period has left them feeling less confident and unable to build effective collaborative relationships. This is in line with Boshoff et al. (2018) perspective that a negative experience with a first-line health professional can have a lasting impact on how parents engage and collaborate with future service providers.

There was also a disparity between the informed and not informed parents in relation to whether enough time was given to parents by the professionals working with their child. While almost two thirds of the informed parents appeared quite positive about how much time was given to them, over a third of the not informed parents felt that they were not given enough time. This suggests a level of dissatisfaction amongst the not informed parents in this research, who may be frustrated with the level of engagement with the service providers and the lack of awareness of the professionals that they, as parents need more time and a more detailed explanation to help them understand the professional's role with their child. This is in line with the perspective of Prezant and Marshak (2006) that for parents of a child with a disability, one of the most important actions a professional can take is to share their expertise and knowledge with them.

The difference in the responses in this research between the informed and not informed parents in relation to whether they believed their role was valued by the professionals was also telling. Almost three quarters of the informed parents felt valued by the professionals, compared with only half of the not informed parents. Moreover, over a quarter of the not informed parents did not feel their role of parent was valued by the professionals, compared with a only a very small percentage of the informed parents. Although parents were not asked to indicate why they did not feel valued, it could be surmised that the reasons that parents in this research did feel valued was because the professionals listen to them and take on board the advice that is given to them about their child. This is in line with Prezant and Marshak (2006) who outline that one of the most important actions professionals can take, is to listen and respect the input provided by parents in relation to their child's impairment. As such, through knowledge and effective advocacy, parents have been able to build collaborative relationships with professionals that allows for frequent, open and honest communication to flow between the professionals and themselves. This supports the work of Hodge and Runswick-Cole (2008), who outline that the parent-professional relationship needs to be fluid, with the professionals being open-minded and willing to take on new perspectives.

Parents expectations of the diagnostic process

Despite the differences in experiences during the diagnostic period, both the informed and not informed parents felt very strongly about what they believed should have happened when their child was diagnosed with CVI. The desire for earlier diagnosis of CVI is entirely justified with respondents to this research having had to wait an average time of 3.6 years for a diagnosis and a number of families experiencing many years of either misdiagnosis or no diagnosis. This length of time to diagnose CVI and the recommendation that professionals need more specific CVI training highlights another pressing need for the field. Although the need for CVI to be better understood by the professionals is well documented (Gorrie et al., 2019; Jackel et al., 2010; Martin et al., 2016), it is still an area that needs urgent attention. A major component of this, is being able to reassure parents when diagnosing their child with CVI. This should also be a fundamental element of the diagnostic process and can be achieved by either telling them that there is the potential to improve their child's vision or by providing them with relevant information in a way that is understandable to them. Not only will this help reduce the stress during this difficult time, it will also go a long way in giving parents the confidence to become effective advocates, as well as cultivating a collaborative relationship between the professional and the family.

Conclusion

With the increased number of children being diagnosed with CVI worldwide and the awareness that this number will continue to rise, it is important that the initial diagnostic process is conducted in a way that not only provides parents with the information they need, but also fosters a level of parental advocacy and empowerment. The impact of not receiving vital information at time of diagnosis can have a lasting impact on not only the child, but also on the parents and their ability to feel confident in supporting their child. As outlined so succinctly by one parent in this research "knowledge is power" and parents have the right to be placed in a position of power right from the outset in their CVI journey with their child. Professionals are in the position to give parents this power by simply providing them with clear and relevant information about CVI at the time of diagnosis. The professionals that are involved with the CVI diagnostic process, as well as those that support children with CVI, therefore, have the responsibility of establishing the best way to provide this information to parents to ensure that parents do not leave appointments with a feeling of hopelessness and helplessness, but instead, feel empowered with a belief that they have a role to play in helping to improve their child's quality of life. Further research needs to be conducted in order to determine a best practice approach for diagnostic professionals in relation to providing essential information that is accessible for all parents of children with CVI in a manner that is empowering and helps support them to become effective parental advocates.

Declaration of interest

The author reports no conflicts of interest.

Chapter conclusion

This chapter is a published article in *Disability and Society* and reports on research undertaken to answer the fifth research question: What role does the attainment of knowledge in relation to CVI play in helping to empower parents to be more involved in the services their child receives? The paper also relates to the overall thesis aim of developing an effective framework for supporting children with CVI. From this research, it was clear that the attainment of CVI specific knowledge at the time of their child's diagnosis did help parents to understand their child's needs better, which in turn, helped them to understand the role and importance of the different services involved in their child’s care. It, therefore, can, be surmised that the attainment of knowledge plays an important role in helping to empower parents to be more involved in the services their child receives, however, further research is needed to corroborate these findings.

In relation to the overall research framework, this paper followed a pragmatist epistemology, in that a problem was identified by the researcher’s own unique experience (that people were not often provided with important information about their visual difficulties at time of diagnosis), and research was undertaken to explore the implications of this problem. In addition, a theoretical philosophy of dialectical pluralism allowed the researcher to listen to the important voices of the parents who shared their experiences, and to speak to the professionals who could use this information to improve their practice. Both a pragmatist epistemology and a theoretical approach of dialectical pluralism also allowed the researcher to draw on both quantitative and qualitative analysis of the survey data to help show a fuller and broader picture of the parents’ experiences and perspectives. It is hoped that this research will be used to help guide practice for the professionals involved in diagnosing and supporting children with CVI.

Chapter Eight – Conclusion

Introduction

The aim of this thesis was to present an effective framework for supporting children with CVI that could be adopted within an education and habilitation/rehabilitation context. The concept of a framework was initially developed by the researcher for herself following the diagnosis of CVI 17 years after acquiring the condition as a teenager. After receiving the diagnosis, the researcher set out to improve her functioning and overall quality of life by developing a deep understanding of this complex condition and how it impacted her on a daily basis. From this experience, it was clear that there were three important components that contributed to the researcher's improved functioning. These included: the development of an individual CVI profile that identified her visual difficulties and resulting emotional and behavioural needs, the development of an individualised programme that included strategies to support the needs identified in the CVI profile, and the empowerment of the researcher through the attainment of CVI knowledge and consequential understanding of her own specific visual difficulties.

With this understanding of how important each of the three components had been in aiding the improvements in her visual and overall functioning, the researcher set out to assess whether this approach could be developed into a practice framework for supporting children who have CVI. As outlined in the introduction chapter, the term practice framework was used to describe a set of principles of practice that are flexible enough and can be tailored to meet the needs of each individual child with CVI.

In order to do this, an overall research framework was developed that included an epistemology of pragmatism, as this was in line with the researcher's perspective that knowledge is always based on experience, that one's perceptions of the world are influenced by our social experiences, and that each person's knowledge is unique, as it is created by his or her unique experiences (Kaushik & Walsh, 2019). Pragmatism also allowed for a range of different research methods to be used throughout the research process, as it is based on the proposition that research should use the philosophical and/or methodological approach that works best for the particular research problem that is being investigated (Kaushik & Walsh, 2019). The use of a range of different research methods was also supported by the overall theoretical perspective of dialectical pluralism, as it allowed the researcher to explore the many different perspectives of the stakeholders involved in supporting children with CVI. Dialectical pluralism can be described as a process of carefully, systematically, and thoughtfully listening, understanding, appreciating, and learning from multiple disciplines, values, methodologies, standpoints and perspectives to try and come together in order to help all stakeholders (Johnson, 2017).

Within a clear overall research framework, six research questions were developed that guided the researcher through in-depth studies relating to the three main components of the framework, as well as examining and reflecting on her own personal experiences in order to evaluate the effectiveness of the proposed framework. Within each of these studies, the researcher also acknowledged that a level of researcher reflexivity was required to ensure that her own insights could be used to form the basis of a more generalised understanding and interpretation in relation to supporting children with the same condition (Finlay, 2002). Alongside researcher reflexivity, the researcher also used a range of qualitative and quantitative research methods in a qualitatively driven mixed methods approach. This approach helped to provide different types of information in relation to supporting children with CVI, which broadened the findings and helped to gain insight into how the multiple layers of CVI impact on a child's life (Hesse-Biber et al., 2015)

To assess whether the different research projects have helped to answer the six research questions and achieve the overall thesis aim, this concluding chapter will address each of these questions in turn by summarising the main findings from the different research projects undertaken. It will also outline recommendations for the field which can be made as a result of this research, outline any limitations, and suggest what further research is needed.

Research question one

- ***What profiling and intervention strategies to improve visual and overall functioning can be extrapolated from the researcher's own experience?***

The in-depth examination of the researcher's personal CVI journey provided valuable insights into the importance of the CVI profile and individualised intervention programme components of the overall framework for supporting children with CVI. In their case study of the researcher, McDowell and Dutton (2019) outline the in-depth process undertaken in order to fully understand the visual difficulties experienced and how they affected the researcher on a daily basis. This process included a review of relevant medical information (including optometrist's and ophthalmologist's assessments, MRI imaging and neuropsychological testing), the use of the structured history taking inventory (Dutton, 2015a; Dutton et al., 2010; Houliston et al., 1999) to ascertain if any visual perceptual difficulties were present, and a thorough CVI specific functional vision assessment to better understand the nature of the visual difficulties identified through the medical review and history taking process (McDowell & Dutton, 2019). This is in line with the view of Sakki et al. (2018), who outline that a multidisciplinary approach of assessment of childhood CVI that includes a full vision assessment, structured history taking and full ophthalmologist examination may be valuable.

However, another important aspect in relation to the development of individual CVI profiles is the purpose of these profiles. Sakki et al. (2018) outline that assessments should always be conducted with the principle aim of improving the understanding of the child's visual needs and limitations and helping to establish appropriate strategies that could be implemented to improve the child's functioning. When the assessment is conducted with this in mind, the CVI profile that is then developed will naturally lead into the development of an individualised habilitation/rehabilitation programme. From the description of the assessment process undertaken to develop the researcher's individual CVI profile in the case study outlined by McDowell and Dutton (2019), it is clear that supporting the researcher to understand her visual difficulties and providing her with useful strategies to improve her functioning was forefront in the assessment process. The detailed tutorial provided to the researcher following her assessment not only helped her to understand the nature of her visual difficulties, but also propelled her into developing and implementing strategies that helped to alleviate some of the more challenging aspects of these difficulties. As such, the tutorial essentially became the first intervention strategy to help improve the researcher's visual and overall functioning, by helping the researcher to "connect her anomalies of visual function to the specific challenges she experienced" (McDowell & Dutton, 2019, p. 4). This, in turn, helped her to establish specific strategies to overcome these challenges. This is in line with the view of Dutton and Bauer (2019) that in order to best support a child with CVI, a well-informed, positive and supported model of care needs to be implemented.

Although McDowell and Dutton (2019) outline some specific strategies the researcher implemented that were related to specific visual difficulties, it is clear that there were a number of generic strategies that also helped the researcher to improve her visual and overall functioning. Developing these latter strategies, however, was only possible once the researcher had recognised that although the issues she had were related to her visual abilities, these issues also caused negative emotional and behavioural responses. This is outlined in more detail by McDowell (2019b) in her personal perspective of living with CVI, where she describes the extreme anxiety and fatigue she experiences when in challenging environments. This is in line with the work of Lam et al. (2010) and Erasmus (2015) who describe children with CVI as experiencing high levels of anxiety and visual fatigue which at times, can lead to challenging behaviours.

With the understanding that her anxiety further impacted on her visual and overall functioning, especially when in challenging environments, the researcher introduced daily mindfulness sessions into her routine. The rationale behind this was that mindfulness has been shown to be effective in treating a variety of mental health conditions in adults and children, including anxiety and stress (Bailey et al., 2018; Bauer et al., 2019; Bohlmeijer et al., 2010; Chiesa & Serretti, 2009; Spijkerman et al., 2016) and therefore, could help a person with CVI regulate their emotions when in challenging environments. This approach proved to be very effective and helped to greatly reduce the episodes of high anxiety and stress experienced by the researcher (McDowell & Dutton, 2019). Another strategy implemented by the researcher was de-cluttering her home and work environments. This was based on the research undertaken by McDowell and Budd (2018) and Little and Dutton (2014) that showed that de-cluttered environments greatly improved the functioning of children with CVI. The final generic strategy that proved effective, was the introduction of calm breaks, which the researcher describes as small breaks away from clutter and noise to help reduce the feeling of sensory overload (McDowell, 2019b).

Research question two

- ***What role does the attainment of knowledge play in empowering a person with CVI?***

To examine the role that attainment of knowledge played in empowering a person with CVI, both the personal case study (McDowell & Dutton, 2019) and the personal perspective of living with CVI (McDowell, 2019b) were used to reflect on the researcher's own personal experience. From these perspectives, it is clear that empowerment was an important component in helping the researcher to improve her overall quality of life. Empowerment can be described as a process of gaining personal power and control (Mulligan et al., 2012) and when it relates to a health issue, may be marked by the attainment of knowledge and skills, awareness of choices, and involvement in decision making (Shulman, 1992). In both the case study (McDowell & Dutton, 2019) and personal perspective of living with CVI (McDowell, 2019b), the researcher describes a process of gaining control over her life through the attainment of CVI specific knowledge, which helped her to develop a deep understanding of her own condition. Also important in the process of being empowered was being listened to by a medical professional and being seen as an expert of her own difficulties (McDowell, 2019b). This is in line with the work of Hodge and Runswick-Cole (2008) in regard to children with disabilities. They outline that in order to develop positive relationships between professionals and parents that ultimately empower parents, medical professionals need to be guided by the parents as the 'expert' of their own child (Hodge & Runswick-Cole, 2008). For the researcher, being empowered through the attainment of CVI specific knowledge gave her the confidence to trial the strategies that had been suggested to her, and to develop her own strategies that helped to improve her overall quality of life (McDowell, 2019b; McDowell & Dutton, 2019).

Research question three

- ***What role does the Austin Playing Card Assessment play in identifying visual, emotional and behavioural responses associated with CVI?***

The first component of the framework for supporting children with CVI is developing an individual CVI profile of their visual difficulties and resulting emotional and behavioural needs. Currently, CVI is investigated as a medical problem with the reliance on clinical examinations to detect the child's visual issues (Hyvärinen, 2009). However, often this can result in visual perceptual difficulties going undetected, as these issues can appear differently in the real world as compared with experimental tasks in clinical settings (Hyvärinen et al., 2012; Williams et al., 2011). This highlights an issue for the field that needs to be addressed: the development of an effective assessment tool to detect and characterise visual perceptual difficulties that can be conducted in real-world situations.

With this in mind, the Austin Playing Card Assessment was developed as a simple, easy to conduct, quick assessment that could be used as part of a wider assessment process to aid in the development of individual CVI profiles. Following research to assess the effectiveness of the Austin Playing Card Assessment it was clear that the assessment tool was able to distinguish between children with perceptual difficulties and children without. It also provided useful information on the nature and degree of the visual perceptual difficulties each child had. These findings have demonstrated that the Austin Playing Card Assessment has the potential to be an effective tool in helping to detect visual, emotional and behavioural difficulties commonly associated with CVI, and therefore could be used as part of a wider battery of assessment tools to help develop individual CVI profiles. However, further research on a larger population of children needs to be conducted to corroborate these findings.

Research question four

- ***What are effective strategies for alleviating the impact of the visual difficulties and the resulting emotional and behavioural responses that are associated with CVI?***

The second component of the framework comprises the compilation of individualised CVI programmes to support the needs that have been identified in the CVI profile. An important element of these programmes is the implementation of specific strategies for alleviating the impact of the child's visual difficulties and resulting emotional and behavioural responses. To help assess the effectiveness of the range of strategies that had been developed by the researcher (McDowell, 2019b; McDowell & Dutton, 2019), as well as strategies suggested in relevant literature (Buultjens et al., 2010), in-depth case studies were conducted on three children with a range of cognitive abilities, each with CVI. Participants in the case studies included the children's families, and education and therapy providers. The strategies trialled were tailored to each child's needs and implemented within their home, school and community environments.

From the detailed qualitative analysis of the research data, it was clear that there were a number of specific strategies that were effective in supporting each child, but more importantly, a number of generic strategies that could be adapted to suit the individual needs of each child. The specific strategies were mainly around supporting the basic visual functions of visual acuity and contrast sensitivity and included strategies such as enlarging text and classroom material, using devices such as an iPad for magnification and to support other classroom work, and ensuring optimal luminance levels. These are in line with the approaches outlined by Buultjens et al. (2010) for the management of visual problems due to CVI in a classroom. The generic strategies helped to support the visual, emotional and behavioural needs of the children. These included education sessions for all participants (including the child when appropriate) about the specifics of each child's visual difficulties, the introduction of a quiet uncluttered space for focused work, the use of calm breaks, and mindfulness.

These simple, yet effective strategies all had a considerable impact on each child's visual and overall functioning. These strategies are also in line with research that shows that when the team supporting a child with CVI is well-informed, the strategies and support will become logical and intrinsic (Dutton & Bauer, 2019); that uncluttered, quiet spaces can improve the functioning and behaviour of children with CVI (Little & Dutton, 2014; McDowell & Budd, 2018); and that calm breaks can help reduce anxiety and fatigue in people with CVI (McDowell, 2019b). The success of the mindfulness interventions also provides more evidence to support the work of Perry-Parrish and Sibinga (2014) and Vigerland et al. (2016), who argue that mindfulness can be an effective tool to help with anxiety and stress in children. However, further research on a larger cohort of children with CVI needs to be conducted in order to corroborate these findings. Overall, these generic strategies have the potential to be effective in helping to alleviate the impact of the visual difficulties and resulting emotional and behavioural responses in children with CVI.

Research question five

- ***What role does the attainment of knowledge in relation to CVI play in helping to empower parents to be more involved in the services their child receives?***

The third component of the framework is empowering children with CVI and their parents/families by helping them to understand the child's visual difficulties better through the attainment of knowledge that is specific to their child's condition. This is an important component, because as outlined by McDowell and Dutton (2019) and McDowell (2019b), being empowered through the attainment of CVI specific information played a significant role in helping the researcher take control of her own life and make the changes needed to improve her overall functioning. To assess whether parents of children with CVI had also found that the attainment of CVI knowledge at the time of their child's diagnosis had empowered them in relation to supporting their child as they developed, parents from around the world were invited to complete a multi-sectioned online survey. Following the analysis of the survey data it was clear that being provided with relevant information about their child's condition at the time of diagnosis did empower parents in relation to supporting their child as they developed. This supports the researcher’s own experience as outlined and provides more evidence to support the view that the attainment of CVI specific knowledge can help empower a person with CVI and/or their parents and loved ones. Over time, this empowerment may lead to greater success of any education or habilitation/rehabilitation programme implemented, as parents may feel more confident to implement the strategies suggested by the professionals supporting their child. This is in line with the view of Rafferty and Sullivan (2017), who highlight that empowerment gained through a clear understanding of their child’s issues, enables parents to be more involved in the services their child receives.

From the research a number of themes also emerged that if considered by the professionals working in the field, may help to enhance parent empowerment and cultivate collaborative relationships between the professionals and the family. These included providing information to parents in an accessible format, information as a tool for advocacy, information as a tool for further learning, information as a tool for empowerment, and information as a tool to help cultivate collaborative relationships with professionals.

Research question six

- ***What is an effective framework for supporting children with CVI?***

In order to assess the effectiveness of the CVI practice framework proposed by the researcher, the case study research (outlined in Chapter 6) used the framework as part of the overall research process. For each case study, this included the first component of the framework: the development of individual CVI profiles following the same process outlined in the case study by McDowell and Dutton (2019). These individual profiles were then used for the second component of the framework: to create individual education/rehabilitation plans that were implemented in the child's home, school and community environments. Finally, the third component of the framework, empowerment of the child with CVI and their family, occurred simultaneously to the first and second components. As each component was vital to the overall success of the framework approach, each component was given equal weighting within the case studies with a strong emphasis on ensuring that each component was effectively implemented and supported by the researcher.

Following the case studies, it was clear that although each component of the framework approach played an important role in supporting the child with CVI, it was the combination of the three components together that made the framework so effective. Each component fed into each other and helped to create an environment where the child and those supporting the child felt supported, educated and empowered. This is again in line with the view of Dutton and Bauer (2019), who recommend a well-informed, loving, positive, supportive model of care matched to the child's needs as the best approach for supporting a child with CVI. Moreover, the child and family centred approach of the CVI practice framework meant that the professionals were able to walk alongside the child and their family on their CVI journey and allowed them to work together to help the child develop to their full potential.

The success of the case studies in improving the visual and overall functioning of the three children involved in the research, as well as the findings from the other research projects undertaken in this doctoral thesis by publication, provide evidence of the effectiveness of the proposed CVI practice framework (see Figure 10). As such, this novel approach to supporting the needs of children with CVI has the potential to make a significant difference to the many children around the world with this condition.

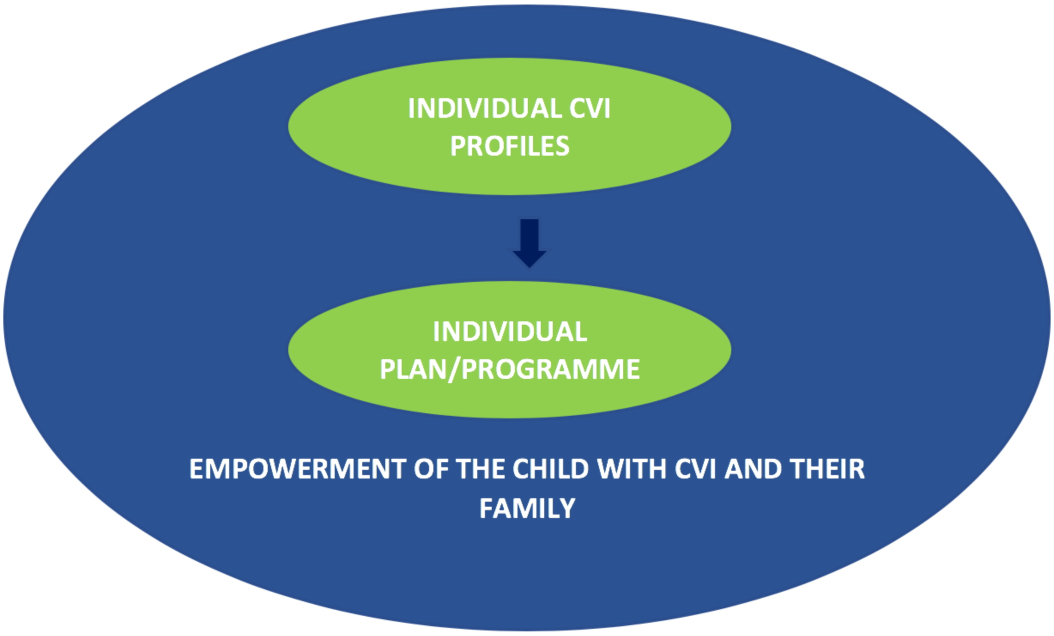

Figure 10. CVI practice framework

Recommendations

There are a number of recommendations that have come out of each individual research project undertaken in this doctoral thesis by publication, and in terms of the overall CVI practice framework. The first component of the CVI practice framework, individual CVI profiles, requires detailed assessment of each individual child with CVI to identify their specific visual, emotional and behavioural needs. In order to assess all areas of a child's visual functioning, a full battery of visual assessment is required. The Austin Playing Card Assessment provides a simple, yet effective tool to detect visual perceptual difficulties and to characterise the nature of these difficulties. As such, the Austin Playing Card Assessment can be used by professionals working in the field of supporting children with CVI, and also by parents, as part of a wider assessment to aid in the development of the child's CVI profile. Moreover, information gathered during the Austin Playing Card Assessment can also be used to inform intervention strategies for each child.

The second component of the CVI practice framework is individualised education/rehabilitation plans, which are based on the needs identified in the individual CVI profile. Although each child may require support around aspects of their visual functioning, especially as it relates to their basic visual skills (i.e. enlarged text, magnification, appropriate lighting), there are also a number of generic strategies that can be implemented to support the child's visual, emotional and behavioural needs. These include CVI education sessions around the child's specific visual needs, the use of quiet un-cluttered spaces and calm breaks, and the introduction of mindfulness into the child's daily routine. As outlined in the case studies (Chapter 6), these strategies can be adapted to meet the specific needs of each child and implemented in the child's home and school environments.

Vital to the overall effectiveness of the CVI practice framework, the third component of empowerment of the child with CVI and their family needs to be implemented simultaneously to component one and two. This can be achieved by helping the child and their family to understand CVI and the specific visual difficulties the child has at the time of diagnosis and during the development of the individual CVI profile. To aid in this, the child and their family can be provided with material in a format that suits their needs and is easily accessible to them. Support for parents could include links to websites, videos describing different aspects of CVI, being connected with other families whose child has CVI, and time with the professionals working with their child to allow them to ask questions. This will help to ensure that parents are able to become advocates for their child and continue to develop their understanding of CVI as their child develops.

As they move onto the next component of the CVI practice framework, the implementation of individual education/rehabilitation programmes, the child and their family can continue to be empowered through regular contact with the professionals supporting the child. During these sessions, the child and their family must be given every opportunity to ask questions and be provided with any relevant information that may help them understand the child better and the reasons behind the strategies that have been implemented for them. It is important that at all times, the child and their parents are seen as the experts and included in any decisions that may impact on the child.

When these components are implemented effectively and understood as a comprehensive approach to supporting a child with CVI, the CVI practice framework has the potential to improve the visual and overall functioning of the many children with this condition. The simplicity of the CVI practice framework also means that it could be easily adopted and implemented within an education or habilitation/rehabilitation context around the world, while still being aligned to different countries' health and education systems.

Recommendations for professionals

The research undertaken for this doctoral thesis by publication has given rise to a number of recommendations that, if implemented by the professionals working in the field of supporting children with CVI, have the potential to greatly improve the visual and overall functioning of children with this condition. Firstly, during the diagnostic period, there needs to be an emphasis on ensuring that parents/caregivers are provided with information about their child's condition in a format that is accessible to them. A best practice approach recommended by Mulligan et al. (2012) and supported by the parent survey research (outlined in Chapter 7), is for professionals to discuss the diagnosis with the family at the time of diagnosis and then to provide written material or recommendations for resources such as websites as follow up information. However, the most useful method for receiving information about their child's condition may differ for each family, and therefore requires professionals to take the time to establish what the family needs in order to understand the complex nature of CVI. Professionals also need to recognise and respect the parents as the expert of their child and take the time to listen to what they have to say about their child.

As a family starts on their CVI journey, professionals need to provide regular support to ensure that the family is developing a clear understanding of their child's condition and how it impacts them on a daily basis. An important part of this is professionals working closely with the family to develop an individualised CVI profile that includes information about the child's visual, emotional and behavioural needs. Professionals then need to work with the family to develop an individualised education/rehabilitation programme that is based on the information gathered in the CVI profile that can be implemented in the child's home, school and community environments. As this programme is implemented, professionals also need to ensure that at all times, everyone, including the child themselves (when appropriate), needs to be on the same page in terms of what the child's needs are and what strategies are being implemented to improve the child's visual and overall functioning.

This child and family-centred approach ensures that professionals and families are walking alongside each other throughout the child's CVI journey. It will also ensure that the family are well-informed about their child's condition and confident in how to support their child as they develop. This, in turn, will lead to the parents/caregivers being empowered and feeling like they can take control and be central to their child's education/rehabilitation programme.

Recommendations for policy makers

The most important recommendation for policy makers to arise from this doctoral research is to ensure that information being provided to parents and professionals around CVI is consistent and scientifically accurate. This includes ensuring that CVI education and training is mandatory for any professional completing a programme (in either medicine, rehabilitation or education) within the field of supporting children who are blind or who have low vision. It is also important for policy makers to set best practice standards for providing parents with relevant information about their child's condition at time of a CVI diagnosis.

As outlined by Sakki et al. (2018), there also needs to be a consensus on firstly, the definition of childhood CVI, secondly the diagnostic and assessment process for CVI, and lastly, the best approach for supporting children with CVI. The CVI practice framework outlined in this thesis by publication provides an approach that can help the field work towards meeting a consensus on these areas.

Recommendations for parents

Historically, parents of children with disabilities have been key influencers in bringing about changes that improve the education and habilitation/rehabilitation outcomes for their children. This is already starting to happen in the field of CVI, with the creation of key organisations such as CVI Scotland and the CVI Community in Australia. Helen St Clair Tracy has made a significant difference to the worldwide understanding of CVI with the creation of a world leading resource, the CVI Scotland website. As a mother of a child with CVI, Helen set out to improve outcomes for her son and then many other children in Scotland and around the world who were being misunderstood and misdiagnosed due to lack of understanding of this complex condition. This website is now the leading internationally available resource on CVI and is used extensively around the world by parents, professionals and universities training education and rehabilitation specialists for children who are blind or low vision. As of March 2020, the website has a total of 46,000 users in 156 different countries. Through the CVI Scotland charity organisation and website, Helen has shown the world what can be achieved through effective parental advocacy. With this in mind, a key recommendation for parents from this research is to continue being advocates for their children. Parents know their children best and they have a unique opportunity to help educate the professionals working with their children on how to best support children with CVI. It is important for parents and professionals to work together to develop collaborative relationship so that they can walk alongside each other on the child's CVI journey. To aid parents with this, advocacy organisations such as CVI Scotland, CVI Society (UK), CVI Community Australia, and Parents of the Visually Impaired (NZ) can be a great source of support and advice. Finally, for parents of children with CVI around the world, know that given the right environment and support, 'your child can learn to fly'.

Limitations

The main limitation of this research is the small number of children the CVI practice framework was trialled upon. However, conducting research on one child from each of the three main education categories outlined by Lueck and Dutton (2015) allowed for the assessment of the framework in different education settings. As such, the research provided a glimpse of how the CVI practice framework could be implemented for children with CVI and a range of cognitive abilities. Furthermore, although CVI is the most common cause of visual impairment affecting children in the economically developed world (Philip & Dutton, 2014), with an estimated prevalence of 3.7% of the population (Williams et al., 2019), it is still a relatively low incidence disability. As such, it can be difficult to conduct research with large numbers of participants, as was shown in all three of the research projects undertaken as part of this doctoral thesis by publication. However, by conducting research on each individual component of the framework it was possible to examine how effective each component could be in the wider framework approach, providing further support for the effectiveness of the CVI practice framework.

The researcher is also aware of the values and beliefs that have guided her while conducting this research. As many aspects of the research were based on the researcher's own personal experience, this may have influenced her interpretation of the findings. However, steps were taken to reduce the impact of researcher bias throughout the research period, including regular consultation with parents of children with CVI, professionals working in the field of supporting children with CVI and international CVI experts.

Further research

There are a number of different areas for further research that have come out of this doctoral thesis by publication. Firstly, each component of the framework needs more research to further strengthen its role in the overall CVI practice framework. For the Austin Playing Card Assessment, further testing needs to be conducted on a larger population of children, both with and without visual perceptual difficulties, to corroborate the findings of the pilot study. This research will be made considerably easier following the development of an App of the Austin Assessment, which will be completed by the end of 2020.

The strategies implemented to support the visual, emotional and behavioural needs of children with CVI will also need to be assessed in a larger population of children with a range of cognitive abilities. This could be done as part of further research using the CVI practice framework. This way, the strategies implemented will be based on the specific needs of each individual child and the research will be helping the children involved.

Further research on the importance of empowering children with CVI and their families could be conducted as part of wider research examining the effectiveness of the CVI practice framework. This way, the empowerment can be seen in the context of the role it plays in enabling the child and their parents to be more involved in the child's individual education/rehabilitation plan. In addition, further research needs to be conducted on the best practice approach for diagnostic professionals in terms of how they provide information to parents on CVI and the specific issues a child has.

Finally, further research on the CVI practice framework needs to be conducted in order to corroborate the findings from the researcher's own personal experience and the case study research that implemented the CVI practice framework as part of the overall research process.

Afterword

When I started on this PhD journey, along with the obvious goal of improving the lives of children with CVI around the world, I also had another goal in mind. I wanted to be seen as an expert in CVI, not just because I had it, but also because I conducted research in the area of understanding and supporting children with this complex condition, and was, therefore contributing to the international scientific literature in the field. This was important to me, as I had experienced on a number of occasions a lack of acknowledgment of my expertise around this condition from different experts. Although difficult to deal with at the time, these experiences had also helped me to see that in order to improve the lives of the many children with CVI, I needed to listen to and speak to the multiple voices that are involved with understanding and supporting children with this condition. This started with the medical profession and relates to the personal case study in Chapter 3. I knew, from experience, that the medical profession in general was not going to listen to my perspectives on CVI unless I could show that I understood the condition from a medical perspective and also that I was able to conduct scientific research into aspects of this condition; specifically in improving visual function in a quantifiable way. By including proof of my improved visual fields as shown in the field vision assessments, in a sense I was able to capture the attention of the medical professionals in this case study and provide evidence to support the hypothesis that improvements in visual functioning could be made.

However, I also recognised that for education and rehabilitation specialists, as well as people with CVI themselves, it was important to show how these improvements could be achieved. This was where I was able to draw on my rehabilitation and education background to outline straightforward, easy to understand, replicable strategies to help improve visual functioning in both the personal case study and personal perspective on CVI. In this way, I was able to speak directly to the rehabilitation and education professionals and provide first-hand accounts of what it is like to live with CVI and how it can impact on all aspects of your life. Within this, I was also speaking from the important voice of lived experience and showing how vital it is to hear and understand this voice. This also supports and upholds the disability rights philosophy of 'nothing about us, without us', thereby ensuring that research into CVI was being conducted by someone with CVI and that this perspective would be recognised and respected.

It was all well and good sharing my own experience of my improved visual and overall functioning and improved quality of life through my home-grown rehabilitation plan, but I also had to show whether this could be replicated for children with CVI. This is where I had the opportunity to step up as a researcher in my own right. I loved the challenge of exploring the different research methods that I could use in the different research projects to help show the effectiveness of each component of the CVI practice framework. At times it was challenging and I felt completely out of my depth, but at other times it was thrilling and I thoroughly enjoyed the roller-coaster experience of conducting both qualitative and quantitative research. The articles outlining these research projects will hopefully be used by medical, education and rehabilitation practitioners alike to help guide practice moving forward and create better outcomes for children with CVI. The whole experience can be described as walking a tightrope between the many different voices, but hopefully this thesis by publication shows that it is possible to listen to and speak to all these voices.

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Appendices

Appendix A. PhD Timetable

Date	General	Personal Case Study	Personal Perspective on CVI	Austin Assessment	Case Studies	Parent Empowerment
April 2017	• Provisional part time registration					
May 2017	• Establishing research problem • Deciding on research questions					
June 2017	• Deciding on research methodology					
July 2017	• Working through thesis by publication framework					
August 2017	• Working on confirmation report					
September 2017	• Working on confirmation report					
October 2017	• Working on confirmation report		• Writing chapter for Routledge Handbook of Vision Impairment			
November 2017	• Working on confirmation report		• Writing chapter for Routledge Handbook of Vision Impairment			
December 2017	• Working on confirmation report					
January 2018	• Completing confirmation report					• Low risk ethics application for survey

Date	General	Personal Case Study	Personal Perspective on CVI	Austin Assessment	Case Studies	Parent Empowerment
February 2018	• Preparing for confirmation event end of February			• Ethics application for Austin Assessment for ethics committee		
March 2018			• Work through edits from editor of book			• Prepare material for online survey (survey, information for social media ads) • Launch survey online
April 2018			• Complete final version of chapter	• Prepare all forms and documents • Complete and submit ethics application		
May 2018		• Write first draft and send to second author				• Tidy up data from survey
June 2018				• Review feedback from ethics committee • Approach schools to advertise AA • Receive/review referrals from parents • Support Parents to complete history taking inventory • Conduct Austin Assessment on research participants		

Date	General	Personal Case Study	Personal Perspective on CVI	Austin Assessment	Case Studies	Parent Empowerment
July 2018		• Review feedback and edits from second author		• Conduct Austin Assessment on research participants • Analyse video recordings of all assessment sessions		
August 2018				• Advertise for control group • Complete inventories for control group • Conduct assessments on control group • Prepare initial research findings of Austin Assessment		
September 2018		• Complete case study and submit to journal		• Prepare teaching resource for Austin Assessment • Literature review and methodology for article	• Preparing material for research • Full ethics application	
October 2018				• Teach RTVs to review videos for interrater reliability • Videos reviewed by two RTVs	• Review feedback from ethics committee • BLENNZ ethics application	
November 2018				• Prepare article on Austin Assessment research and send to sups for feedback	• Consents for category two and three case study participants	

Date	General	Personal Case Study	Personal Perspective on CVI	Austin Assessment	Case Studies	Parent Empowerment
December 2018					• Conduct FVA's on category two and three child • Analyse FVA's	• Start analysing survey results
January 2019				• Continue working on article ready to submit • Submit article to journal	• Write FVA reports • Interview parents for category two and three children	
February 2019		• Re-submit article after making changes suggested by reviewer			• Interviews of other participants for category two and three child • Transcribe all interviews	
March 2019		• Paper published	• Book that chapter is in published		• Work with BLENNZ to find category one child • Consents for category one case study participants • Develop programme for category two and three children and implement	
April 2019						• Continue analysis of survey • Prepare journal article on parent empowerment and send to sups for feedback

Date	General	Personal Case Study	Personal Perspective on CVI	Austin Assessment	Case Studies	Parent Empowerment
May 2019					• FVA on category one child • Interviews on category one participants	• Continue working on article
June 2019				• Article rejected by journal	• Transcribe interviews • Develop programme for category one child and implement • Monitor all three programmes	• Submit article
July 2019				• Edit article and resubmit to second journal	• Continue to monitor all three case studies, visiting schools every couple of weeks and visits to home	
August 2019	• Start working on literature review				• Continue to monitor all three case studies, visiting schools every couple of weeks and visits to home • Conduct observations on children in each case study	
September 2019	• Finish first draft of literature review and send to supervisors • Start working on introduction chapter			• Make changes suggested by reviewer and resubmit	• Continue to monitor all three case studies, visiting schools every couple of weeks and visits to home • Conduct observations on children in each case study	

Date	General	Personal Case Study	Personal Perspective on CVI	Austin Assessment	Case Studies	Parent Empowerment
October 2019	• Complete literature review and send to be considered for special edition in IJIE			• Make final changes to article and resubmit		• Revision to article and resubmit
November 2019					• Interviews/focus groups for category two and three participants • Continue monitoring category one child • Transcribing interviews/focus groups	
December 2019	• Appendices in final document				• Interviews/focus group category one participants • Write literature review case studies • Write methods section case study article	
January 2020				• Article published	• Analyse all data • Write results and discussion section case study article • Send article to supervisors for feedback	

Date	General	Personal Case Study	Personal Perspective on CVI	Austin Assessment	Case Studies	Parent Empowerment
February 2020	• Complete introduction chapter and send to supervisors for feedback				• Submit article to journal	• Edit article and submit final version to journal
March 2020	• Edit introduction chapter • Write conclusion chapter send to supervisors • Edit conclusion chapter • Edits to literature review article for publication (in press)					
April 2020	• Edit final document • Write abstract • Write acknowledgments • Final document to supervisors to check • Final documents to proof reader • Submit thesis					• Article published

Appendix B. Austin Assessment Research

(1). Flowchart

Research is advertised through local schools and relevant social media outlets

Parents/caregivers contact researcher by phone or email if they feel the information provided in the advertisement relates to their child and they would like their child to participate in the research.

To establish whether their child is eligible, the researcher will ask the parents/caregivers five screening questions taken from Dutton's (2015) history taking inventory, and ask them to respond based on the range of: never, rarely, sometimes, often, always. If parents respond with often or always to three of the five questions, their child is eligible.

Potential participants are provided with parent/caregiver and child information sheets. If they wish to participate in the research they are also provided with informed consent forms for both children and parents/caregivers to sign.

The child's school is approached by researcher and provided with an information sheet. Researcher will discuss with school principal and/or BOT and the classroom teacher about conducting research. Permission to conduct research in their school will be asked for.

Once informed consent from child and parents/caregivers, and permission from school, the researcher will conduct full history taking inventory with parents/caregivers and child either at their home or at the child's school.

Austin Assessment is conducted on the child on three separate occasions, at the same time of day. Twice in a quiet location in the school and once in the child's classroom.

Answers from the history taking inventory and observations from the Austin Assessment will be analysed and results determined. A summary of the results will be provided to the parents/caregivers and the school.

(2). Flyer Advertising Austin Assessment Research

MASSEY UNIVERSITY
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UNIVERSITY OF NEW ZEALAND

INVITATION TO PARENTS OF CHILDREN (AGED BETWEEN 6-11) TO PARTICIPATE IN NEW ZEALAND RESEARCH ON THE "EFFECTIVENESS OF THE AUSTIN ASSESSMENT IN DETECTING VISUAL PERCEPTUAL DIFFICULTIES".

Do you have concerns about your child's vision? If so, please consider the following statements:

1. **My child has no difficulty walking down stairs.**
2. **My child looks down when crossing floor boundaries e.g. When lino meets carpet.**
3. **My child has difficulty seeing something which is pointed out in the distance.**
4. **My child does not have any difficulty finding a close friend or relative who is standing in a group.**
5. **My child finds copying words or drawings time consuming and difficult.**

Are any of these statements relevant to your child? If so, your child may have an issue with the way they process visual information. Difficulties that children with visual perceptual difficulties have at school, include:

- difficulties with specific subject areas, such as maths and reading,
- difficulties copying from the board and concentrating,
- display challenging behaviours,
- are easily distracted and
- are unwilling to participate in fast moving team sports and activities.

Also, visual perceptual difficulties are more common in children who:

- were born extremely premature (before 32 weeks' gestation),
- are diagnosed with dyslexia and/or dyspraxia,
- have been diagnosed with ADHD,

If you feel any of the above information relates to your child and you are interested in your child participating in this research, please contact the researcher, Nicola McDowell on either [redacted] or [redacted] for further discussion to see whether your child is eligible.

(3). Child Information Sheet

EVALUATION OF THE AUSTIN VISION ASSESSMENT

INFORMATION SHEET FOR CHILDREN

Hello XXXX,

My name is Nicola McDowell. I am studying at Massey University.

As part of my study I want to find out if an assessment tool I have been developing, is able to highlight some difficulties that children have in processing visual information. I have talked with your parents about my study and they have given me permission to ask you if you would like to take part.

What will we be doing?

If you want to take part in my study, I will visit you and your parents in your home to ask some questions about how well you see some things. For example, do you have trouble finding your favourite toy in a toybox?

Once we have completed the questions together, I will come to your school where we will complete a simple activity of matching playing cards called the **Austin Assessment**. You will do this activity of matching playing cards three times - once in your classroom and twice in a quiet room in your school. I will be making a video recording of all three sessions.

I will also talk to your teacher and school to explain what we are doing.

What will happen to the video and my answers to your questions?

The videos will be seen by me and someone who I have worked with and we will be making notes about what you did during the assessment.

The answers you gave me to the questions I asked you at home and the recordings of the three sessions of the card matching activities will be kept on a computer that only I will be able to access.

I will keep this information for up to five years to write about it in books and journals.

Your parents will be given a summary of all the things that we find out during the activity.

Your Rights to be involved in my study

You do not have to take part in this study if you do not want to. You can stop being in my study even if you change your mind within three weeks after taking part in answering questions at home.

If you find the card matching activities hard or tiring, we can stop at any time.

If you take part in my study you can pick a name (other than your own) that you would like to be referred to as and I will use this name when writing about this research.

After reading this information if you want to take part in my study, then I will give you a form to sign your name to say that you have agreed to take part.

If you have questions at any time when you are in my study, you can contact me on my mobile phone or by e-mailing me. My contact information is:

Nicola McDowell
[redacted]

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 18/20. If you have any concerns about the conduct of this research, please contact Dr Rochelle Stewart-Withers, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x [redacted]*, email humanethicsouthb@massey.ac.nz*

(4). Parent Information Sheet

EVALUATION OF THE AUSTIN VISION ASSESSMENT

INFORMATION SHEET FOR PARENTS/CAREGIVERS

Dear parent/caregiver,

Hi, my name is Nicola McDowell and I am a PhD student at Massey University. Prior to starting my PhD, I was a Resource Teacher of Vision. I intend to evaluate an assessment tool that I have been developing to highlight issues with the way children process visual information. The tool is called the Austin Assessment and it involves a simple activity of matching playing cards. Thank you for contacting me after seeing the advertisement for this research.

Who can participate in the study?
Recruitment for this research is based on parent/caregivers contacting me after seeing the research advertisement. In the initial contact, you will be asked five screening questions about your child's vision. Your responses to these questions will help establish whether your child is eligible to participate in this research.

I am aiming to assess between 6 – 10 children aged between 6 and 11, as this will ensure I obtain enough preliminary information about the effectiveness of the assessment tool. The first ten eligible referrals that I receive that provide parental and child consent will be included.

What is this study about?
Some children have issues with the way they process visual information, which is known as a visual perceptual difficulty. However, it can be very difficult to identify visual perceptual problems in children, as it's not always obvious that their difficulties are related to their vision and often, children can present with a range of learning and behaviour difficulties (as listed above).

My study therefore, aims at trialling and evaluating a simple assessment tool (the Austin Assessment) that I have developed to highlight the visual, emotional and behavioural responses that are associated with a visual perceptual difficulty.

The research project is made up of two phases, the first phase involves interviewing you about your observations of your child's visual behaviours, using a history taking inventory. This interview will be conducted at a location that suits you (either your home or your child's school), at a time that suits you. The interview will take approximately 30-40 minutes.

Following the interview, the study moves to the second phase in which I will undertake the Austin Assessment with your child in their education setting. While your child is completing the Austin Assessment by matching playing cards laid out in front of them, I will be observing their visual, emotional and behavioural responses. I will conduct the assessment three times, twice in a quiet environment and once in their usual classroom environment at the same time as the others in the class are engaged in their regular classroom activities. Each assessment will take around 20 minutes and it will be video recorded so that myself and another vision teacher are able to watch the assessment again later and analyse the session. The filming will be done by setting up the camera on a tripod and it will only focus on the researcher and your child and will not be filming other children. The person who will also assess the video recordings will sign a confidentiality agreement, which means they are not able to talk about this research to anyone else.

Prior permission will be obtained from the principal and Board of Trustees and the classroom teacher to undertake the Austin Assessment in the classroom. The school will also be provided with a summary of the research findings.

If the history taking inventory and the Austin Assessment identifies your child as having visual processing difficulties, I will be able to explain to you what this means and also provide intervention support for your child and the teacher.

As part of my PhD research, I am also conducting further research into supporting children with visual perceptual difficulties in 2019. As a result of the findings from the Austin Assessment, your child may also be eligible for this research. Further information will be provided about this in due course, but please let me know if you do not want your child involved.

Data Management

Data that will be gathered during this research project will include responses to the history taking inventory, observation sheets from the Austin Assessment and also video recordings of the Austin Assessments. All data will be stored securely on my computer, which is password protected and in a locked filing cabinet in my office at home. All data relevant to the research will be destroyed after five years. The school will be provided with a summary of the research findings at the completion of the research project.

Participant Rights

Participants are under no obligation to accept this invitation. If you and your child decides to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study within three weeks of the final assessment;
- ask any questions about the study at any time during participation;
- provide information on the understanding that their name or the name of the school will not be used unless permission has been given to the researcher to do so;
- be given access to a summary of the project findings when it is concluded.

Please do not hesitate to contact either my PhD supervisors or me at any time if you have any questions about the project. Contact details are as follows:

Student	**PhD supervisor**
Nicola McDowell Phone [redacted] Email: [redacted]	Associate Professor Alison Kearney Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]
PhD supervisor	
Dr Julia Budd Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]	

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 18/20. If you have any concerns about the conduct of this research, please contact Dr Rochelle Stewart-Withers, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x [redacted], email humanethicsouthb@massey.ac.nz

(5). School Information Sheet

EVALUATION OF THE AUSTIN VISION ASSESSMENT

INFORMATION SHEET FOR SCHOOLS

Dear School Principal/Board of Trustee chairman,

My name is Nicola McDowell and I am a PhD student at Massey University. Prior to starting my PhD, I was a Resource Teacher of Vision and registered teacher. I want to find out if an assessment tool that I have been developing, is able to highlight issues with the way children process visual information. The tool is called the Austin Assessment and it involves a simple activity of matching playing cards.

The information flyer about the study was sent to parents through a number of local schools' newsletters and on relevant social media outlets. As a result a child that attends your school was nominated for this research by their parents. I am therefore, requesting permission from you to allow me to conduct part of the research within your school environment. The flyer has been attached for your information.

Purpose of the project
Some children have issues with the way they process visual information, which is known as a visual perceptual difficulty. However, it can be very difficult to identify visual perceptual problems in children, as it's not always obvious that their difficulties are related to their vision. Instead, children can present with a range of learning and behaviour difficulties, including:

- Difficulties with subjects such as maths and reading,
- Difficulty copying off the board,
- Difficulty concentrating for periods of time and/or are easily distracted,
- An unwillingness to participate in fast moving sporting activities.

Children who are more likely to have visual perceptual difficulties include:

- Children that have been diagnosed with ADHD,
- Children that have been diagnosed with dyslexia,
- Children that have been diagnosed with dyspraxia,
- Children born extremely premature (before 32 weeks).

My study therefore, aims at trialling and evaluating a simple assessment tool (the Austin Assessment) that I have developed to highlight the visual, emotional and behavioural responses that are associated with a visual perceptual difficulty.

Project Description
The research project is made up of two stages.

Stage One involves interviewing parents about their observations of their child's visual behaviours, using a history taking inventory. This interview will be conducted at a location that the parents choose, at a time that suits them. The interview will take approximately 30-40 minutes.

In Stage Two, I will be undertaking the **Austin Assessment** with the child in your school. The assessment involves matching playing cards. I will conduct the assessment three times, once in their classroom at the same time as the peers are doing regular class work, and twice in a quiet environment within the school.

Each assessment will take around 20 minutes. I will be observing and recording their visual, emotional and behavioural responses during the activities and it will also be video recorded. The video recordings are to enable me and another vision educator to conduct further analysis of the assessment to ensure consistency in the analysis. The camera will be set up in a manner that no other child will be in the video.

If the results of Stages One and Two suggest that a child has some visual processing difficulties, I will provide information to parents and teachers to help support the child. I will also provide information to those who provide support for the child's learning (i.e. teacher aide, Resource Teacher Learning and Behaviour, Resource Teacher Vision, school SENCo).

Participant Identification and Recruitment
Recruitment for this research was based on parents/caregivers contacting the researcher after seeing the research advertisement. Parents/caregivers were then asked five screening questions about their child's vision and their responses helped to establish whether their child was eligible.

I am aiming to assess between 6 – 10 children aged between 6 and 11, as this will ensure I obtain enough preliminary information about the effectiveness of the assessment tool. The first ten eligible referrals that I receive that provide parental and child consent will be included.

Data Management
Data that will be gathered during this research project will include responses to the history taking inventory, observation sheets from the Austin Assessment and also video recordings of the Austin Assessments. All data will be stored securely on my computer, which is password protected and in a locked filing cabinet in my office at home. All data relevant to the research will be destroyed after five years. The school will be provided with a summary of the research findings at the completion of the research project.

Participant Rights
Participants are under no obligation to accept this invitation. If they decide to participate, they have the right to:

- decline to answer any particular question;
- withdraw from the study within three weeks of the final assessment;
- ask any questions about the study at any time during participation;
- provide information on the understanding that their name or the name of the school will not be used unless permission has been given to the researcher to do so;
- be given access to a summary of the project findings when it is concluded.

Please do not hesitate to contact either my PhD supervisors or me at any time if you have any questions about the project. Contact details are as follows:

Student	**PhD supervisor**
Nicola McDowell Phone [redacted] Email: [redacted]	Associate Professor Alison Kearney Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]
PhD supervisor	
Dr Julia Budd Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]	

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 18/20. If you have any concerns about the conduct of this research, please contact Dr Rochelle Stewart-Withers, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x [redacted]*, email* humanethicsouthb@massey.ac.nz

(6). Child Participant Consent Form

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EVALUATION OF THE AUSTIN VISION ASSESSMENT

PARTICIPANT CONSENT FORM – CHILD

I have read the Information Sheets and I have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

Please circle the face that best shows your answer:

My assessment can be sound recorded - Yes ☺ or No ☹

My assessment can be image recorded - Yes ☺ or No ☹

I would like to have the recordings returned to me - Yes ☺ or No ☹

I agree to participate in this study under the conditions set out in the Information Sheet -

Yes ☺ or No ☹

Signature: .... **Date:** ....

Please print your name: ....

(7). Parent Participant Consent Form

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UNIVERSITY OF NEW ZEALAND

EVALUATION OF THE AUSTIN VISION ASSESSMENT

PARTICIPANT CONSENT FORM – PARENT/CAREGIVER

I have read the Information Sheets and I have had the details of the study explained to me. I have also discussed the study with my child. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the assessment being sound recorded.

I agree/do not agree to the assessment being image recorded.

I wish/do not wish to have the recordings returned to us.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: .... **Date:** ....

Full Name of child - printed ....

(8). School Participant Consent Form

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UNIVERSITY OF NEW ZEALAND

EVALUATION OF THE AUSTIN VISION ASSESSMENT

PARTICIPANT CONSENT FORM – Principal/BOT

I have read the Information Sheets and I have had the details of the study explained to me. I have also discussed the study with the relevant school staff involved. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the functional vision assessment being conducted in this school.

I agree/do not agree to observations being conducted in this school.

I agree/do not agree to the functional vison assessment and observations being video recorded.

I agree/do not agree to the focus group being held in the school.

I agree for my school to participate in this study under the conditions set out in the Information Sheet.

Signature: .... **Date:** ....

Name of School: ....

(9). Confidentiality Agreement

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

EVALUATION OF THE AUSTIN VISION ASSESSMENT

CONFIDENTIALITY AGREEMENT FOR VISION EDUCATOR/SUPPORT PERSON

I .... (Full Name - printed)

agree to keep confidential all information concerning the project

....

....

....

.... (Title of Project).

I will not retain or copy any information involving the project.

Signature: .... **Date:** ....

(10). Austin Assessment Observation Tool

Austin Assessment – Observation form

Date: …………………Observer:…………………………………………………………………………

Name of child:……………………………………………………………………………………………

Location of assessment:………………..……………………………………………Assessment no:…………

Time of day:…………………………………………Duration of assessment:……………………………

Learner background information relevant to assessment gathered during discussion with parents (i.e. learning and behaviour difficulties, presence of diagnosed conditions):

Description of environment (i.e. lighting, clutter, noise, other people present, distractions, where child is sitting, what are they facing into):

Visual behaviours	Observations:
Eye movement (is their eye movement controlled or sporadic) **Search technique** (do they have a systematic search pattern or is it random) **Other visual behaviour**	**1 Pair**
	2 Pair
	3 Pair
	4 Pair
	5 Pair
Visual attention (where is the focus of their visual attention) **Finding pairs** (is the child able to match the pairs? How long does it take them?)	**1 Pair**
	2 Pair
	3 Pair
	4 Pair
	5 Pair
Visual fatigue (has the child shown signs of visual fatigue i.e. rubbing eyes, blinking, watery eyes, looking away from task). **General fatigue/posture** (Do they show signs of general fatigue, i.e. yawning, fidgeting, slumping in their chair)	**1 Pair**
	2 Pair
	3 Pair
	4 Pair
	5 Pair

Emotional/Behaviours	**Observations:**
Concentration (is the child able to concentrate on the activity? For how long?) **Response to distractions** (are they easily distracted from the assessment? What distracted them i.e. noise, movement, smell) **Emotional responses** (Do they get frustrated? Angry? Upset? Do they seem anxious?)	**1 Pair**
	2 Pair
	3 Pair
	4 Pair
	5 Pair
Accuracy of reach (Do they reach for the cards accurately?)	**1 Pair**
	2 Pair
	3 Pair
	4 Pair
	5 Pair

(11). Video Sharing Consent

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UNIVERSITY OF NEW ZEALAND

EVALUATION OF THE AUSTIN VISION ASSESSMENT

CONSENT TO SHARE VIDEOS TO AID IN THE CREATION OF AN ASSESSMENT APP

Dear parents,

As an extension of the research I conducted last year on the effectiveness of the Austin Assessment, I am now working with software developers to turn this assessment into an app to be used by vision education and rehabilitation specialists. To aid Springload (the company I am working with to produce this app) in understanding the assessment process and the different features the app would need to measure, I would like to share the videos of your child completing the assessment.

The videos would only be viewed by the team working on this project and would not be shared with anyone outside the company.

Please do not hesitate to contact either my PhD supervisors or me at any time if you have any questions about the sharing of the videos. Contact details are as follows:

Student	**PhD supervisor**
Nicola McDowell Phone [redacted] Email: [redacted]	Associate Professor Alison Kearney Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]
PhD supervisor	
Dr Julia Budd Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]	

If you consent for the videos to be shared in the ways outlined above, please sign and return this letter to me.

Signature: .... **Date:** ....

Full Name of child - printed ....

(12). Screening questions[11]

1. Does your child have difficulty walking down stairs?

2. Does your child look down when crossing floor boundaries, that is, where line meets carpet?

3. Does your child have difficulty seeing something which is pointed out in the distance?

4. Does your child have difficulty finding a close friend or relative who is standing in a group?

5. Does your child find copying words or drawings time consuming and difficult?

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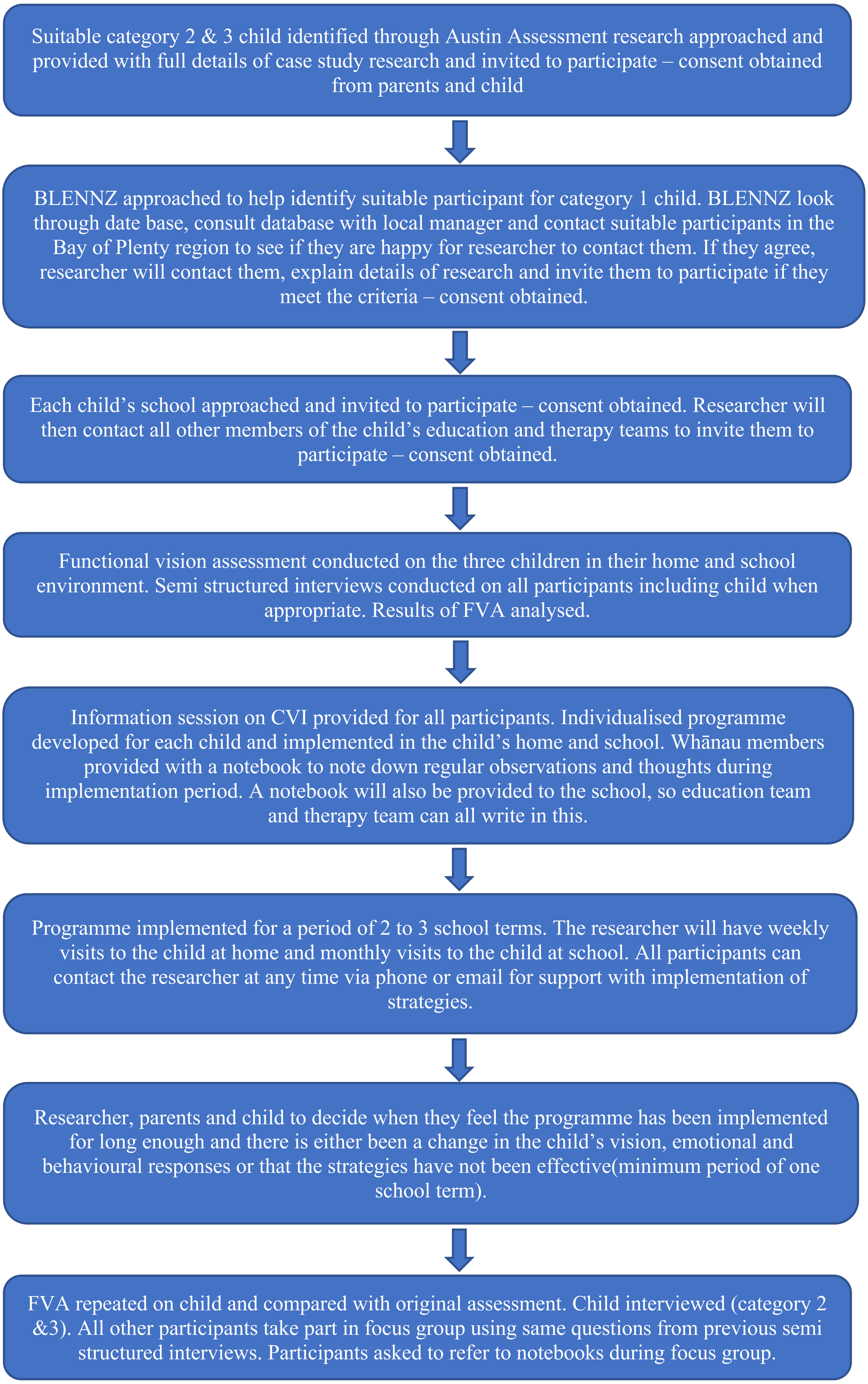
[11] A. Chandna, personal communication, April 15, 2018, taken from the Dutton et al. (2010) validated history-taking inventory.

Appendix C. Case Studies Research

(1). Flowchart



Suitable category 2 & 3 child identified through Austin Assessment research approached and provided with full details of case study research and invited to participate – consent obtained from parents and child

BLENNZ approached to help identify suitable participant for category 1 child. BLENNZ look through date base, consult database with local manager and contact suitable participants in the Bay of Plenty region to see if they are happy for researcher to contact them. If they agree, researcher will contact them, explain details of research and invite them to participate if they meet the criteria – consent obtained.

Each child's school approached and invited to participate – consent obtained. Researcher will then contact all other members of the child's education and therapy teams to invite them to participate – consent obtained.

Functional vision assessment conducted on the three children in their home and school environment. Semi structured interviews conducted on all participants including child when appropriate. Results of FVA analysed.

Information session on CVI provided for all participants. Individualised programme developed for each child and implemented in the child's home and school. Whānau members provided with a notebook to note down regular observations and thoughts during implementation period. A notebook will also be provided to the school, so education team and therapy team can all write in this.

Programme implemented for a period of 2 to 3 school terms. The researcher will have weekly visits to the child at home and monthly visits to the child at school. All participants can contact the researcher at any time via phone or email for support with implementation of strategies.

Researcher, parents and child to decide when they feel the programme has been implemented for long enough and there is either been a change in the child's vision, emotional and behavioural responses or that the strategies have not been effective(minimum period of one school term).

FVA repeated on child and compared with original assessment. Child interviewed (category 2 &3). All other participants take part in focus group using same questions from previous semi structured interviews. Participants asked to refer to notebooks during focus group.

(2). Letter to BLENNZ

MASSEY
UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

BLENNZ
[redacted]
Auckland [redacted]
New Zealand

[redacted]

6th November, 2018

Dear Karen,

As part of my PhD ‘Thesis by Publication’ I am looking to carry out research aimed at establishing effective strategies for supporting children with cerebral visual impairment (CVI) in their home, school and community environment. For this research, I would like to conduct case studies on three children from the three main education categories outlined by Professor Lueck and Professor Dutton. These include:

- Children with profound visual impairment due to CVI, many of whom also have additional disabilities.
- Children with CVI who have functionally useful vision and cognitive challenges.
- Children with CVI who have functionally useful vision and who are able to work in or near the expected academic level for their age group.

The case studies will involve the learner, their whānau, their education and therapy teams, and any other support service they receive.

The recruitment process to select the three children will be different between the categories. Potential participants for category two and three have already been identified following research I have conducted this year on assessing the effectiveness of an assessment tool I have developed for detecting visual processing difficulties in children.

To find a suitable participant for category one, I would like to work with BLENNZ to find a primary school aged child who has a diagnosis of CVI and additional disabilities and lives in the Bay of Plenty region. I have therefore, completing a full ethics application after gaining ethics approval for the research from the Massey University Ethics committee.

As part of the research, I will be asking for BLENNZ ethical approval to work with a learner, their whānau, their classroom teacher, their teacher aide, their RTV, their DOM and any other members of the educational and therapy team that have regular contact with the learner and their whānau.

Please find included all documents pertaining to the ethics application.

Kind regards,

Nicola McDowell
Massey University Doctoral Student

(3). Child Information Sheet

DEVELOPING EFFECTIVE WAYS OF SUPPORTING CHILDREN WITH CVI

INFORMATION SHEET FOR CHILDREN

Hello XXXX,

My name is Nicola McDowell. I am studying at Massey University.

As part of my study I want to find out what is the best way to help children who have some difficulties with the way they see. I have talked with your parents about my study and they have given me permission to ask you if you would like to take part.

What will we be doing?

If you want to take part in my study, I will be spending a lot of time with you and your whānau for a period of around four school terms, as I will be developing a programme of different things that may help you. The first thing I will do, is use some fun activities to look at the way you use your vision at home and at school. These activities will be video recorded so that I can look at it again afterwards. I will also sit with you and ask you some questions about how you see, how it makes you feel and what things make it harder for you to see. Your whānau, your teacher and any other adult that supports you will also be asked the same questions. These talks will all be sound recorded so that I can make notes of what everybody says.

I will then create a programme for you that will include some things you can use at home, at school and in the community to help make it easier for you to do different activities you sometimes find hard. The programme will also involve your whānau, your class teacher, your teacher aide (if you have one) and any other adult that supports you (such as a Resource Teacher Vision or Physiotherapist). During this time, I will come and visit you and your whānau at home once a week and your school once a month to check out how things are going and watch you as you are doing different things. Some of these observations will be video recorded so I can look at them again afterwards. If you like, you can also keep a note book to note down your thoughts during this time and write down anything about the things that you like or dislike.

Once you, your whānau and I decide that the programme has been running long enough, I will ask everyone the same questions I asked before we started the programme.

What will happen to the video and sound recordings and my note book?

The videos taken during the activity at the start and when I watch you doing different things at home and school will be seen by only me and I will be making notes about what you did during the assessment.

Following the talks, I will be writing out what everyone has said. If you would like, you can have them read to you what I have written once I have completed this. The notes from all the talks and focus groups be kept on a computer that only I will be able to access.

I will keep this information for up to five years to write about it in books and journals. Your parents will be given a summary of all the things that we find out during the activity.

Your Rights to be involved in my study

You do not have to take part in this study if you do not want to. You can stop being in my study even if you change your mind within three weeks after taking part in answering questions at home.

If you find the vision activities or any of things I suggest hard or tiring, we can stop at any time.

After this information has been read to you if you want to take part in my study, then I will give you a form to sign your name to say that you have agreed to take part.

If you have questions at any time when you are in my study, you can contact me on my mobile phone or by e-mailing me. My contact information is:

Nicola McDowell
[redacted]

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application SOA 18/68. If you have any concerns about the conduct of this research, please contact Dr Lesley Batten, Chair, Massey University Human Ethics Committee: Southern A, telephone + 64 6 356 9099 x [redacted]*, email humanethicsoutha@massey.ac.nz.*

(4). Parent Information Sheet

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

DEVELOPING EFFECTIVE WAYS OF SUPPORTING CHILDREN WITH CVI

INFORMATION SHEET FOR PARENTS/CAREGIVERS/WHĀNAU MEMBERS

Dear parent/caregiver/whānau member,

Hi, my name is Nicola McDowell and I am a PhD student at Massey University. Prior to starting my PhD, I was a Resource Teacher of Vision and a Developmental Orientation and Mobility Specialist. As part of my PhD research, I would like to work with children who display characteristics that are associated with cerebral visual impairment (CVI), their families/whānau and their education and therapy teams to establish an effective framework for supporting children with CVI. The aim of the study is to provide children with a range of strategies that will help to lessen the impact of the visual difficulties and the resulting effect on their emotions and behaviour.

Who can participate in the study?
To ensure that my research focuses on a range of children with CVI, I am conducting case study research on one child from each of the three CVI education categories outlined by Professor Gordon Dutton and Professor Amanda Lueck. These categories include: children with profound visual impairment due to CVI, many of whom also have additional disabilities. Children with CVI who have functionally useful vision and cognitive challenges, children with CVI who have functionally useful vision and who are able to work in or near the expected academic level for their age group.

The children involved in this research will, therefore, need to fit into one of those categories and be primary school aged to make it easier to implement strategies within their school environments. Alongside the child, their whānau, their teacher and teacher aide, any other educational support (such as RTV or ORS teacher) and any therapy providers (such as OT or SLT) will also be invited to become participants in the case study.

To help understand your child better, I would also like to have access to information about the different support services your child receives.
Once you have given consent for your child and your whānau to be involved in the case study, I will approach your child's school and their therapy teams to invite them to participate in this research.

What is this study about?
Although CVI is regarded as a visual impairment, for many children with this condition, their visual issues may influence their behaviours and emotional reactions to different experiences and activities. The aim of this study therefore, is to provide children with a range of strategies that will help to lessen the impact of the visual difficulties and the resulting effect on their emotions and behaviour.

To do this, I would like to work closely with children, their whānau and educational and therapy teams over a period of up to four school terms (depending on the needs of the child), following a framework that I have developed. This framework will include establishing an individual CVI profile based on your child's specific visual issues. I will then use this profile to develop individualised programmes that will use a range of different visual and emotional strategies within a child's home, school and community environment. The last part of this framework will focus on empowering the child and their whānau to be able to implement these strategies whenever they need them.

What is involved in the study?

The first stage of the study, developing an individual CVI profile, will involve conducting a thorough CVI specific functional vision assessment (FVA) at your home and at your child's school. This should take around one hour in each location. This FVA will help to establish the specific visual issues associated with CVI that your child has. I will then use this information to develop an individualised programme for your child.

Before the programme is implemented, I will interview each participant separately using a semi structured interview schedule. This will include: your child, relevant whānau members, their education and therapy team and any other support services they receive. Before the programme starts, I will spend time with each person to ensure they understand what CVI means and how to implement the strategies. During the implementation period of the project, you and your child will be encouraged to use the different strategies at home, school and when out in the community. The other participants will also be asked to implement the strategies when spending time with your child (i.e. in the classroom or during therapy sessions).

This programme will run for between one and four school terms, depending on the needs of your child. During this time, I will visit your child and you at home once a week to support the implementation of the programme and to make observations of your child using different strategies. These visits will be for around an hour at a time. However, if you do not feel that you need to be supported once a week, I can visit less frequently. I will also visit your child and his/her education team at school once a month for around an hour to support the programme. I will ask participants to note down regular observations and thoughts in a notebook that I will provide, as part of the data gathering process. This notebook can then be referred to during the final stage of the research. All participants involved in the research will be able to contact me via email or phone at any stage to ask for further support.

The implementation of the strategies will continue for no more than four school terms, or less if as a team, we decide that either the strategies have been effective, or that they have not been effective in supporting your child. The last part of the project will then be re-assessing your child's functional vision using some of the assessments we did at the start of the project. I will also repeat the interview process I did at the start of the research, however, for the education and therapy teams this will be done through a focus group as opposed to individual interviews. I will interview whānau members separately.

Data Management

Data that will be gathered during this research project will include video recordings of the FVAs and observations at home and at school, sound recordings of the interviews and focus groups, transcripts of the interviews and focus groups and participant journals (if you chose to allow me to have these). Following the interviews and focus groups, you will have the opportunity to review the transcripts to ensure that it is an accurate representation of what you said. All data will be stored securely on my computer, which is password protected and in a locked filing cabinet in my office at home. All data relevant to the research will be destroyed after five years by deleting it from my computer and shredding any paper data. All participants involved in the research will be provided with a summary of my research findings at the completion of the research period. The research will also be disseminated through conferences and journals relevant to the field of supporting children with visual issues.

Participant Rights

Participants are under no obligation to accept this invitation. If you and your child decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study within three weeks of the final assessment;
- ask any questions about the study at any time during participation;
- provide information on the understanding that their name or the name of the school will not be used unless permission has been given to the researcher to do so;
- be given access to a summary of the project findings when it is concluded.

Please do not hesitate to contact either my PhD supervisors or me at any time if you have any questions about the project. Contact details are as follows:

Student	**PhD supervisor**
Nicola McDowell Phone [redacted] Email: [redacted]	Associate Professor Alison Kearney Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]
PhD supervisor	
Dr Julia Budd Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]	

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application SOA 18/68. If you have any concerns about the conduct of this research, please contact Dr Lesley Batten, Chair, Massey University Human Ethics Committee: Southern A, telephone + 64 6 356 9099 x [redacted]*, email humanethicsoutha@massey.ac.nz.*

(5). Other Adult Information Sheet

DEVELOPING EFFECTIVE WAYS OF SUPPORTING CHILDREN WITH CVI

INFORMATION SHEET FOR EDUCATION / THERAPY PROVIDERS

Dear Education / Therapy provider,

Hi, my name is Nicola McDowell and I am a PhD student at Massey University. Prior to starting my PhD, I was a Resource Teacher of Vision and a Developmental Orientation and Mobility Specialist. As part of my PhD research, I would like to work with children who display some characteristics that are associated with cerebral visual impairment (CVI), their families/whānau and their education and therapy teams to establish an effective framework for supporting children with CVI. The aim of the study is to provide children with a range of strategies that will help to lessen the impact of the visual difficulties and the resulting effect on their emotions and behaviour. The whānau of a child that you currently work with, has indicated that they would like to be involved in this research.

Who can participate in the study?

To ensure that my research focuses on a range of children with CVI, I am conducting case study research on one child from each of the three CVI education categories outlined by Professor Gordon Dutton and Professor Amanda Lueck. These categories include: children with profound visual impairment due to CVI, many of whom also have additional disabilities. Children with CVI who have functionally useful vision and cognitive challenges, children with CVI who have functionally useful vision and who are able to work in or near the expected academic level for their age group.

The children involved in this research will therefore, need to fit into one of those categories and be primary school aged to make it easier to implement strategies within their school environments. Alongside the child, their whānau, their teacher and teacher aide, any other educational support (such as RTV or ORS teacher) and any therapy providers (such as OT or SLT) will also be invited to become participants in the case study.

To help understand the child better, I would also like to have access to information about the different support services the child receives.

The child that you work with and their whānau have given consent to be involved in this research. I have also invited and gained consent from the child's school and I would like to invite you to also participate in this research.

What is this study about?

Although CVI is regarded as a visual impairment, for many children with this condition, their visual issues may influence their behaviours and emotional reactions to different experiences and activities. The aim of this study, therefore, is to provide children with a range of strategies that will help to lessen the impact of the visual difficulties and the resulting effect on their emotions and behaviour.

To do this, I would like to work closely with children, their whānau and educational and therapy team over a period of up to four school terms (depending on the needs of the child), following a framework that I have developed. This framework will include establishing an individual CVI profile based on the child's specific visual issues. I will then use this profile to develop individualised programmes that will use a range of different visual and emotional strategies within a child's home, school and community environment. The last part of this framework will focus on empowering the child, their whānau and their education/therapy teams to be able to implement these strategies whenever they need them.

What is involved in the study?
The first stage of the study, developing an individual CVI profile, will involve conducting a thorough CVI specific functional vision assessment (FVA) at the child's home and at his/her school. This should take around one hour in each location. This FVA will help to establish the specific visual issues associated with CVI that the child has. I will then use this information to develop an individualised programme for the child.

Before the programme is implemented, I will interview each participant separately using a semi structured interview schedule. This will include: child, relevant whānau members, their education and therapy team and any other support services they receive. Before the programme starts, I will spend time with each participant to ensure they understand what CVI means and how to implement the strategies. During the implementation period of the project, the whānau, education and therapy teams will be encouraged to use the different strategies when spending time with the child at home, school and when out in the community.

This programme will run for between one and four school terms, depending on the needs of the child and his/her whānau. During this time, I will visit the whānau at home a maximum of once a week to support the implementation of the programme and to make observations of the child using different strategies. These visits will be for around an hour at a time. I will also visit the child and his/her education team at school once a month for around an hour to support the programme. I will ask participants to note down regular observations and thoughts in a notebook that I will provide, as part of the data gathering process. This notebook can then be referred to during the final stage of the research. All participants involved in the research will be able to contact me via email or phone at any stage to ask for further support.

The implementation of the strategies will continue for no more than four school terms, or less if, as a team, we decide that either the strategies have been effective, or that they have not been effective in supporting your child. The last part of the project will then be re-assessing the child's functional vision using some of the assessments we did at the start of the project. I will also repeat the interview process I did at the start of the project, however, for the education and therapy teams this will be done through a focus group as opposed to individual interviews.

Data Management
Data that will be gathered during this research project will include video recordings of the FVAs and observations at home and at school, sound recordings of the interviews and focus groups, transcripts of the interviews and focus groups and participant journals (if they chose to allow me to have these). Following the interviews and focus groups, you will have the opportunity to review the transcripts to ensure that it is an accurate representation of what you said. All data will be stored securely on my computer, which is password protected and in a locked filing cabinet in my office at home. All data relevant to the research will be destroyed after five years by delating it from my computer and shredding any paper data. All participants involved in the research will be provided with a summary of my research findings at the completion of the research period. The research will also be disseminated through conferences and journals relevant to the field of supporting children with visual issues.

Participant Rights
Participants are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study within three weeks of the final assessment;
- ask any questions about the study at any time during participation;
- provide information on the understanding that their name or the name of the school will not be used unless permission has been given to the researcher to do so;
- be given access to a summary of the project findings when it is concluded.

Please do not hesitate to contact either my PhD supervisors or me at any time if you have any questions about the project. Contact details are as follows:

Student	**PhD supervisor**
Nicola McDowell Phone [redacted] Email: [redacted]	Associate Professor Alison Kearney Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]
PhD supervisor	
Dr Julia Budd Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]	

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application SOA 18/68. If you have any concerns about the conduct of this research, please contact Dr Lesley Batten, Chair, Massey University Human Ethics Committee: Southern A, telephone + 64 6 356 9099 x [redacted]*, email humanethicsoutha@massey.ac.nz.*

(6). School Information Sheet

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

DEVELOPING EFFECTIVE WAYS OF SUPPORTING CHILDREN WITH CVI

INFORMATION SHEET FOR PARENTS/CAREGIVERS

Dear School Principal/Board of Trustee chairman,

Hi, my name is Nicola McDowell and I am a PhD student at Massey University. Prior to starting my PhD, I was a Resource Teacher of Vision and a Developmental Orientation and Mobility Specialist. As part of my PhD research, I would like to work with children who display characteristics that are associated with cerebral visual impairment (CVI), their families/whānau and their education and therapy teams to establish an effective framework for supporting children with CVI. The aim of the study is to provide children with a range of strategies that will help to lessen the impact of the visual difficulties and the resulting effect on a their emotions and behaviour. A whānau from your school has indicated that they would like their child, themselves and their child's education and therapy teams to be involved in this research.

Who can participate in the study?
To ensure that my research focuses on a range of children with CVI, I am conducting case study research on one child from each of the three CVI education categories outlined by Professor Gordon Dutton and Professor Amanda Lueck. These categories include: children with profound visual impairment due to CVI, many of whom also have additional disabilities. Children with CVI who have functionally useful vision and cognitive challenges, children with CVI who have functionally useful vision and who are able to work in or near the expected academic level for their age group.

The children involved in this research will, therefore, need to fit into one of those categories and be primary school aged to make it easier to implement strategies within their school environments. Alongside the child, their whānau, their teacher and teacher aide, any other educational support (such as RTV or ORS teacher) and any therapy providers (such as OT or SLT) will also be invited to become participants in the case study.

To help understand the child better, I would also like to have access to information about the different support services the child receives.

The child from your school and their whānau have given consent to be involved in this research and I would like to invite your school to participate in this research. I will also invite members of the child's education and therapy teams to participate in this research.

What is this study about?
Although CVI is regarded as a visual impairment, for many children with this condition, their visual issues may influence their behaviours and emotional reactions to different experiences and activities. The aim of this study, therefore, is to provide children with a range of strategies that will help to lessen the impact of the visual difficulties and the resulting effect on their emotions and behaviour.

To do this, I would like to work closely with children, their whānau and educational and therapy team members over a period of up to four school terms (depending on the needs of the child), following a framework that I have developed. This framework will include establishing an individual CVI profile based on the child's specific visual issues. I will then use this profile to develop individualised programmes that will use a range of different visual and emotional strategies within a child's home, school and community environment. The last part of this framework will focus on empowering the child, their whānau and their education / therapy teams to be able to implement these strategies whenever they need them.

What is involved in the study?
The first stage of the study, developing an individual CVI profile, will involve conducting a thorough CVI specific functional vision assessment (FVA) at the child's home and at his/her school. This should take around one hour in each location. This FVA will help to establish the specific visual issues associated with CVI that the child has. I will then use this information to develop an individualised programme for the child.

Before the programme is implemented, I will interview each participant separately using a semi structured interview schedule. This will include: child (when appropriate), relevant whānau members, their education and therapy team and any other support services they receive. Before the programme starts, I will spend time with each participant to ensure they understand what CVI means and how to implement the strategies. During the implementation period of the project, the whānau, education and therapy teams will be encouraged to use the different strategies when spending time with the child at home, school and when out in the community.

This programme will run for between one and four school terms, depending on the needs of the child and his/her whānau. During this time, I will visit the whānau at home a maximum of once a week to support the implementation of the programme and to make observations of the child using different strategies. These visits will be for around an hour at a time. I will also visit the child and his/her education team at school once a month for around an hour to support the programme. I will ask participants to note down regular observations and thoughts in a notebook that I will provide as part of the data gathering process. This notebook can then be referred to during the final stage of the research. All participants involved in the research will be able to contact me via email or phone at any stage to ask for further support.

The implementation of the strategies will continue for no more than three school terms, or less if, as a team, we decide that either the strategies have been effective, or that they have not been effective in supporting the child. The last part of the project will then be re-assessing the child's functional vision using some of the assessments we did at the start of the project. I will also repeat the interview process I did at the start of the project, however, for the education and therapy teams this will be done through a focus group as opposed to individual interviews.

Data Management
Data that will be gathered during this research project will include video recordings of the FVAs and observations at home and at school, sound recordings of the interviews and focus groups, transcripts of the interviews and focus groups and participant journals (if they chose to allow me to have these). Following the interviews and focus groups, you will have the opportunity to review the transcripts to ensure that it is an accurate representation of what you said. All data will be stored securely on my computer, which is password protected and in a locked filing cabinet in my office at home. All data relevant to the research will be destroyed after five years by delating it from my computer and shredding any paper data. All participants involved in the research will be provided with a summary of my research findings at the completion of the research period. The research will also be disseminated through conferences and journals relevant to the field of supporting children with visual issues.

Participant Rights
Participants are under no obligation to accept this invitation. If school decides to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study within three weeks of the final assessment;
- ask any questions about the study at any time during participation;
- provide information on the understanding that their name or the name of the school will not be used unless permission has been given to the researcher to do so;
- be given access to a summary of the project findings when it is concluded.

Please do not hesitate to contact either my PhD supervisors or me at any time if you have any questions about the project. Contact details are as follows:

Student	**PhD supervisor**
Nicola McDowell Phone [redacted] Email: [redacted]	Associate Professor Alison Kearney Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]
PhD supervisor	
Dr Julia Budd Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]	

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application SOA 18/68. If you have any concerns about the conduct of this research, please contact Dr Lesley Batten, Chair, Massey University Human Ethics Committee: Southern A, telephone + 64 6 356 9099 x [redacted]*, email humanethicsoutha@massey.ac.nz.*

(7). Child Participant Consent Form

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

DEVELOPING EFFECTIVE WAYS OF SUPPORTING CHILDREN WITH CVI

PARTICIPANT CONSENT FORM – CHILD

The Information Sheets has been read to me and I have talked with my parents about the study. I now understand what the study involves. The questions I had have been answered and I know that I can ask more questions at any time.

Please circle the face that best shows your answer:

When I am having my vision tested, you can video record me - Yes ☺ or No ☹

You can video record me working at school - Yes ☺ or No ☹

My interview can be sound recorded - Yes ☺ or No ☹

I would like to have all the recordings returned to me - Yes ☺ or No ☹

When you write up what I said in my interview, I want to get a copy of this and make changes if I want to

Yes ☺ or No ☹

I agree to participate in this study after having the information sheet read to me - Yes ☺ or No ☹

Signature: .... **Date:** ....

Please print your name: ....

(8). Parent Participant Consent Form

MASSEY
UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

DEVELOPING EFFECTIVE WAYS OF SUPPORTING CHILDREN WITH CVI

PARTICIPANT CONSENT FORM – PARENT/CAREGIVER

I have read the Information Sheets and I have had the details of the study explained to me. I have also discussed the study with my child. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the FVA assessment of my child being video recorded.

I agree/do not agree to the observations of my child being video recorded.

I wish/do not wish to have the recordings returned to us.

I agree/do not agree to the interviews being sound recorded.

I agree/do not agree to the focus group being sound recorded.

I would/would not like the opportunity to edit the transcripts of my interviews/focus group.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: .... **Date:** ....

Full Name of child - printed ....

(9). Other Adult Participant Consent Form

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

DEVELOPING EFFECTIVE WAYS OF SUPPORTING CHILDREN WITH CVI

PARTICIPANT CONSENT FORM – EDUCATION / THERAPY PROVIDER

I have read the Information Sheets and I have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I agree/do not agree to the focus group being sound recorded.

I would/would not like the opportunity to edit the transcripts of my interviews/focus group.

I agree/do not agree to observations of me working with the child being video recorded.

I wish/do not wish to have the recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: .... **Date:** ....

Full Name - printed ....

(10). School Participant Consent Form

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DEVELOPING EFFECTIVE WAYS OF SUPPORTING CHILDREN WITH CVI

PARTICIPANT CONSENT FORM – Principal/BOT

I have read the Information Sheets and I have had the details of the study explained to me. I have also discussed the study with the relevant school staff involved. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the functional vision assessment being conducted in this school.

I agree/do not agree to observations being conducted in this school.

I agree/do not agree to the functional vison assessment and observations being video recorded.

I wish/do not wish to have the recordings returned to the school.

I agree/do not agree to the interviews and focus group being held in the school.

I agree for my school to participate in this study under the conditions set out in the Information Sheet.

Signature: .... **Date:** ....

Name of School: ....

(11). Participant Data Gathering

Participant	Pre implementation	Hrs	Implementation Period	Hrs	Post implementation	Hrs
Child	Functional vision assessment (FVA) school / home Interview (category 2 & 3)	2 1	Journal (category 3) Session with researcher for observations / support	As needed 1 x week at home and 1 x month at school	Repeat some assessments from FVA Interview	2 1
Family	Interview	1	Session with researcher to set up Journal Session with researcher for observations / support *	2 As needed 1 x week	Focus group	1
Class teacher	Interview	1	Session with researcher to set up Session with researcher for observations / support * Collective journal	1 1 x month As needed	Focus group	1
Teacher aide	Interview	1	Session with researcher to set up Session with researcher for observations / support * Collective journal	1 1 x month As needed	Focus group	1
ORS / RTV	Interview	1	Session with researcher to set up Additional time with researcher as and when needed * Collective journal	1 As needed	Focus group	1
PT/OT/SLT	Interview	1	Session with researcher to set up Additional time with researcher as and when needed * Collective journal	1 As needed	Focus group	1
Other	Interview	1	Session with researcher to set up Additional time with researcher as and when needed * Collective journal	1 As needed	Focus group	1

*Participants will be able to contact the researcher by phone or email for support at any stage throughout the research period. Visits to provide support can depend on the participants' needs. However, visits to the family will be no more than once a week and visits to the school will be no more than once a month.

(12). Interview and Focus Group Schedule

DEVELOPING EFFECTIVE WAYS OF SUPPORTING CHILDREN WITH CVI

SEMI STRUCTURED INTERVIEW / FOCUS GROUP SCHEDULE

Visual functioning

1. Can you please describe in your own words, your / the child's vision?

2. When in the home / school / community environment, how do your / the child's visual difficulties affect your / the child's visual functioning?

3. What strategies (if any), do you / does the child implement to help deal with your / the child's visual difficulties?

Emotional

4. Can you please describe your / the child's emotions? i.e. are they generally calm and relaxed or do they get anxious and upset at times?

5. When in the home / school / community environment, do you think your / the child's visual difficulties cause certain emotional responses?
    a. If so, can you please describe some of these emotional responses:

6. What strategies (if any), do you / the child implement to help deal with any emotions that are related to your / the child's visual difficulties?

Behaviours

7. Can you please describe your / the child's behaviour? i.e. Do they listen when you are talking to them? Do they get on with other children? Do they do what they have been told / asked to do?

8. When in the home / school / community environment, do you think your / the child's visual difficulties cause certain behaviours?

    a. If so, can you please describe some of these behaviours:

9. What strategies (if any), do you / the child implement to help deal with any behaviours that are related to your / the child's visual difficulties?

General

10. Is there any location / activity you know you do not like / you cannot take the child?
    a. Why?

11. Is there any location / activity that helps to calm you down / you know you can take the child to calm him/her down?

12. How are you / the child in unknown or unfamiliar places i.e. a supermarket, shopping mall, walk in the country, visit to a new beach?

13. How are you / the child when meeting unfamiliar/new people?

14. Have you noticed that he/she needs a familiar person, object or shield (i.e. their tray on their wheelchair, supermarket trolley) when entering an environment that they do not like or that makes them feel anxious?

15. In general, what kinds of activities / experiences are the most challenging for you / the child?

16. In general, what kinds of environments / experiences are the most challenging for you / the child?

17. Do you notice a time or a place where you / the child is the most relaxed?

18. What do you / the child do to relax?

(13). Focus Group Guide

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FOCUS GROUP GUIDE

Following a period of between one and three school terms of implementation of the individualised programme, focus groups will be organised to help ascertain whether the implemented strategies have been effective or not in helping to alleviate the visual, behavioural and emotional challenges associated with CVI. The focus groups will be divided into two: the child and his / her whānau and the education and therapy teams. The reason for choosing focus groups over interviews, is that it will give the participants a chance to discuss together how they think the strategies went and whether or not they were useful in different contexts. It is also important to have the separate groups, to ensure that each participant feels comfortable to be open with their discussions.

The following people will be invited to participate in the focus groups (if they do not wish to take part in a focus group, they will be interviewed separately).

- The child’s parent/caregiver
- Whānau members who have taken part in the research
- The child’s teacher
- The child’s teacher aide
- Any other members from the child’s education team (i.e. RTV or ORS teacher)
- Members from the child’s therapy team

The focus group will be run at a time that is suitable to all participants. In order to establish a suitable time, all participants will be invited to complete on online poll (i.e. doodle poll) that will include a number of different time and day options.

The focus groups will be run at a location that is suitable to all participants and this may be different for the three different case study categories. For instance, for the category three child, participants in the focus group will only include the whānau and the child’s teacher. Therefore, the focus group could be run at the child’s home or school. For category one and two, it may be more appropriate for the focus group to be run at the child’s school as more participants will be present from the educational and therapy teams.

The focus group schedule will be the same as the interview schedule that was conducted at the start of the research project.

All of the focus groups will be sound recorded to allow the researcher to transcribe discussions following the focus group. All participants will have the opportunity to review the transcript to ensure that it is an accurate account of their discussion.

To help ensure that participants are relaxed and at ease during the focus group, the researcher will provide snacks and drinks. The focus groups will go for no longer than two hours.

(14). Confidentiality Agreement

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UNIVERSITY OF NEW ZEALAND

DEVELOPING EFFECTIVE WAYS OF SUPPORTING CHILDREN WITH CVI

CONFIDENTIALITY AGREEMENT

I .... (Full Name - printed)

agree to keep confidential all information concerning the project

....

....

....

.... (Title of Project).

I will not retain or copy any information involving the project.

Signature: .... **Date:** ....

(15). Transcript Release Form

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UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

DEVELOPING EFFECTIVE WAYS OF SUPPORTING CHILDREN WITH CVI

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: .... **Date:** ....

Full Name - printed ....

Appendix D. Parent Empowerment Research

(1). Survey Monkey Survey

Parents/caregivers of children with cerebral visual impairment

Information

Hello, my name is Nicola McDowell and I am from New Zealand. I am a vision education/rehabilitation specialist for children who are blind or who have low vision and I am currently completing a PhD in Education. My research is focused on establishing effective ways to better support children with cerebral visual impairment (CVI).

One part of this research is a survey for parents/caregivers of children with cerebral visual impairment. The focus of this survey is to better understand how you obtain information on CVI in general and how you use this information to be able to help your child as well as you can. Your answers to the questions in this survey will help me to do this.

This survey is open to parents/caregivers from any country around the world, who have a child of any age with CVI. Your child does not have to be officially diagnosed with CVI, but they must have visual difficulties that are consistent with this condition.

For non-English speaking participants, please use Google Translator to translate the questions into your language of choice. Or you can contact me to provide a translated version.

Confidentiality

You will not be asked to provide your name, your child's name, or any contact information during the survey. All responses will therefore be anonymous. However, if you wish to provide more information that the survey does not ask for, but you feel is relevant, you can email me at [redacted].

All of the research data will be collected and securely stored on my computer for a period of five years.

Completing this survey

This survey should take about 15 minutes to complete. Section one of the survey has one compulsory question (question 5) that you must respond to, so that you will be directed to the appropriate section of the survey. For all other questions in the survey, you may decline to answer any particular question simply by leaving it blank.

If you wish to navigate back and forth through your responses, please use the "Prev" and "Next" buttons provided within the survey. The survey is completed by clicking the "Done" button at the end. Once you have submitted the survey, you will not be able to edit your responses.

Queries

If you have any queries about this research, please contact me, Nicola McDowell [redacted]. Thank you for taking the time to respond to this survey.

About your child

1. Please state your child's gender;

2. How old is your child?

3. What country do you live in?

4. Does your child have a diagnosed visual condition? Yes / No

* 5. If your child has CVI, who made the diagnosis?
Doctor
Ophthalmologist
Optometrist
Neuropsychologist
Multi-disciplinary team
N/A
Other (please specify)

Children that have received a diagnosis of CVI - Your experience with CVI

6. What age did your child develop CVI? E.g. birth or acquired after birth;

7. What age was your child diagnosed with CVI?

8. When your child was first diagnosed with CVI, did you receive any information about CVI in general?
Yes / No

9. How was this information provided? (Please select as many as apply)
Discussions with professionals at the time of the diagnosis
Books
Leaflets / Pamphlets
Link to local organisation Website
Parent course
N/A
Other (please specify)

10. Who provided this information? (Please select as many as apply)
Doctor
Ophthalmologist Optometrist Neuropsychologist Multi-Disciplinary team Education provider Nurse
N/A
Other (please specify)

11. Was the information relevant to your child and his/her needs?
Yes / No / NA

12. Did you understand the information that was provided to you?
Yes / No / NA
Please explain your answer;

13. Did you feel that this information helped you to become an advocate for your child?
Yes / No / NA
Please explain your answer;

14. Please describe your child's visual issues when they were first diagnosed with CVI;

15. Can you please describe how your understanding of your child's condition has developed over time?

16. As your child has developed, what have you found to be the most useful resource in helping you to understand your child's visual world better? (You may choose more than one option)
Your child
Books
Presentations
Websites

Facebook / Social media groups
Real life experiences from people with CVI Other parents
Professionals
Other (please specify)

17. Can you please explain why you found these resources useful?

18. How have you used the information you gathered about CVI to help your child at home?

19. How have you used the information you gathered about CVI to help your child at school?

20. How have you used the information you gathered about CVI to help your child out in the community?

21. What do you think would have happened if you had not received/found the information about CVI that you did?

22. Is there any vital information about how best to help your child that you wish you had known right from the time they were diagnosed?

23. Are you happy with the answers you have provided for this section? Yes / No

Children that have not received a diagnosis of CVI but parents suspect they have CVI - Your experience with CVI

24. What age do you think your child developed CVI? E.g. birth or acquired after birth.

25. What age was your child when you suspected he/she had CVI?

26. How did you learn about CVI?

27. What resources have you used to develop your understanding of CVI? (You may chose more than one option)
Your child
Books
Presentations
Websites
Facebook / Social media groups Simulation activities
Real life experiences from people with CVI Other parents
Professionals
Other (please specify)

28. Can you please explain why you found these resources useful?

29. Was this information relevant to your child and their needs?
Yes / No / NA
Please explain your answer

30. Did this information help you to become an advocate for your child?
Yes / No / NA
Please explain your answer

31. How would you describe your child’s visual issues when you first established he/she had CVI?

32. Have you raised your concerns about your child’s visual difficulties with a medical professional?
Yes / No / NA
If yes, who with and what was their response? If no, why not?

33. Have you raised your concerns about your child’s visual difficulties with your education provider?
Yes / No / NA
If yes, who with and what was their response? If no, why not?

34. Please describe how your understanding of your child’s condition has developed over time?

35. As your child has developed, what have you found to be the most useful resource in helping you to understand your child's visual world better? (You may choose more than one option)
Your child
Books
Presentations
Websites
Facebook / Social media
Simulation activities
Real life experiences from people with CVI Other parents
Professionals
Other (please specify)

36. Can you please explain why you found these resources so useful?

37. How have you used the information you gathered about CVI to help your child at home?

38. How have you used the information you gathered about CVI to help your child at school?

39. How have you used the information you gathered about CVI to help your child out in the community?

40. What do you think would have happened if you had not found the information on CVI that you have?

41. Is there any vital information about how best to help your child that you wish you had known right from the time you first suspected they had CVI?

42. Are you happy with the answers you have provided for this section?
Yes
No

Services your child receives

This section is focused around services your child receives and your relationship with these service providers. Professionals refers to anyone working with your child including; specialists, therapists, education providers.

43. Do you feel that you have a clear understanding of the role of each of the professionals working with your child?
Never / Rarely / Sometimes / Often / Always / N/A / Some professionals but not others;
Please state which ones and why? (Please do not provide names, just service they provide)

44. Do you think you need to understand the reason why the professionals involved with your child makes the decisions they do?
Never / Rarely / Sometimes / Often / Always / N/A
Please explain your answer;

45. Do you want to know more about the reasons why the professionals involved with your child make the decisions they do?
Never / Rarely / Sometimes / Often / Always / N/A
Please explain your answer;

46. Do you feel able to ask for a more detailed explanation from the professionals working with your child?
Yes / No / With some professionals

47. Can you please provide more details about the professionals you consider you are able to question and why? (Please do not provide names, just the professional role)

48. If there is insufficient time for the professional to provide a more detailed explanation, are you likely to accept what the professionals recommend?
Never / Rarely / Sometimes / Often / Always / N/A

49. Do you feel enough time in general, is given to explain the reasons behind the professional's decisions affecting your child's care?
Never / Rarely / Sometimes / Often / Always / N/A

50. Have you ever disagreed with a professional?
Never / Rarely / Sometimes / Often / Always / N/A

51. If you have disagreed with a professional, was there a system to resolve the matter?
Yes / No / N/A
Please explain your answer;

52. Do you feel that your role as a parent/caregiver is valued by the professionals working with your child?
Never / Rarely / Sometimes / Often / Always / N/A
For some professionals but not others
Please state which professionals and why; (please do not provide names, just their professional roles)

53. Please describe the way professionals have demonstrated that they value your knowledge and input in the services your child receives?

54. Please describe actions you would like professionals to take in order to show you that they value your knowledge and input in relation to your child?

55. Can you explain a time when you were able to use your knowledge about CVI for the benefit of your child?

56. Can you explain a time when you felt you lacked the knowledge about CVI to ensure that your child had their needs met?

57. Are you happy with the answers you have provided in this section?
Yes
No
If no, why not?

Thank you for participating in this survey, your feedback is extremely valuable. If you would like to provide further information relevant to this topic, please contact the researcher at
[redacted]

(2). Application to Advertise Online Survey Through Blind Foundation

Blind Foundation

Beyond vision loss

RESEARCH INTENT FORM

The Blind Foundation aims to support high quality, ethical research which is in the interests of current or future clients, as resources allow, and in keeping with our mission and values. Please complete all sections of this form by tabbing through the fields and e-mail with the additional information requested to [redacted].

Date of application: 28.3.2018

Lead researcher name and affiliation Nicola McDowell

Telephone number [redacted]

E-mail address [redacted]

Title of project: The role of the attainment of knowledge in empowering parents of children with cerebral visual impairment.

Describe an observation or problem that has motivated this project: To ensure that an individualised programme is effective for a child with CVI, professionals working with these children need information and support from parents for a number of reasons. Firstly, parents are the people that know their child the best and they are also the ones that spend the most time with their child, which puts them in the best position to help implement any strategies that are recommended. However, to be confident to take a lead role in supporting their child, as well as knowing their child well, parents need to have a deep understanding of their child's specific visual issues and associated behavioural and emotional responses. However, because there is often a lack of understanding and awareness of CVI by medical providers (Martin et al., 2016), parents commonly receive only general information about CVI, misinformation about different aspects of CVI, or information that is not relevant to their child and, therefore, not useful to them (H. St Clair Tracy, personal communication, February 12, 2018). This therefore, potentially puts parents of children with CVI at a disadvantage, especially in relation to empowering them to be more involved with their child's education and rehabilitation/habilitation programme. In general, empowerment can be described as a process of gaining personal power and control (Mulligan et al., 2012). Specific features of empowerment may include; active participation, awareness of choices, feelings of self-efficacy, respect, hope, and involvement in decision making (Shulman, 1992). However, Shulman (1992) also outlines, that one of the most important features of empowerment, is the attainment of knowledge and skills. But the attainment of knowledge will only be beneficial for parents if they can understand the information that they are provided with (or gather themselves) and if they find it relevant to their child. Therefore, parents need to firstly understand CVI in general and, then in relation to their child, to ensure that they are aware of the services their child is entitled to, as well as to be confident in their decision-making and involvement in the services their child receives.

Research Objectives: (Include research question or hypothesis being addressed.) Research aim: To establish whether an increased understanding of CVI helps parents to better understand the impact their child's visual issues has on their functioning and whether the attainment of knowledge about CVI helps to empower parents to be involved in their child's programme.

Research question: What role does the attainment of knowledge in relation to CVI play in helping to empower parents to be more involved in the services their child receives?

Relevance of the project to the mission and goals of the Blind Foundation's strategic plan and/or the field of blindness/vision loss research and/or the community of people with vision loss, including expected benefits. CVI is now the most common cause of vision impairment affecting children in the developed world. It is therefore important that this complex condition is better understood by professionals working in the field. This research will hopefully help medical professionals understand the kind of information parents need to be able to understand their child better.

Please provide a research proposal which includes the following information:

Table 1

Information required	Check box if attached	Comment
Description of work plan and methods, including dates for completion of each element	☐	The parent/caregiver survey will go live online on the 29th March. The survey will stay open for at least two months. Participation is voluntary and all responses will be anonymous.
Nature of Blind Foundation staff/ client/ volunteer involvement requested	☐	Advertisement of research on Blind Foundation website and Facebook page, to alert parents of children with CVI to the survey.
Participant information sheet including consideration of accessible format requirements	☐	No information sheet, information about the research is on the first page of the online survey.
Ethical considerations and approvals gained	☐	Ethical approval has been granted from Massey University after completing an online ethics application process. The research has been deemed low risk.

Funding agency, including conflict of interest declaration and planned reimbursements of expenses	☐	No funding agency.
Academic supervisor contact details	☐	Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted] Dr Julia Budd Massey University Institute of Education Private Bag 11 222 Palmerston North Phone [redacted] Email: [redacted]
Plans for dissemination of results, including consideration of accessible format requirements	☐	This research is part of a PhD thesis by publication. It will therefore be published through a vision related journal. Results from the survey will also be discussed with relevant service providers, including the Blind Foundation.

Do you wish to make any other comments?

We engage in a formal approval process and aim to inform you of the outcome of your application within two weeks of receiving all the required information

Claire Fitzgerald

Research Practice Advisor

[redacted]

[redacted]

(3). Application to Advertise Online Survey on CVI Scotland Website

Study: Survey for parents/caregivers of children with CVI.

Closing Date: Project ongoing
Participant Details:

- **Country:** Any country
- **Age:** This study is open to parents/caregivers of children of any age with CVI.
- Children do not have to be diagnosed with CVI for parents/caregivers to participate in the survey. However, they must have visual issues that are consistent with CVI.

Participant Requirements:
Parents will be asked to complete an anonymous multi-sectioned online survey about their experiences of cerebral visual impairment with their child. Questions focus on how parents have developed their understanding of CVI and also, their involvement in the services their child receives. It should take around 10 minutes to complete.

Purpose of Study:
The purpose of this study is to develop an understanding of how parents access information on CVI and how they use this information to help support their child. Information gathered in this survey will help professionals understand the best ways to provide accessible CVI specific information to parents/caregivers of children with CVI.

Researcher:
This research is being carried out by Nicola McDowell, as part of a PhD in Education focusing on developing effective support for children with CVI. Nicola is completing her PhD at Massey University, New Zealand.

Ethics approval has been granted by Massey University.

Contact:
Nicola McDowell
Email: [redacted]

Survey:
If you would like to take part in this research, please click here and you will be directed to the survey.
[redacted]

Appendix E. Statement of Contribution Forms

DRC 16

MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

STATEMENT OF CONTRIBUTION
DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the candidate and the candidate's Primary Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of candidate:	Nicola McDowell
Name/title of Primary Supervisor:	Associate Professor Alison Kearney
Name of Research Output and full reference:	
McDowell, N. (in press). A review of the literature to inform the development of an effective framework for supporting children with cerebral visual impairment (CVI).	
In which Chapter is the Manuscript /Published work:	Chapter two
Please indicate:	
- The percentage of the manuscript/Published Work that was contributed by the candidate:	100%
and	
- Describe the contribution that the candidate has made to the Manuscript/Published Work:	
The candidate is the sole author of the article	
For manuscripts intended for publication please indicate target journal:	
International Journal of Inclusive Education	
Candidate's Signature:	Nicola McDowell Digitally signed by Nicola McDowell Date: 2020.04.17 09:09:48 +12'00'
Date:	17.4.20
Primary Supervisor's Signature:	Alison Kearney Digitally signed by Alison Kearney Date: 2020.04.17 15:59:48 +12'00'
Date:	17.4.20

(This form should appear at the end of each thesis chapter/section/appendix submitted as a manuscript/ publication or collected as an appendix at the end of the thesis)

GRS Version 4– January 2019

DRC 16

MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

STATEMENT OF CONTRIBUTION
DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the candidate and the candidate’s Primary Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate’s contribution as indicated below in the *Statement of Originality*.

Name of candidate:	Nicola McDowell
Name/title of Primary Supervisor:	Associate Professor Alison Kearney
Name of Research Output and full reference:	
McDowell, N., & Dutton, G. N. (2019) Hemianopia and Features of Balint Syndrome following Occipital Lobe Hemorrhage: Identification and Patient Understanding Have Aided Functional Improvement Years after Onset.	
In which Chapter is the Manuscript /Published work:	Chapter 3
Please indicate:	
• The percentage of the manuscript/Published Work that was contributed by the candidate:	90%
and	
• Describe the contribution that the candidate has made to the Manuscript/Published Work:	
The candidate wrote the majority of the paper and addressed all comments following the peer review process.	
For manuscripts intended for publication please indicate target journal:	
The article has been published in Case Reports in Ophthalmological Medicine	
Candidate’s Signature:	Nicola McDowell Digitally signed by Nicola McDowell Date: 2020.04.16 20:26:58 +12'00'
Date:	16.4.2020
Primary Supervisor’s Signature:	Alison Kearney Digitally signed by Alison Kearney Date: 2020.04.16 20:36:55 +12'00'
Date:	16.4.20

(This form should appear at the end of each thesis chapter/section/appendix submitted as a manuscript/ publication or collected as an appendix at the end of the thesis)

DRC 16

MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

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DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the candidate and the candidate's Primary Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of candidate:	Nicola McDowell
Name/title of Primary Supervisor:	Associate Professor Alison Kearney
Name of Research Output and full reference:	
McDowell, N. (2019). A personal perspective on CVI. In J. Ravenscroft (Ed.), The Routledge handbook of visual impairment (1st ed., pp. 70-78). Routledge.	
In which Chapter is the Manuscript /Published work:	Chapter four
Please indicate:	
• The percentage of the manuscript/Published Work that was contributed by the candidate:	100%
and	
• Describe the contribution that the candidate has made to the Manuscript/Published Work:	
The candidate is the sole author of the chapter	
For manuscripts intended for publication please indicate target journal:	
The Routledge handbook of visual impairment	
Candidate's Signature:	Nicola McDowell Digitally signed by Nicola McDowell Date: 2020.04.17 09:12:54 +12'00'
Date:	17.4.20
Primary Supervisor's Signature:	Alison Kearney Digitally signed by Alison Kearney Date: 2020.04.17 16:00:27 +12'00'
Date:	17.4.20

(This form should appear at the end of each thesis chapter/section/appendix submitted as a manuscript/ publication or collected as an appendix at the end of the thesis)

DRC 16

MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

STATEMENT OF CONTRIBUTION
DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the candidate and the candidate’s Primary Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate’s contribution as indicated below in the *Statement of Originality*.

Name of candidate:	Nicola McDowell
Name/title of Primary Supervisor:	Associate Professor Alison Kearney
Name of Research Output and full reference:	
McDowell, N. (2020). A pilot study of the Austin Playing Card Assessment: A tool to detect and find the degree of visual perceptual difficulties related to clutter.	
In which Chapter is the Manuscript /Published work:	Chapter five
Please indicate:	
• The percentage of the manuscript/Published Work that was contributed by the candidate:	100%
and	
• Describe the contribution that the candidate has made to the Manuscript/Published Work:	
The candidate is the sole author of the article	
For manuscripts intended for publication please indicate target journal:	
British Journal of Visual Impairment	
Candidate’s Signature:	Nicola McDowell Digitally signed by Nicola McDowell Date: 2020.04.17 09:15:17 +12'00'
Date:	17.4.20
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DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the candidate and the candidate's Primary Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of candidate:	Nicola McDowell
Name/title of Primary Supervisor:	Associate Professor Alison Kearney
Name of Research Output and full reference:	
McDowell, N. (under review, March 2020). Supporting the visual, emotional and behavioural needs of children with cerebral visual impairment (CVI).	
In which Chapter is the Manuscript /Published work:	Chapter six
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